





"There's no such thing as a baby...

There is a baby and someone."

— D. W. Winnicott

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## Centering families

As the Administration for Children and Families explains,

"strong family engagement is central in promoting children's healthy development and wellness, including:

- social-emotional and behavioral development;
- preparing children for school;
- seamlessly transitioning them to kindergarten; and
- supporting academic achievement in elementary school and beyond."



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## Centering families

Many systems are *intended* to serve families, but are they actually *designed* to serve them?

Continuum of Family Engagement\*



- Meaningful family engagement can look different depending on the organization and setting, but at its core, it is an **equitable partnership**.
- Meaningful family engagement engages the whole family not just moms

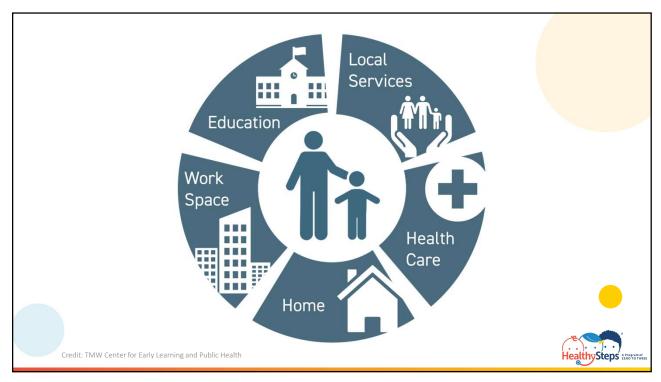


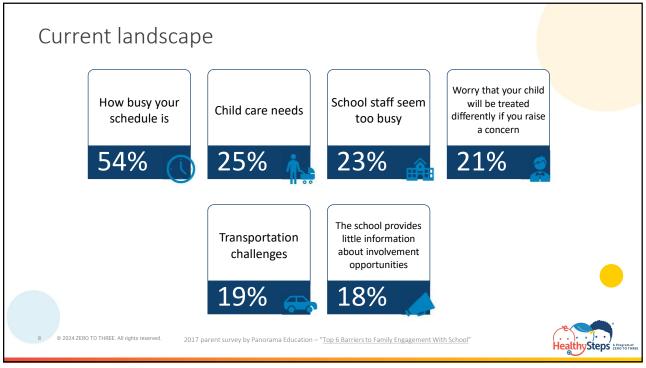
- Parent Interview Study, Martine Lappé, PhD & Research Team

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 $* \ Adapted \ from: \\ \underline{https://www.acf.hhs.gov/opre/report/engaging-families-state-initiatives-case-study-lessons-learned and the state-of-state and the state-of-stat$ 







## Current landscape

- In a <u>2018 survey</u>, Texas families stated they want to help their children but lack the confidence to support them academically due to uncertainty about how to interact with school personnel, particularly if there are cultural and language barriers.
- The Texas survey also found that teachers face several barriers to family
  engagement and identified the need for preparation and supports to engage
  diverse families in their children's learning.
- A <u>2018 study</u> on family engagement and retention of young children in mental health care found that **key barriers were stigma**, **lack of integrated health care services**, and a shortage of providers with the necessary expertise in early childhood mental health care.



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## THREE MOTHERS, ON THE BRINK

Eleven months, multiple breakdowns, one harrowing realization: They've got to get back up and do it all again tomorrow.

## THIS ISN'T BURNOUT, IT'S BETRAYAL

A psychiatrist suggests ways moms can fight back when the system is stacked against them.

## HOW TO HELP WORKING PARENTS RIGHT NOW

From flexible schedules to paid leave, what the government, employers and the rest of us can do.





Image credit: The New York Times headlines; slide credit: TMW Center for Early Learning and Public Health; Parent Nation

# Surgeon General: Parents Are at Their Wits' End. We Can Do Better.

Aug. 28, 2024



Parents Under Pressure: The U.S. Surgeon General Advisory on the Mental Health and Well-Being of Parents

This Surgeon General's Advisory highlights the stressors that impact the mental health and well-being of parents and caregivers, the critical link between parental mental health and children's long-term well-being, and the urgent need to better support parents, caregivers, and families.

Image credit: The New York Times; HHS Office of the Surgeon Genera



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## Why Health Care Workers Are Burning Out

## With Pandemic Money Gone, Child Care Is an Industry on the Brink

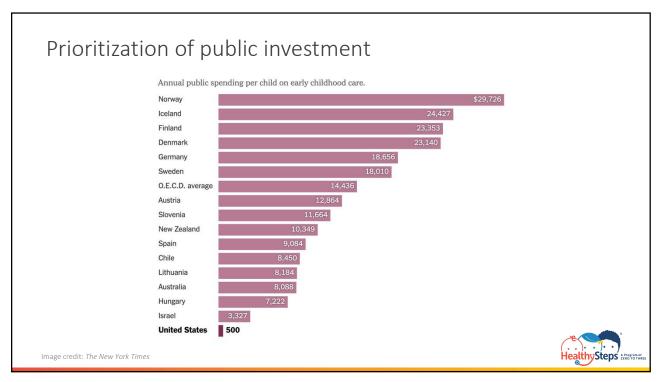
Five months after the expiration of federal funds, running a child care business is more precarious than ever, and many parents struggle to pay tuition, surveys show.

## Solving the Mental Health Provider Shortage

Almost half of the U.S. lives in a mental health workforce shortage area.

Image credit: The New York Times & Psychology Today headlines





	United States	California
Babies in families with poor or low income	39%	34%
Babies living in poverty	19%	16%
% of Black babies	35%	27%
% of Hispanic babies	25%	21%
% of AI/AN babies	38%	37%*
% of White babies	12%	9%



I had no one coordinating my son's care, to the point that I had a team of over 10 different health care professionals that I was managing at one point in time, and they all had differing opinions of each other.

I was doing it all because there was no one, because our health care system is so fractional. And it's so disseminated that there is not any real care coordination...

- 38-year-old white, married mother of four children, ages 11, 8, 3, & 6 weeks



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Credit: Parent Interview Study, Martine Lappé, PhD & Research Team



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I would always love to have more information or different ways to like assess, you know, how my son is doing, and anything that we could improve upon. But I do think the downside is that parents already have so many checklists and so many expectations, whether direct or kind of assumed...

- 37-year-old white, married mother of a 6-month-old son



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I could see parents being nervous like, 'okay, is this going to be documented like, is somebody going to be calling CPS on me?' I could see that being the main concern for parents' feelings. Or, just feeling like, 'is this a safe space for me to open up about things at home?'

So, I think that it needs to be said: 'This is a safe space to talk about this.' Because I did have a CPS case open against me from [my daughter's] doctor and not going to her visits, and that was extremely hard... and I think that CPS is phenomenal. I think that it is absolutely necessary. I'm glad that they came to my house, and that they were concerned about my child.

But what about parents and their well being? Because if CPS is being called, it's likely that parents' needs are also not being met... And I would like for parents to be advocated for, as well as children..."

- 26-year-old Native American single mother of a 3-year-old daughter



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Credit: Parent Interview Study, Martine Lappé, PhD & Research Team



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I've always had private insurance from my parents... and so when I was like 26 or 27 I lost that, I think like 6 months after [my daughter] was born and I had to navigate Medi-Cal... [and] that was so traumatizing. I've never experienced that kind of rudeness, and just because I received public benefits? [...] So, it's advertised that you can still receive high quality care through Medi-Cal when, really, that was not the case. And it's really unfortunate... Like this is not the way it should be.

– 29-year-old African American, married mother of a 3-year-old daughter



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Credit: Parent Interview Study, Martine Lappé, PhD & Research Team



## Emily's Story



[ I am a mother from the Bronx that endured great adversity and lack of resources while raising my now 18-year-old son. From domestic violence shelters to being told 'teen mothers from the Bronx don't know anything,' and much more, urban areas are riddled with stereotypes that are eventually embedded into our DNA and make us hesitant to ask NECESSARY questions about our child's development and needs... much less to ask questions about our own needs! These same resources, while more notably available, still seem inaccessible to most.

The social-emotional needs of so many 0–3-year-olds go unmet because families in low-income areas aren't presented with the information so they can be better informed and prevent, to the best of their abilities, long-term impacts of not rendering proper medical care—physical and mental.



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You come across people in life that are meant to be for whatever the reason... No matter how man years go by, no matter how many conversations are or aren't had, no matter what the high or low points are- they are just in your

Even now, when I encounter someone who THINKS they can speak or treat myself or others in a demeaning manner because we are from a particular socioeconomic background, I think of her and remind myself there are people in the world, in OUR community that are willing to fight the good fight along our sides no matter how different they may be on paper, in color, or in any other way that others seem to feel gives them an upper hand.

ady nad this strong sense of advocacy to get nim the services he needed and not to be treated as another Bronx teen mom stereotype... but man oh man (or woman lol), when I met Dr. Briggs she lit several fires under me burn! When people ask me why I am so passionate about helping advocate for the community, she is one of the four people I give a tremendous amount of thanks to.

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## Barriers to family engagement

- Lack of trust/comfort
  - Culturally sensitive care
  - Importance of pediatric primary care, especially in the first few years
  - Need professionals who have the bandwidth to make it a comfortable/comprehensive setting
- Lack of access to services and connection between services, particularly for lower-income and rural communities
  - Closing the referral loop (many barriers, including changing phone #s and addresses)
  - Transportation; language; formats lack of accessibility, inconsistencies across services
  - Provider/professional resources and capacity makes it harder for them to support (or even identify the need for support)
- Funding/investment
  - Paying for treatment, not prevention/promotion; mental block against dyadic approach (stuck thinking in individuals as the patient)
  - Lack of reliable, robust data can make it hard to understand specific challenges and make the case for investment







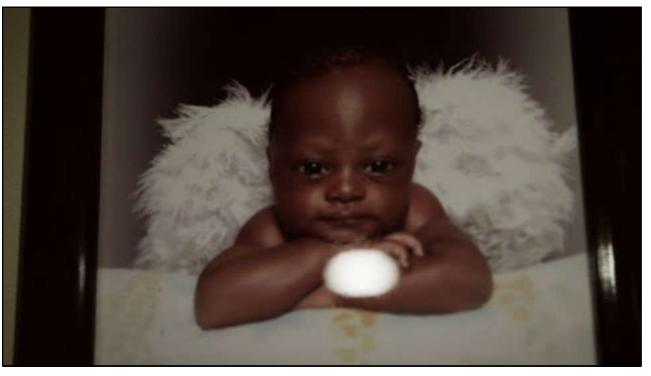
## Solutions/Strategies

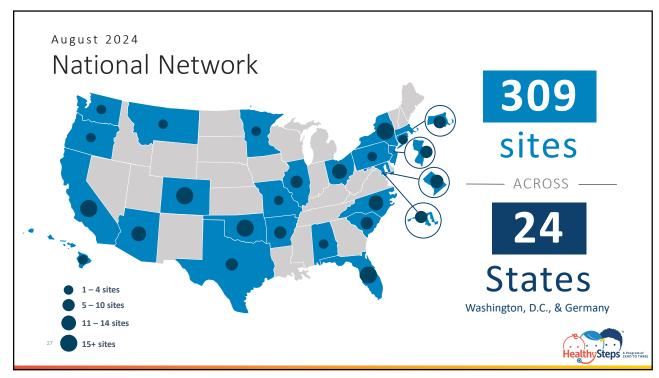
- A robust workforce that is well-trained to provide culturally sensitive, dyadic care and services, especially in pediatric primary care
  - Empowering caregivers as the expert(s) on their child(ren) making sure they have the appropriate
    information, resources, and support to set them up for success
- Team-based approaches that support improved delivery of services and connection/coordination between systems (not just one person's responsibility)
  - Importance of pediatric primary care as a connector
- Evidence-based **information/resources** for families available in multiple formats, languages informed by family needs (surveys, advisory groups, etc.)
- Technology and processes that support improved coordination and data collection across systems and the will and investment to roll them out widely and consistently
- Public investment supporting all the above
  - ★ Center family voices in all aspects "nothing about us, without us" ★











## HealthySteps in California

- Grown from 1 site in 2018 to 28 sites reaching nearly 50,000 children and their families\*
  - 9 sites in onboarding, reaching ~18,500 additional children
- 10 new HealthySteps sites in Orange County and more to come in Riverside and San Bernardino Counties
  - Made possible in partnership with First 5 and local health plans (CalOptima and IEHP)
- Expansion in Los Angeles supported by philanthropic investments from the Conrad N. Hilton and Tikun Olam Foundations

\* Data as of 9/16/24
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My family has recently moved from another state to CA and my son was previously receiving services for his disability. I was very concerned about having to start the process all over again in a new state and wasn't sure how long it would take. I was honestly dreading it, thinking my son would go months without therapy. I was surprised at the first visit to my son's pediatrician to establish care and get the referral process started for his services, [the HealthySteps Specialist] entered the room and began discussing everything from regional, school district, and Rady's services. She provided all the contact information for everyone, and she also checked in every couple of weeks to discuss the progress of getting my son assessed.

The organization and resources that were provided by the HealthySteps Specialist was so helpful to me, as a caretaker/advocate. [...]This program is so beneficial to the development of children with special needs.

- HealthySteps parent, Rady Children's Hospital



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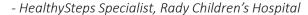
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I noticed that [the child's grandmother, her primary caregiver] has had a lot of questions about the CPS system, stating that she does not feel her social worker is very supportive, does not know how she can gain educational rights, and does not understand how to advocate for [her granddaughter]. During my calls, I provided her with guidance on navigating the system and encouraged her to call CASA [Court Appointed Special Advocates for Children] for a referral. She never knew about CASA before and was also thankful for helping me guide her through the process.

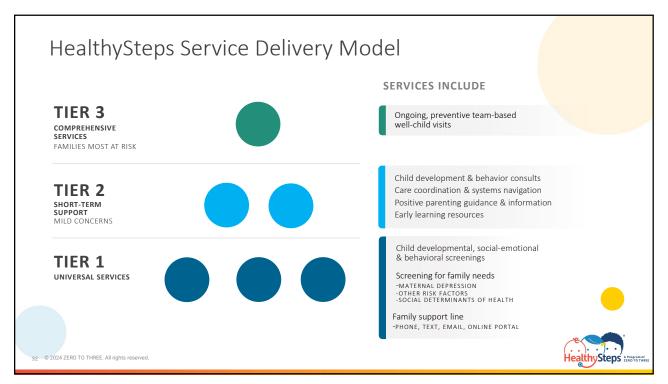
Her granddaughter is now on the waiting list for CASA and **she remains hopeful that she can continue to advocate for [her granddaughter]** with HealthySteps guidance, [Rady Children's Developmental Evaluation Clinic (DEC)] mental health support, and (soon to be) CASA's help. I am continuing to follow the family to ensure that CASA starts and to answer any questions she may have along the way regarding advocacy.



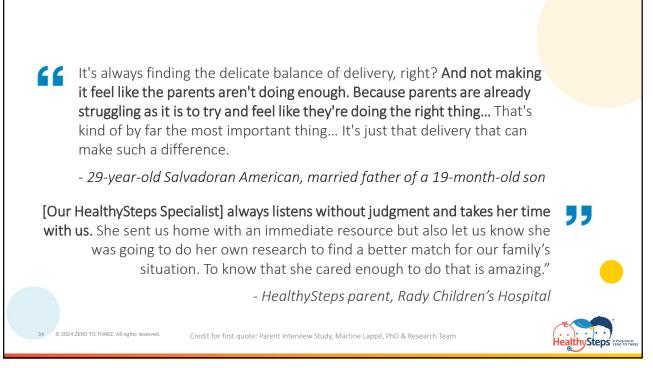


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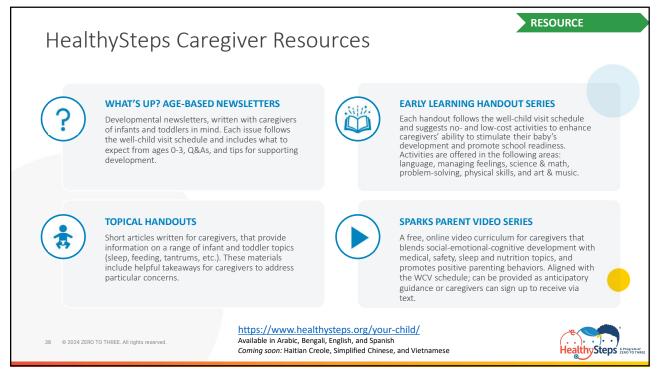














### A Smart Investment



#### CHILD-FOCUSED INTERVENTIONS

- Oral health
- Asthma\*
- Appropriate use of care for ambulatory sensitive conditions
- Flu vaccine



#### **ADULT-FOCUSED INTERVENTIONS**

- Breastfeeding
- Postpartum maternal depression
- Intimate partner violence
- Healthy birth spacing
- Smoking cessation

Annual Savings to Medicaid

## 163% AVERAGE ANNUAL ROI

Includes analyses at state, health system, and site levels with both well-established and new sites, leveraging the HealthySteps cost savings model developed by Manatt Health.

For every \$1 invested in HealthySteps, an estimated \$2.63 in savings is realized by state Medicaid agencies each year.

\*Asthma is a recently added cost savings intervention and therefore is not captured in the 163% annual ROI calculation.

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HealthySteps A Program of ZERO YOTHRE

**RESOURCE** 

### A Smart Investment

- Without a payment model to support dyadic services in primary care, we are unable to serve families effectively and are therefore forced to wait until a mental health diagnosis develops to provide a billable service.
  - → By the time this happens, the trajectory of mental illness has already set in, and it is often too late to stop it.
- With a pathway to pay for primary-care based dyadic behavioral health services (i.e., "dyadic billing"), programs like HealthySteps can support a workforce with the ability to transform the way we care for babies, young children, and their families on a population level.







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## **Timely/Continued Care and Vaccinations**



- ✓ Timely and complete wellchild visits
- ✓ Reduced disparities in wellchild visit attendance
- ✓ Timely and up-to-date vaccinations
- ✓ Better continuity of care

#### TIMELY AND COMPLETE WELL-CHILD VISITS

- HS children were more likely to attend all of the first 10 recommended well-child visits, more likely to attend 6 or more visits in the first 15 months of life (a key indicator of quality care). and were twice as likely to attend specific visits and for visits to be on time 3,4,10,14,15,
- Three HS sites found a reduced disparity between well-child visit attendance and insurance coverage; attendance rates for sites serving high proportions of children with Medicaid were on par with rates for children with commercial insurance
- Plack and Hispanic HS children with Medicaid insurance received more well-child visits and were more likely to see the same provider during a one-year period than their counterparts<sup>3</sup>

#### **TIMELY AND UP-TO-DATE VACCINATIONS**

HS children were up to 1.6x more likely to receive timely vaccinations and 1.4x more likely to be up to date on vaccinations by age  $2^{4,10,13}$ 

#### **BETTER CONTINUITY OF CARE**

- Continuity of care with the same provider was significantly better for HS children and families were nearly twice as likely to remain with the practice through 20 months<sup>3,17,18</sup>
- HS children with Medicaid insurance received more well-child visits and were more likely see the same provider during a one-year period than their counterparts

Emerging evidence includes research that has not yet been published in a peer-reviewed journal or presented at an academic/scientific conference



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## **Screening and Connection to Services**



- ✓ Early identification of child and family needs
- ✓ Improved connection to services

#### **ADDRESSING CHILD NEEDS**

- HS children were 8x more likely to receive a developmental assessment and had significantly higher rates of developmental and other nonmedical referrals.<sup>4,5,6</sup>
- A network of three HS sites (two with dedicated community health workers) found nearly 90% of families were successfully connected with needed community services?
- One HS site with a dedicated family services coordinator quadrupled its early intervention (EI) successful referral rate after implementing HS<sup>8</sup>
- Among HS children with Medicaid, receipt of any developmental screening was 1.4x higher for HS children; screening rates for Hispanic and Black HS children were 1.6 – 1.7x higher than their counterparts.<sup>3</sup>
- Among children with Medicaid, HS children had higher rates El service receipt (14% vs. 9%) which also held true for Hispanic HS children compared with their counterparts (17% vs. 1184) 3

#### **ADDRESSING FAMILY NEEDS**

- HS mothers had significantly higher rates of maternal depression referrals and were 4x more likely to receive information on community resources.<sup>4</sup>
- HS mothers with Medicaid had higher rates of receipt of family planning services and postpartum care.<sup>3</sup>

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Emerging evidence includes research that has not yet been published in a peer-reviewed journal or presented at an academic/scientific conference.



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[A family that immigrated from Guatemala came in], having a language barrier and being unfamiliar with the U.S. health system. They had a baby and did not yet have health coverage or employment.

Upon receiving HealthySteps screenings, needs were identified, and referrals and resources were offered. With our help, the parents found jobs, applied for welfare benefits, obtained Medi-Cal insurance for PT. Both parents are adjusting well and keeping up with PT appointments. Family is no longer having financial difficulties.

– HS Specialist & Community Health Worker team, Riverside University Health System

This is all I know and it's the only place that I really feel safe and accepted.





- Anna, HealthySteps parent



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### **Practice Impacts**



- ✓ Parents more satisfied with their care
- ✓ Equitable care

#### **INCREASED PATIENT SATISFACTION**

- HS families were significantly more likely to report practice staff went out of the way for them, that they relied on practice staff for advice (rather than a friend or relative) and that they received needed emotional support<sup>4,22</sup>
- HS families rated their provider as more competent and caring and were significantly more likely to believe that the health plan cared about them and to recommend their clinic to a friend or family member<sup>9,22</sup>

#### **MORE EQUITABLE CARE**

 One HS site with integrated behavioral care found that families received equitable advice regardless of race, ethnicity, or language, suggesting that HS can help mitigate existing disparities in the quality of pediatric primary care<sup>28</sup>

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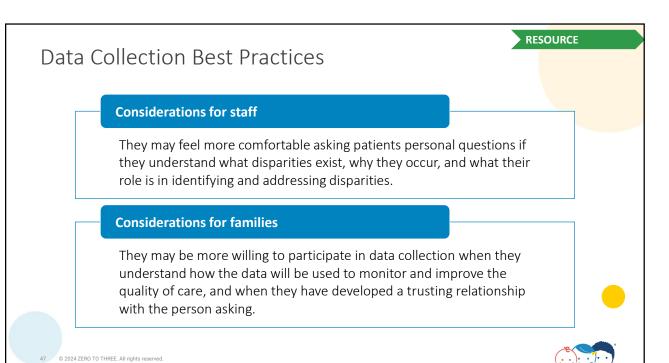
### Data Collection

- Data helps us better understand the current landscape of disparities and how to address those disparities we uncover as we strive to provide more equitable care.
- Barriers to collecting race, ethnicity, and language data include:
  - > a lack of standardization of data collection in health care settings;
  - ➤ limited (federally defined) categories families can choose from, which often do not reflect how they identify; and
  - **families' concerns around privacy** and potential discrimination based on their racial or ethnic identity.



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## Data Collection: Epic® Turbocharger Package

**RESOURCE** 



Current electronic health records (EHR) platforms are rarely equipped to adequately capture pediatric and family-based behavioral and social care needs, leaving practitioners with minimally effective documentation and collaborative tools to deliver care.

- We worked with a health IT consulting firm to design a HealthySteps workflow in Epic® that would help improve the team-based pediatric care experience by streamlining documentation and reporting, reducing clinician burden, and improving efficiency—allowing providers to have more meaningful and consistent interactions with patients and their families.
- This workflow is now available as a complimentary collection of records (the Epic® HealthySteps Turbocharger Package), allowing practices to import and integrate the workflow guidelines more quickly and easily.

"[The Turbocharger supports] seamless communication amongst all providers with a family."

- HealthySteps Specialist, Rady Children's Hospital



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## Family-Centric Design

RESOURCE



Examples of formalized family engagement approaches at ZERO TO THREE:

- HealthySteps Family Advisors
- Pediatrics Supporting Parents
- Safe Babies Parent Leaders

Helpful resource: Family Voices' <u>Family</u> <u>Engagement in Systems Assessment Tools</u> (FESAT)

 Self-assessment that early childhood organizations can use to plan, assess, and improve family engagement in policies, programs, and other systems-level initiatives.



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## **Family Advisory Purpose Statement**

The HealthySteps Family Advisory Group supports the expansion of services to help make materials and programming more approachable and user friendly for real life families. We are deeply dedicated to an allinclusive experience for every family, every dynamic, every (healthy) step of the way!

healthysteps.org



#### **RESOURCE**

### Call to Action – We Can't Wait → We Don't Wait

- Think about your work, the system(s) you're a part of and/or have influence over.
  - Are there things you can start doing on your own? Are there things that may be feasible on a larger scale?
- Share resources with your team, especially leadership when possible; ask:
  - "How do we think about family engagement as part of our work and overall guiding strategy?"
  - "Did you know that there is [RESOURCE] from [CREDIBLE SOURCE]?"

Consider different ways to share... is it in a conversation with your supervisor and/or supervisees, in a team meeting, in a digital channel, a brown bag lunch and learn.

Are there others you work with that are willing to advocate with you?

- What positive outcome(s) will this approach offer? Make sure that's part of your pitch.
  - When possible, include tangible examples of professionals and families validating the value of implementing the resource/strategy
  - Back it up with data when possible



**RESOURCE** 

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## think Advocacy Resources

Visit ZERO TO THREE's Think Babies<sup>TM</sup> website for <u>advocacy resources</u>, including

resources and templates for events that center family voices in your advocacy.



INFANT-TODDLER ADVOCACY TRAINING

**INFANT-TODDLER POLICY FORUM** 

FAMILY LISTENING SESSION

**ENGAGING FAMILIES IN POLICY CHANGE** 

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We need advocates for families that can't advocate for themselves. Maybe because they don't have the capacity to, they don't have the means to, the list goes on. But I feel like it's not fair to let people slip through the cracks.

### Why not have a safety net?

And the medical system has let me slip through the cracks quite a bit... so I think having advocates connected to it would help.

- 26-year-old Native American, single mother of a 3-year-old daughter



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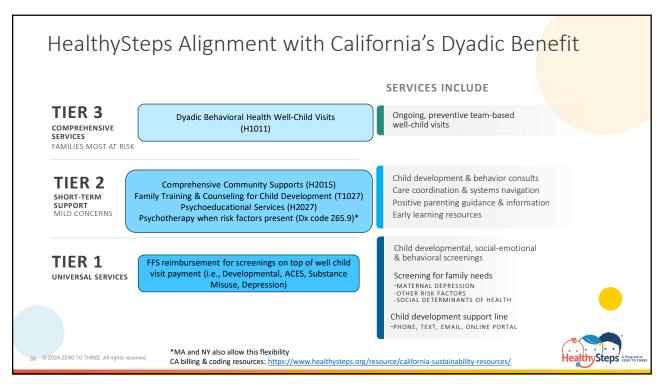
Credit: Parent Interview Study, Martine Lappé, PhD & Research Team











#### RESOURCE

## Parent Leaders: Keys for Implementation

- There is a **high level of commitment** to support parent leadership.
- There are at least two parent leaders to support each other and represent parent voice at the site, state, or national level.
- There is an **identified staff support person** within the program committed to parent leaders that can provide a reflective space and can ensure parent leaders have adequate preparation, time to debrief, and support within the team.
- There is clarity of everyone's role, and it is clearly explained to all, including parent leaders.
- Parent leaders have the information and resources they need to participate (for example, virtual accessibility, interpreters, etc.).
- Parent leaders have **equal voice/partnership** with the other professionals on the team.
- Parent leaders are **representative** of the races, ethnicities, gender, cultures of the state/site demographics.
- Parent leaders are able to bridge the gap between families and other professionals in the decisionmaking process of practice change.



Parent leaders are active participants in priority initiatives/collaboratives.

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Adapted from ZERO TO THREE, Safe Babies, "Parent Leaders Are Vital for Stronger Early Childhood Systems," 2023.

