

# As you're joining, please chat in:

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- Interest in and/or experience with organizational health literacy

# Applying Organizational Health Literacy for Health Equity in Early Childhood

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**Lindsay Rosenfeld, ScD, ScM**  
**Cathy Leslie, PhD, OTR/L, CEIS**



## Lindsay Rosenfeld



- Public Health Professional (ScD, ScM)
  - Research: Brandeis University
  - Practice: National Network of Public Health Institutes
  - Teaching: Harvard T.H. Chan School of Public Health
- Parent of two kids with complex medical/developmental journeys

## Cathy Leslie



- PhD in Rehabilitation Science
- Pediatric Occupational Therapist
- Previously an Early Intervention Provider
- Higher Education Faculty, Researcher

# Session Objectives

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1. Identify the components of organizational health literacy.
2. Explain the relationship between organizational health literacy, health equity, and early childhood research and practice.
3. Explore implementation of organizational health literacy best practice in early childhood.

# Healthy People 2030: Health Literacy



- Health literacy is a central focus of Healthy People 2030.
- One of the initiative's overarching goals demonstrates this:

**“Eliminate health disparities, achieve health equity,  
and attain health literacy to improve  
the health and well-being of all.”**

# Definition of Health Literacy

## Healthy People 2030

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### Personal Health Literacy

- The degree to which **individuals** have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

### Organizational Health Literacy

- The degree to which **organizations** equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

# 2022 Health Literacy Compilation Report



HEALTH LITERACY IN  
THE UNITED STATES  
Enhancing Assessments  
and Reducing Disparities

CLAUDE LOPEZ, PHD, BUMYANG KIM, PHD,  
AND KATHERINE SACKS, PHD



## Continued mismatch between the skills of the public and system demands.

- **At least 88 percent of adults living in the US have health literacy inadequate to navigate the healthcare system and promote their well-being**
  - 55 percent intermediate proficiency, 22 percent basic proficiency, and 14 percent below basic proficiency
  - Only 12 percent are proficiently health literate
- **Adults with lower health literacy are more likely to:**
  - return incomplete medical forms/assessment tools
  - miss appointments with health providers
  - neglect follow-ups to required medical procedures
  - postpone communications with health providers
  - have difficulty maintaining consistent medical histories

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# Organizational Health Literacy & Child Health

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## Health Literacy: Implications for Child Health

Morrison, A. K., Glick, A., & Shonna Yin, H. (2019). Health literacy: Implications for child health. *Pediatrics in Review*, 40(5), 263–277

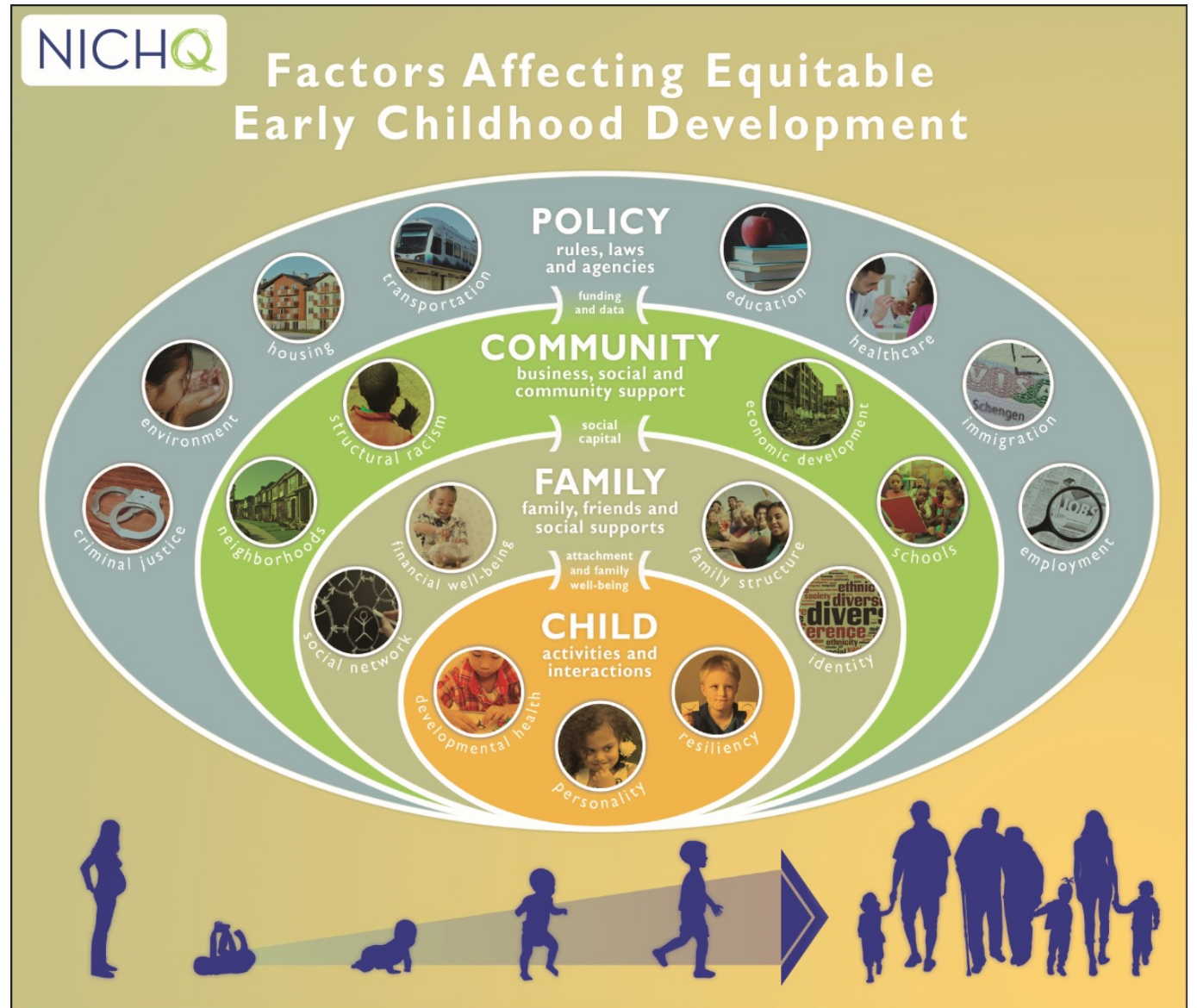
- Parent literacy impacts child health – and **system is part of the problem**
- Need for organizational health literacy to “**align health-care demands with the health literacy skills of families**”
- 1 in 4 parents have skills that **don’t match system demand**
- Use a “**universal precautions approach**” in use of clear communication strategies

<https://pubmed.ncbi.nlm.nih.gov/31152099/>



# In Context: Structural and Systems Perspectives

- Health Literacy
- Equity: health, racial, gender, disability, & more
- Social Ecological/Multi-level
- Social and Structural Determinants of Health
- Life Course
- Family Engagement



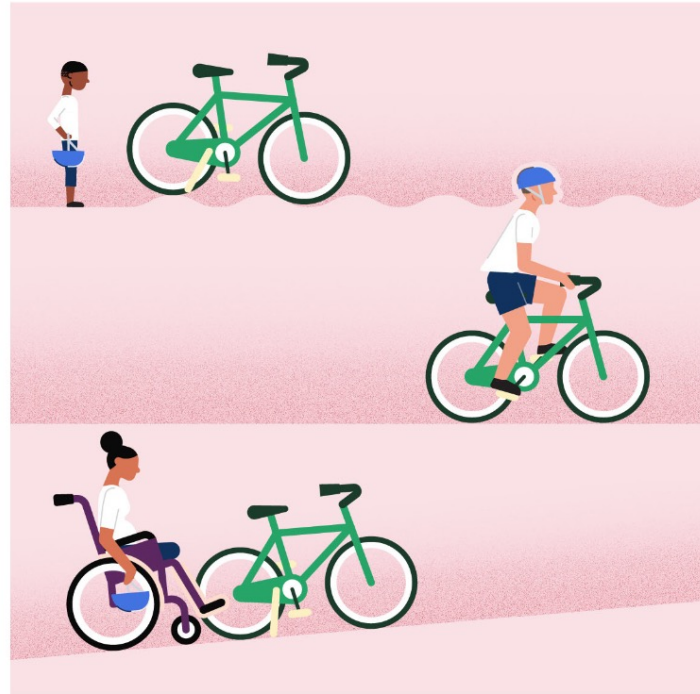
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# Organizational Health Literacy Can Help Improve Equity in Early Childhood

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## EQUALITY:

Everyone gets the same—regardless if it's needed or right for them.



## EQUITY:

Everyone gets what they need—understanding the barriers, circumstances, and conditions.



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# In Context: Structural and Systems Perspectives

- **Health Literacy**
- Equity: health, racial, gender, disability, & more
- Social Ecological/Multi-level
- Social and Structural Determinants of Health
- Life Course
- Family Engagement

## Health Literacy is an Interaction



# Health Literacy as an Interaction: Questions Across Domains

Shown in context of *Health Literacy as an Interaction* [Rima E. Rudd, 2022]

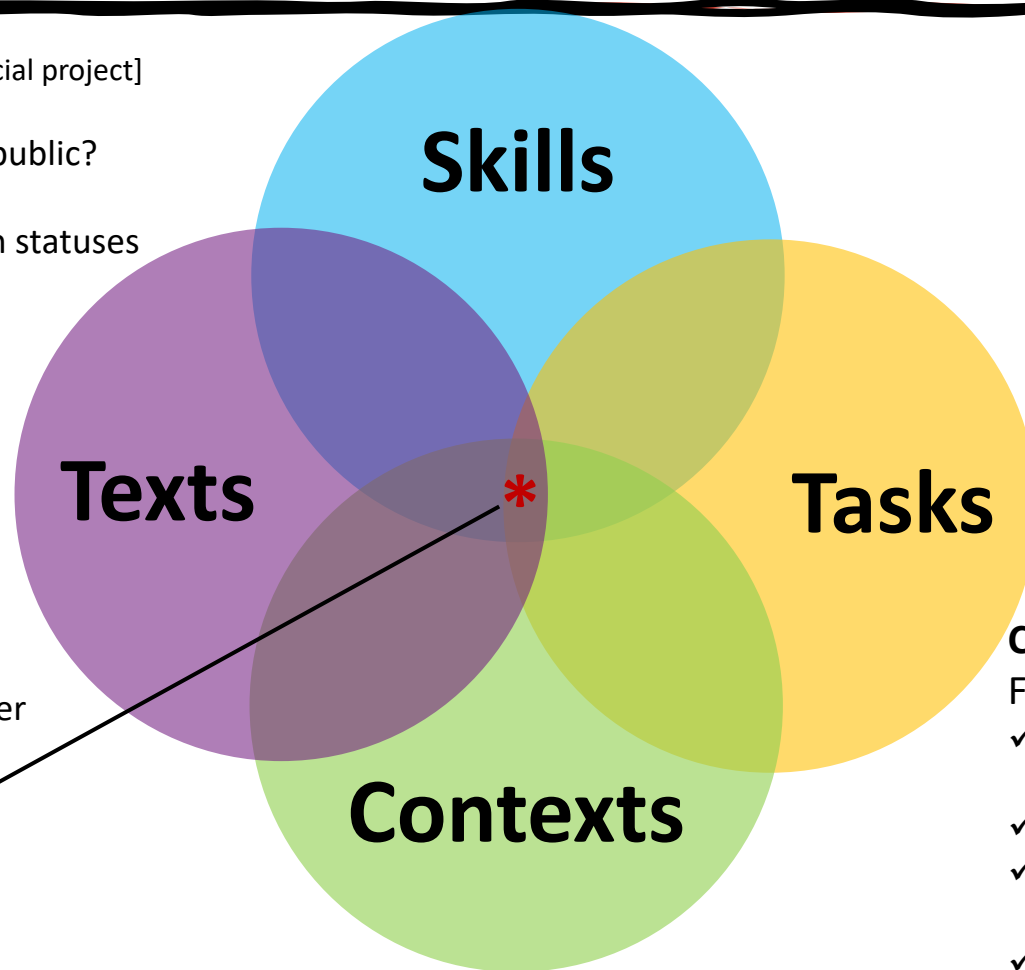
## Skills of Individuals: [research or special project]

- ✓ What are the skills of individuals/public? (use available data)
- ✓ How do skills change across health statuses or the life course?
- ✓ What sectors can I partner with to increase equity in skills?

## Texts:

- ✓ What is the demand of the text?
- ✓ Does demand match individual/population skills?
- ✓ How can the burden of the text be reduced?
- ✓ Where are plain language and other best practices being followed?

**Health  
Literacy**



## User Engagement across all Domains:

What does the public say about the ease of getting services or care?

## Skills of Professionals:

- ✓ Is health literacy training required?
- ✓ Where are staff using evidence-based methods, e.g., teach back?
- ✓ When are professionals engaged in discussions about systems improvement?

## Tasks - Activities:

- ✓ What are the steps to complete a common task, e.g., finding or using a service?
- ✓ Who and what is involved in completing the task?
- ✓ How can individual burden be reduced?

## Contexts – System Level

### Facilitators & Barriers:

- ✓ What is the experience of finding or using a service?
- ✓ What aids or complicates a task across levels?
- ✓ How can someone get help, i.e., in-person, online, or completing a task?
- ✓ What policies and practice reduce the burden?

# Organizational Health Literacy Case Study



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# Case Study Manuscript

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- McManus, B. M., Richardson, Z., Schenkman, M., Murphy, N. J., Everhart, R. M., Hambidge, S., & Morrato, E. (2020). **Child characteristics and early intervention referral and receipt of services: a retrospective cohort study.** *BMC Pediatrics*, 20(1), 84. <https://doi.org/10.1186/s12887-020-1965-x>

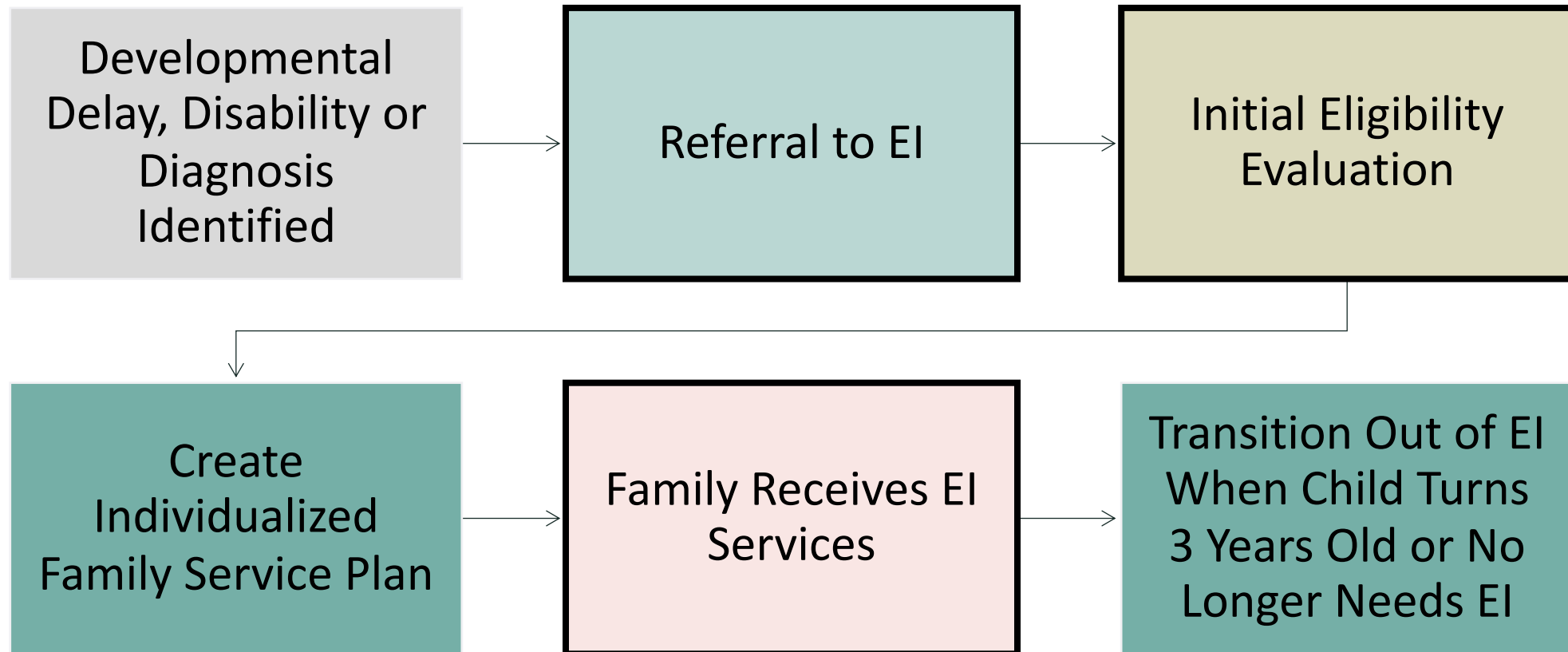
# Manuscript Background

(McManus et al., 2020)

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- What is Early Intervention (EI)?
  - Federally mandated, state-administered system for children with developmental delays and disabilities under the age of three.
  - Part C of the Individuals with Disabilities Education Act.
- Gaps exist in the process of families accessing EI through pediatric primary care.
- Low rates of EI access are well documented and disproportionately affect poor and minority children.
- Evidence reflects that many referrals are missed due to simple oversight or communication failure between primary care, EI, and families because referral outcomes often are not formally tracked.
- This study followed EI-referred children in an urban safety-net population with high rates of developmental delay longitudinally to understand EI service use gaps from EI referral to EI service utilization.

# Early Intervention (EI) Services Process



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# Manuscript Aims, and Methods

(McManus et al., 2020)

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## Aims

- To examine child characteristics associated with gaps in EI 1) referral, 2) access and 3) service use.

## Methods

- Retrospective cohort design: 14,710 children with developmental disability or delay.
- Linked pediatric primary care records between a large, integrated safety net health system in metro Denver and its corresponding EI program (2014–2016).
- Estimated gaps in EI referral, access, and service type (ex., physical, occupational, and speech therapy, and developmental intervention).

# Study Results and Conclusions

(McManus et al., 2020)

## • Results (Abbreviated)

- Cohort: 14,710 children with developmental disability or delay identified
- Referred to EI: Only 2,746 (18.7%) of those EI-eligible were referred
- Accessed EI: Only 722 (26.3%) of those with a referral received an IFSP
- Service Use: Only 571 children initiated EI services
- **Overall net enrollment rate of less than 5% of the 14,710 EI-eligible children**
- Children who were Black, non-Hispanic (BNH) were less likely to be referred to EI.

## • Conclusions

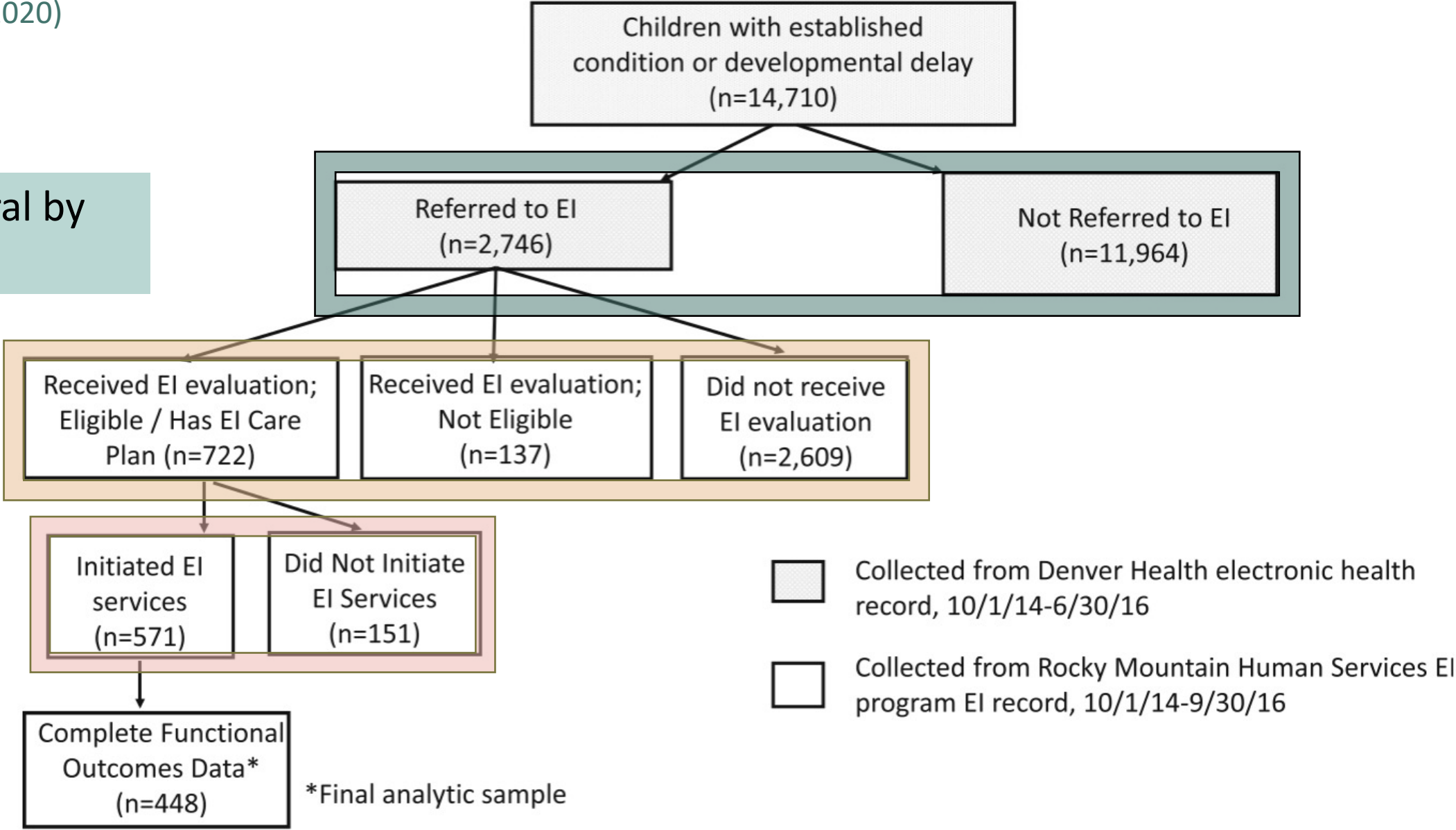
- Gaps in EI referral, access, and service use were identified.
- Study findings suggest a need for improved family engagement, as well as communication and coordination between pediatric primary care and EI systems at each step of the EI enrollment process.

(McManus et al., 2020)

Step 1: Referral by pediatrician

Step 2: Access: Eligibility Evaluation

Step 3: Service Use



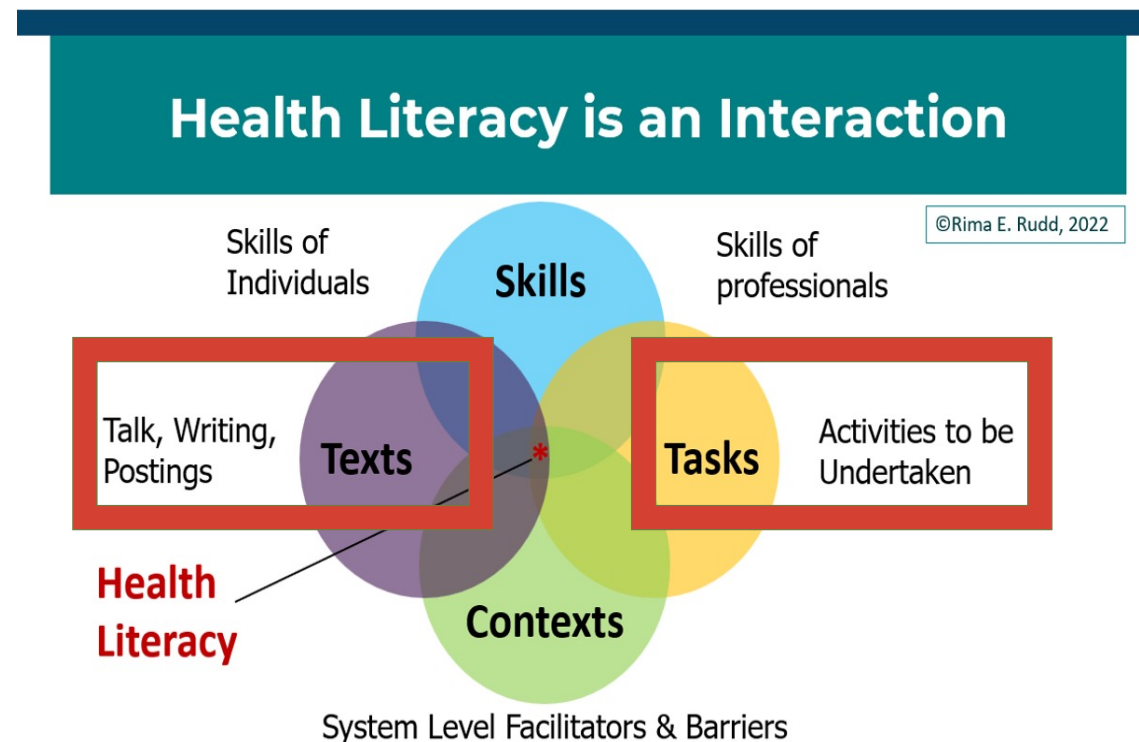
**Fig. 1** Consort Diagram of Study Sample Selection

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# Activity: Case Study

- **Goal:**
  - Focus on Texts and Tasks components (organizational Health Literacy model) to identify possible barriers and facilitators to success for families during the EI services process.
- **Breakout rooms**
  - Each room will be assigned one of 3 steps of the EI process to discuss
    - **Step 1: Referral to EI**
    - **Step 2: Access- Completed an eligibility evaluation**
    - **Step 3: Service use- EI services started**
  - Focus on 2 of the 4 components of the OHL model
    - **Tasks and Texts**



# OHL Components for Case Study

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## Tasks

- What are the steps to complete a common task, e.g., finding or using a service?
- Who and what is involved in completing the task?
- How can individual burden be reduced?

## Texts

- What is the demand of the text?
- Does demand match individual/population skills?
- How can the burden of the text be reduced?
- Where are plain language and other best practices being followed?

# In Your Breakout Room

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- Introduce yourselves.
- Use the Google doc and scroll to find your breakout room number.
  - Google doc link: <https://tinyurl.com/HARC-2023-Activity>
- During your discussion, please add some facilitators and barriers related to your assigned step in the EI process in the textbox.
- As a group, decide on 2 insights/ ah-ha moments to share with the larger group in the chat or during our discussion.

# Discussion/Questions

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(McManus et al., 2020)

Step 1: Referral by pediatrician

Step 2: Access: Eligibility Evaluation

Step 3: Service Use

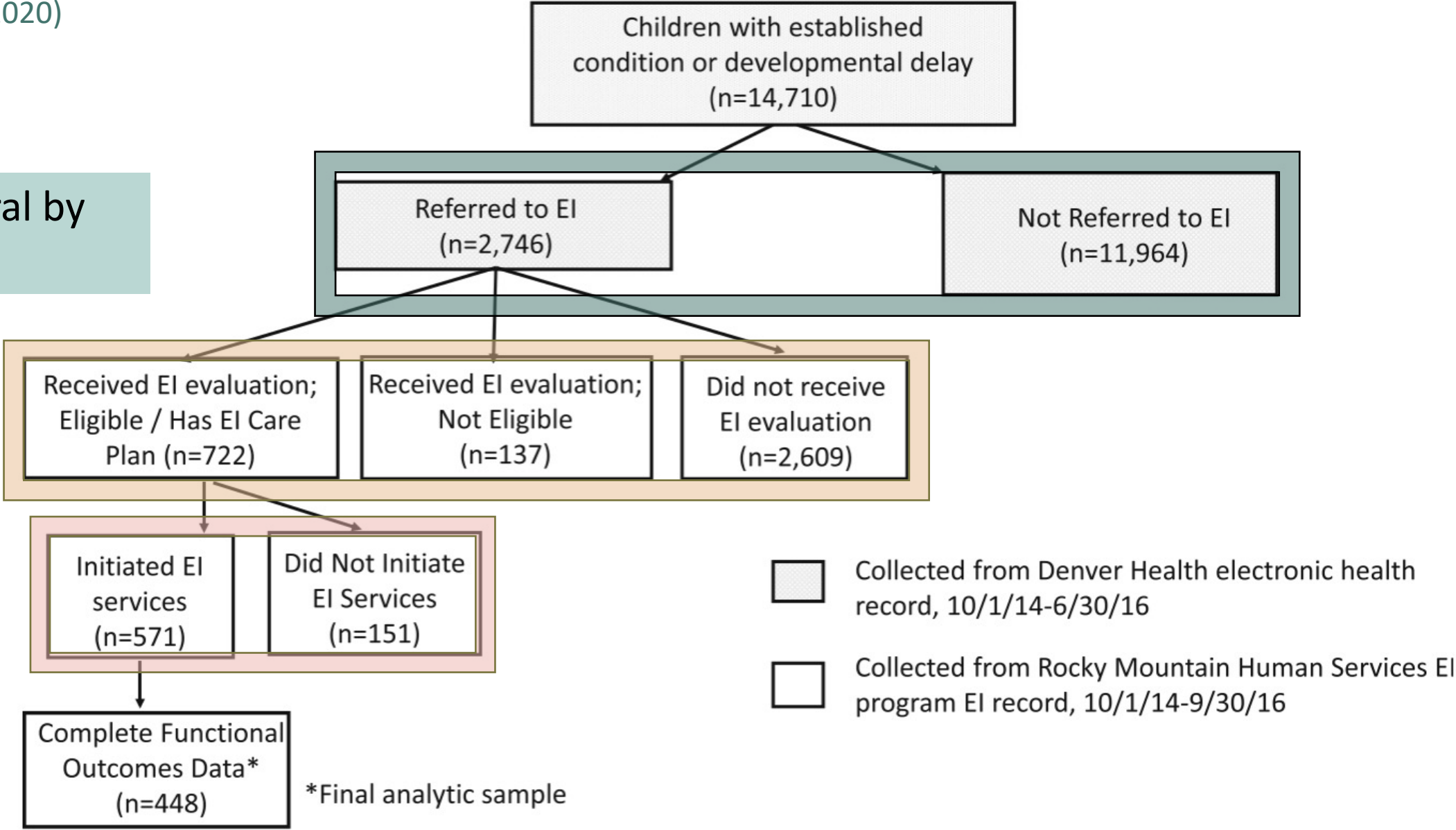


Fig. 1 Consort Diagram of Study Sample Selection



# Thank You!

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