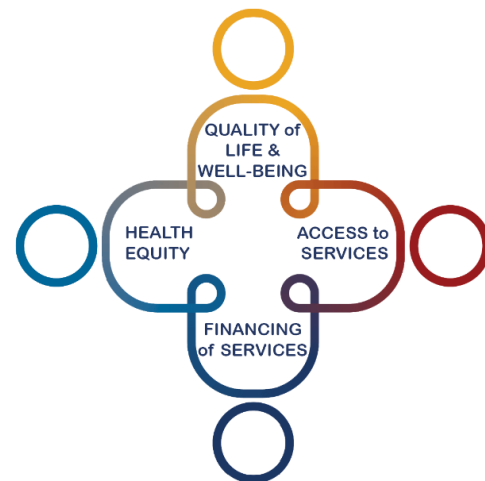


Asking the Money Question:

The Intersectionality of
Money Stress and Early
Supports for
Families with D/HH Children



Critical Areas for a Well-Functioning System

Jodi Roberts, MS, parent
Sara Kennedy, parent, Hands & Voices

**“It is important for providers to
ask the money question.”**

Today's Learning Objectives

Participants will describe or identify...

1. How SES factors impact access to essential resources, early intervention, and specialized education programs for D/HH children (especially birth to 8)
2. Two potential solutions and strategies suggested by families themselves
3. Three potential best practices or resources that can increase access to needed services.



Be careful at the EHDI poster session:



Where were parents from?



24 states, + B.C.

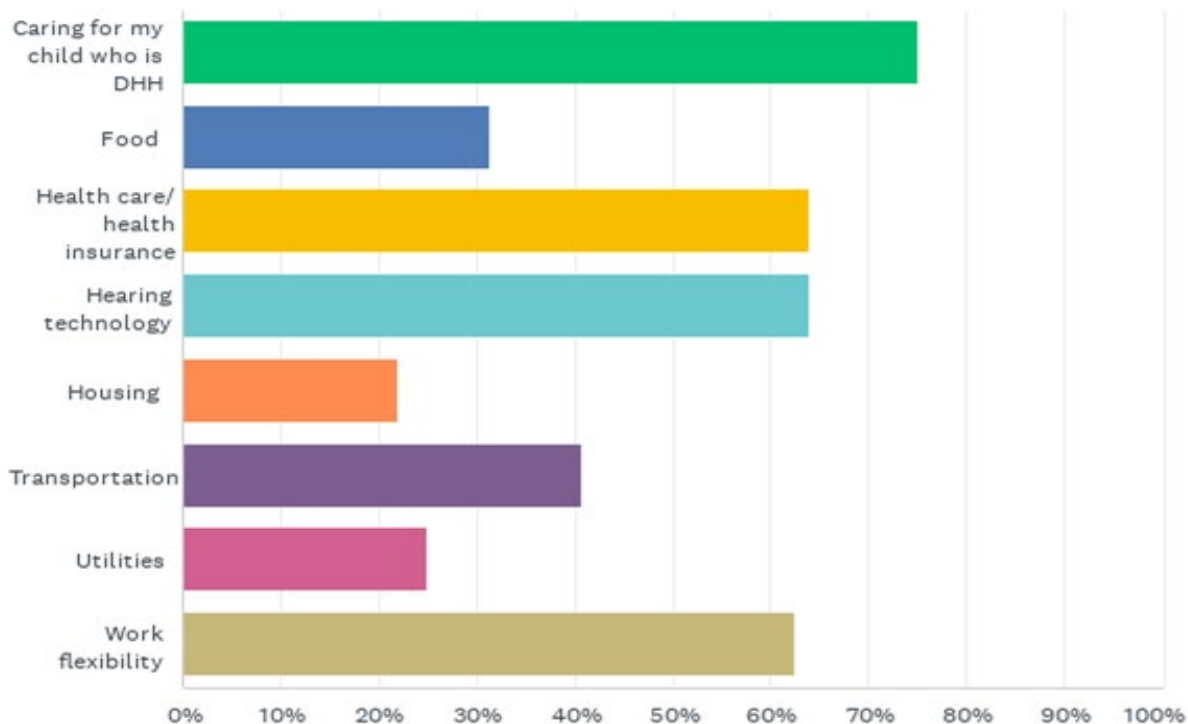
- 15 Urban*
- 24 Suburban*
- 21 Rural*

2 anonymous

Total: 62 analyzed

*self-identified

Q4 These issues are sources of money stress related to my child. (Check all that apply)



Caring for my child

“She needs trained Interveners as PCAs/caregivers. She does not qualify for the major respite facility...she does not have a condition known to be life-threatening.

The typical person getting respite needs nursing services.

My daughter is deafblind with quadriplegic cerebral palsy making her 100% dependent for communication and ADLs.

But she does not need a respirator, a feeding tube or infusions.”

Caring for My Child, Results

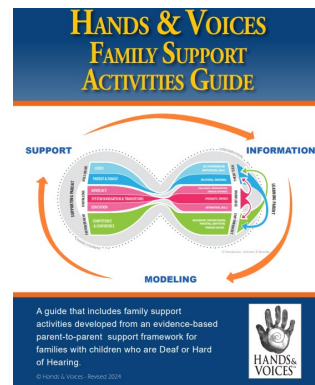
75.4% Caring for my child who is DHH: 46/61

- 10/15 urban, 18/24 suburban, 18/21 rural

Policy improvement ideas from parents

“More deaf friendly daycare options- like every district that has a centerbased preschool should have a centerbased daycare, preferably gov’t funded for DHH kids.”

- Childcare: Local ideas: Virginia, 2-1-1
- Family Support Orgs, Guide By Your Side Programs
- Rural Families: <https://handsandvoices.org/virtual-waiting-room/docs/ruralliving.pdf>



Healthcare/Health Insurance

“Paid out of pocket (private pay insurance wouldn’t cover hearing aids) for years. (A) group of WOMEN went to the state legislature and got a rule change and now they are pretty much covered. Not sure if every child who needs them gets them covered but it is better, at least until age 26 then we’re on our own again.

So yes, it is stressful.”

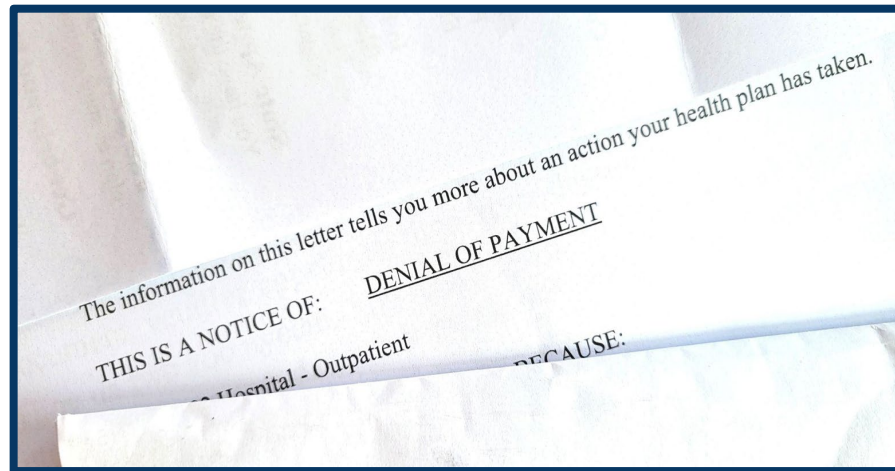
Health Care/Health Insurance, Results

65.6% Health Care / Health Insurance:
40/61

- 10/15 urban,
- 15 /24 suburban,
- 14/21 rural,
- 1 unknown

“Talk to billing departments and ask about discounts/write-offs.”

- Medicaid buy-in
- Parent as CNA



Federally Qualified Health Centers
have case management for lower SES families.

“Hearing aids are too expensive even with what little insurance covers. Earmolds are not covered.”



COLORADO
HANDS & VOICES
Fall 2013



- Ally's Act
- ELSA

Hearing Technology, Results

63.9% Hearing Tech: 39/61

- 11/15 urban, 15/24 suburban, 13/21 rural

Suggestions from parents for system:

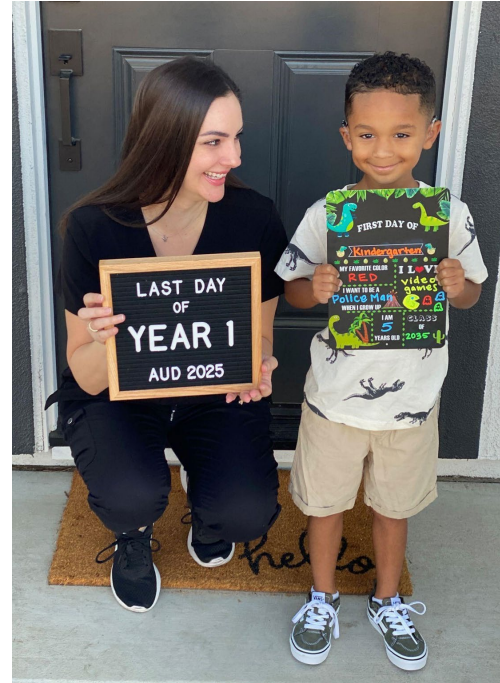
- Audis: Ask if we need help with funding
- Explore that with us or find someone who can
- Refer early - especially DHH Plus to additional assistance quickly (waitlists, etc.)



Transportation / Work Flexibility

“Found about medical transport via my state medical coverage though it was not reliable.

Drivers would get lost trying to find my address and then made us late to our medical appointment.”



Transportation / Work Flexibility, Results

42.6% Transportation: 26/61

- 4/15 urban, 8/24 suburban, **13/21 rural (61.9%)**, 1 unknown

59.0% Work Flexibility: 36/61

- 8/15 urban, 15/24 suburban, 13/21 rural, 1 unknown

Best practice idea:

- “Intensive care coordinators/care coordinators are a great resource for being able to manage services.”

Worries from parents:

- “Keeping your job with all the medical appointments even with FMLA”
- “Taking unpaid time for appointments or Sped meetings at school.”
- “Most reputable specialist care is at least 300 miles away.”

Transportation: A rural case study

First year as a parent, medical only:

30 appointments to NICU, Pediatrician,
Audiology:

- 7200 miles (240 miles round trip)

6 appointments to medical specialty services:

- 3312 miles (552 miles round trip)

10,512 miles: Total miles est first year



Parent best practice suggestion:

Training for what it is like to travel long distances, what it means for parents.

Try to find joyful moments in the long travel days & early years.

*Medicaid reimbursement for travel, *telehealth

“What is my child missing?”



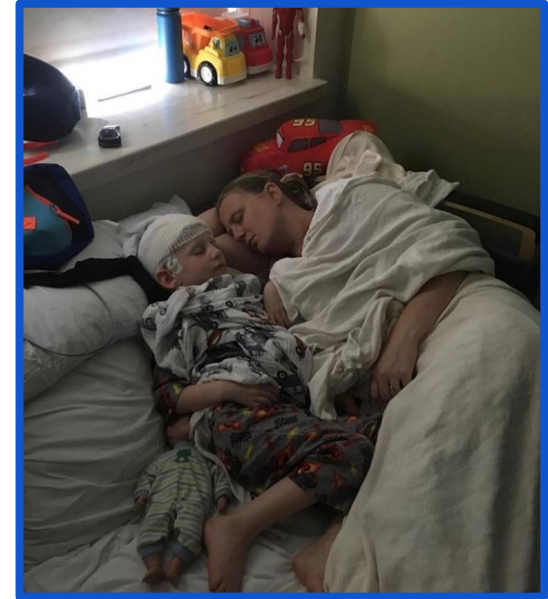
Parents' Wishlist

- Make it possible for parents to stay home during the first year of life.
- Reduce shame.
- Support quality childcare options during this critical language growth period.
“Making do hurts kids.”
- Help with high speed internet (that can handle VRS).
- Easy ways to learn about financial supports, waivers, and other services that might be available.



What do lower SES DHH Plus families face?

- Be mindful of the burden of care.
- Employment needs: Can't work regular hours. Parents as CNA's for medically complex kids (limited states have this program).
- Training for healthcare / social workers / other 'support' to help them understand caring for a DHH Plus child
- [DHH Plus Guide](#)
- [Neverending Story: A DHH Plus Mom's Need for Community](#) / Kristin Stratton, H&V Military Project



Comments from parents that worried us

“No help for families with jobs.”

“Took a long time to learn about waiver programs.”

“My husband and I have never been on a date.”

“Too smart to qualify for an IEP.”

“We were only offered Zoom EI, and 4 visits per year.”

“Didn’t know about grants/charities to support purchasing HA’s or therapy.”

“Mental health therapy has high co-pays or is cash only.”



Why does this matter?

Lower socioeconomic status can limit access to EHDI 1-3-6 and beyond.

How will you use this information...

- to make a difference in your local EHDI system?
- In your audiology or therapy practice?
- In your early intervention practice?
- In your family support program?



SurveyMonkey link: <https://www.surveymonkey.com/results/SESSurvey>

Thank you!



Survey
here
closing
April 1!

Jodi Roberts, Mom, MS: robe2398@umn.edu

Sara Kennedy, H&V: Sara@handsandvoices.org

Money Stress Survey: https://www.surveymonkey.com/results/SM-Ow5A1lgkxwGGaEkLo36aSw_3D_3D/