

Weighted Family Perceptual Factors Impacting Early Intervention Services for Children who are Deaf and Hard of Hearing

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INTRODUCTION

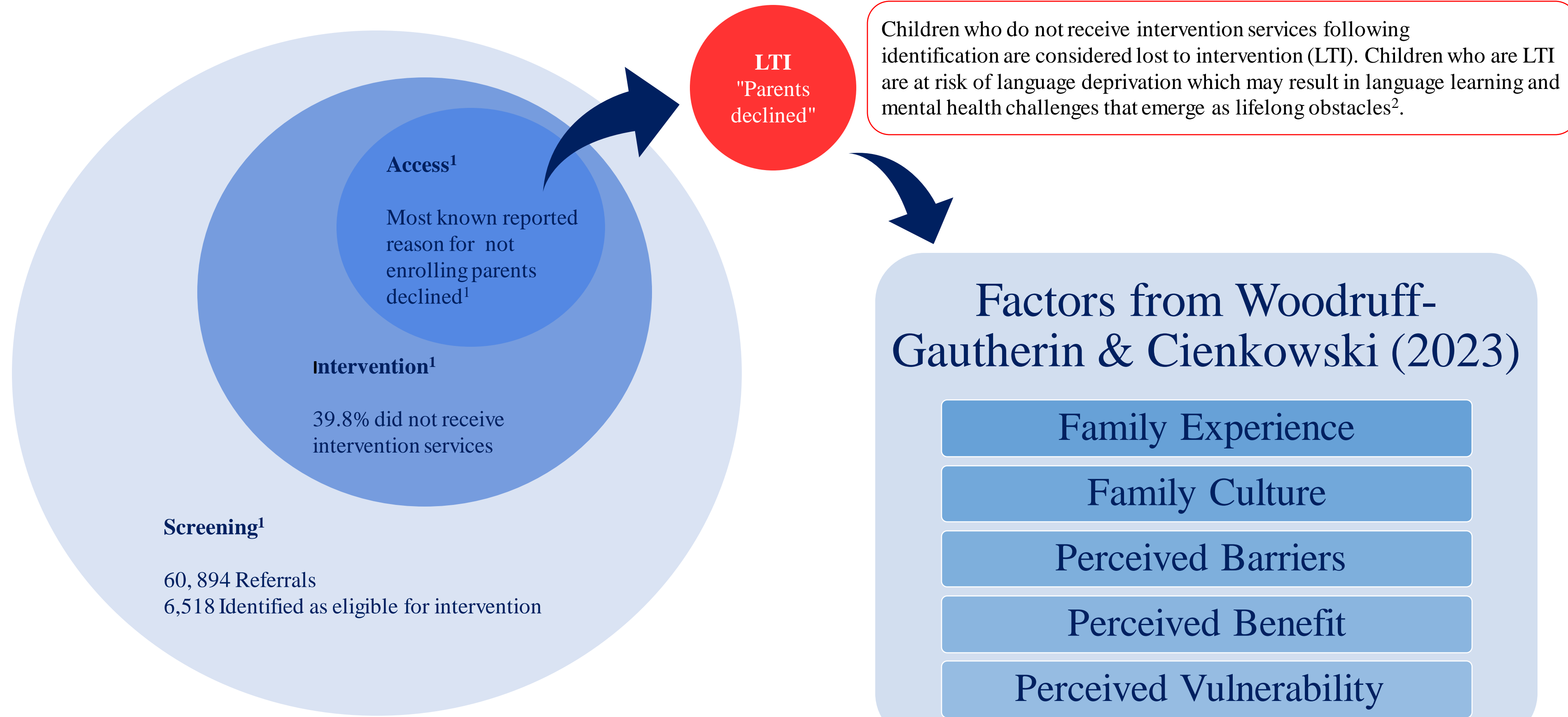


Figure 1. Illustration of children referring from newborn screening and diagnostic identification of D/deaf or hard of hearing to percent receiving services to most known reported reason to not access services.^{1,3}

Factors from Woodruff-Gautherin & Cienkowski (2023)

- Family Experience
- Family Culture
- Perceived Barriers
- Perceived Benefit
- Perceived Vulnerability

Figure 2. Factors identified by Woodruff & Cienkowski (2023).

Purpose

The following presentation is a review of the Weighted Factors study investigating the five identified factors from Woodruff-Gautherin & Cienkowski (2023) and the relative impact of their influence on those LTI from the perspective of a panel of experts.

RESULTS

Participants

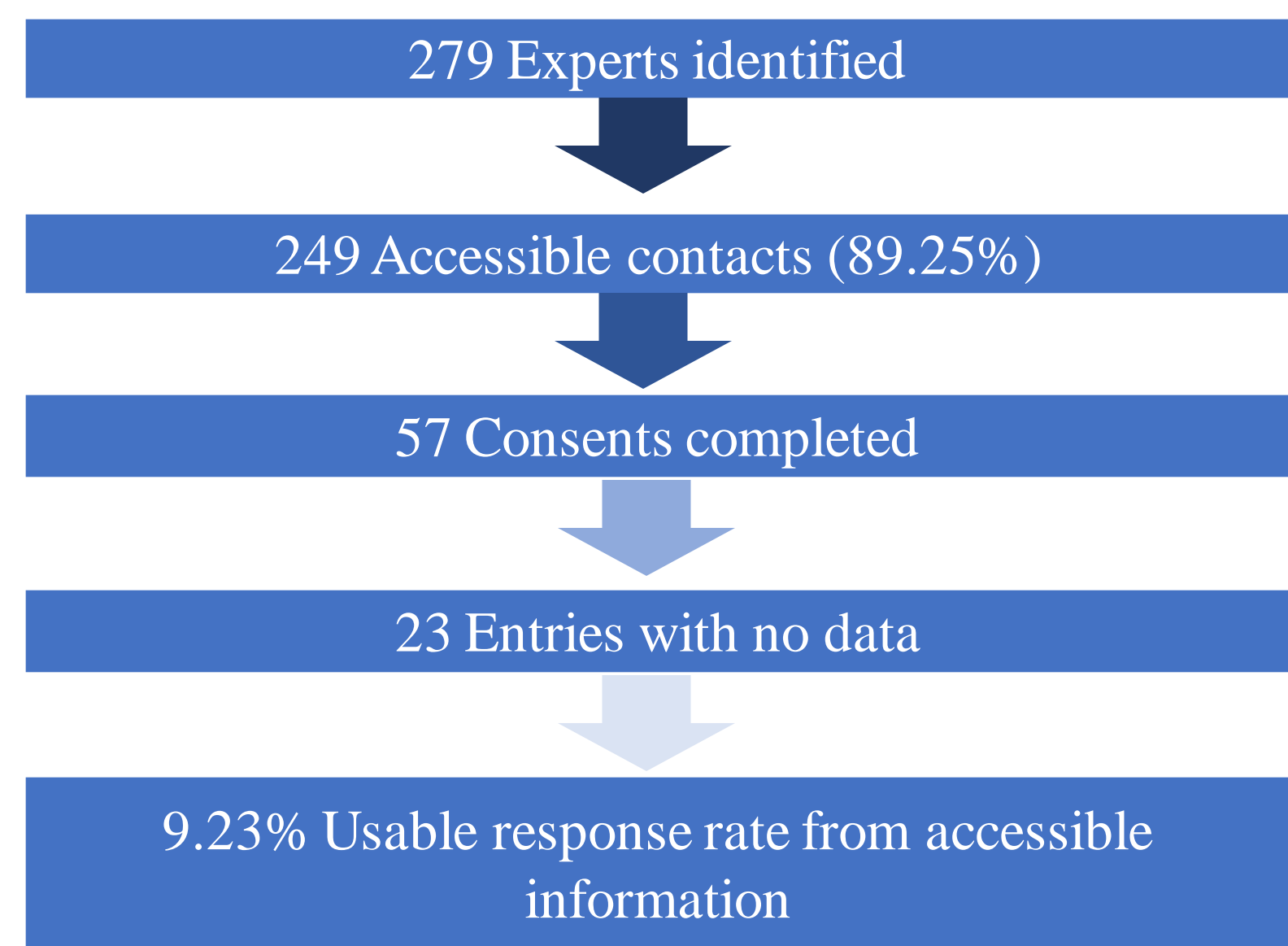


Figure 6. Participant breakdown.

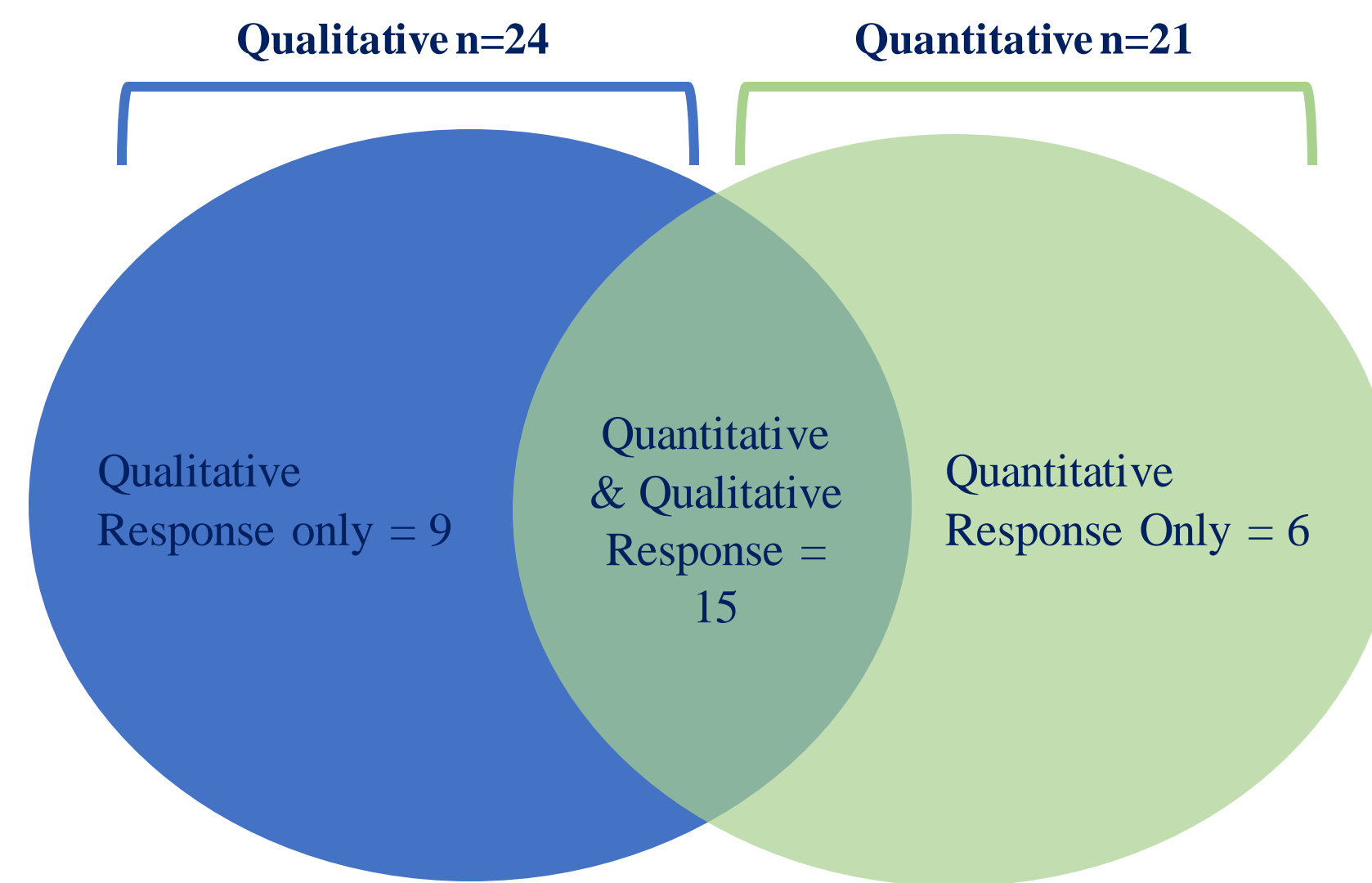


Figure 7. Types of responses received (n=34).

Statistical Analysis

Pair-wise analysis using Wilcoxon signed-rank testing did not yield any significant differences ($p > .05$) between any of the five parameters accessed in this study and described in the original model.

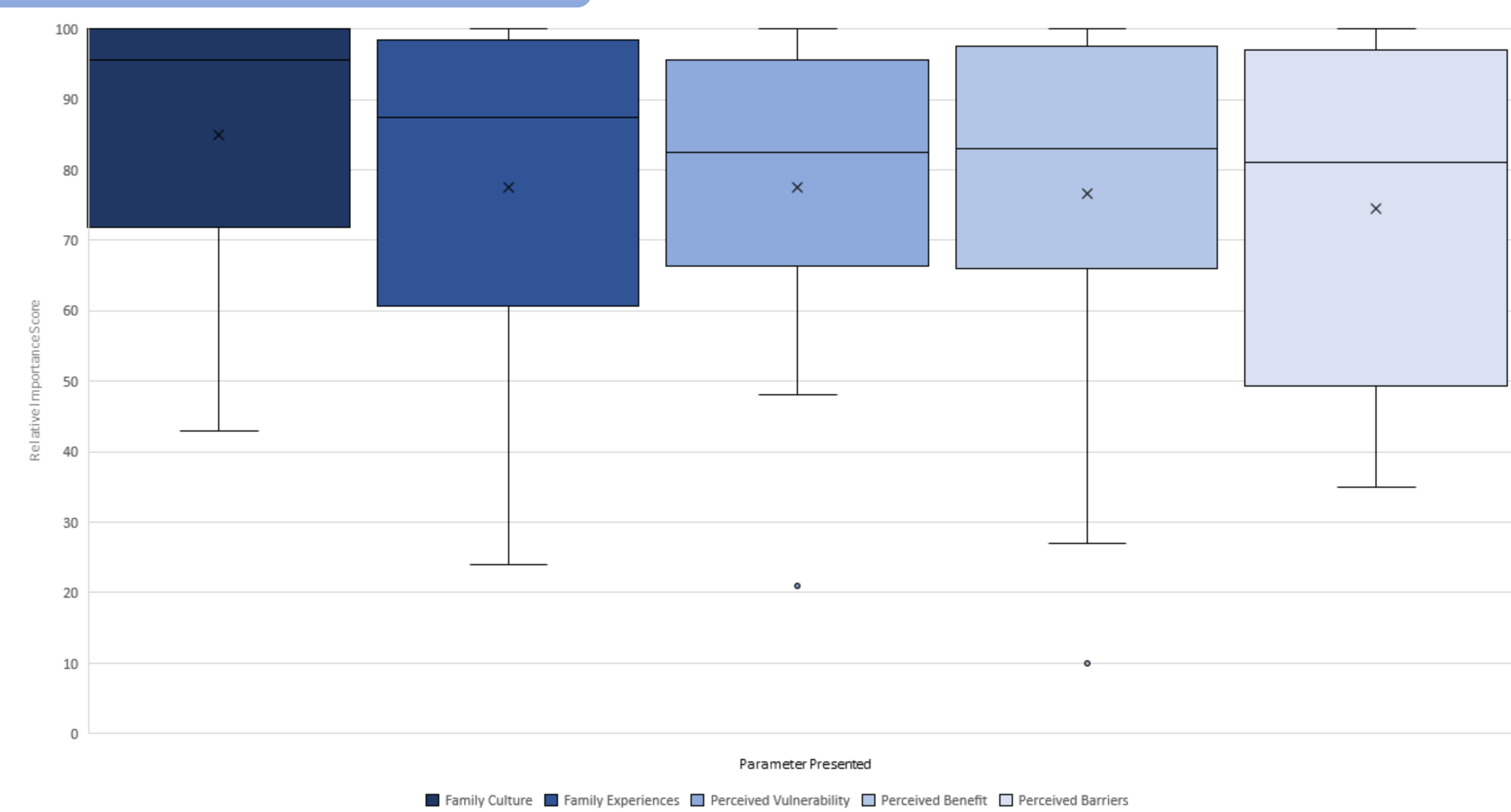
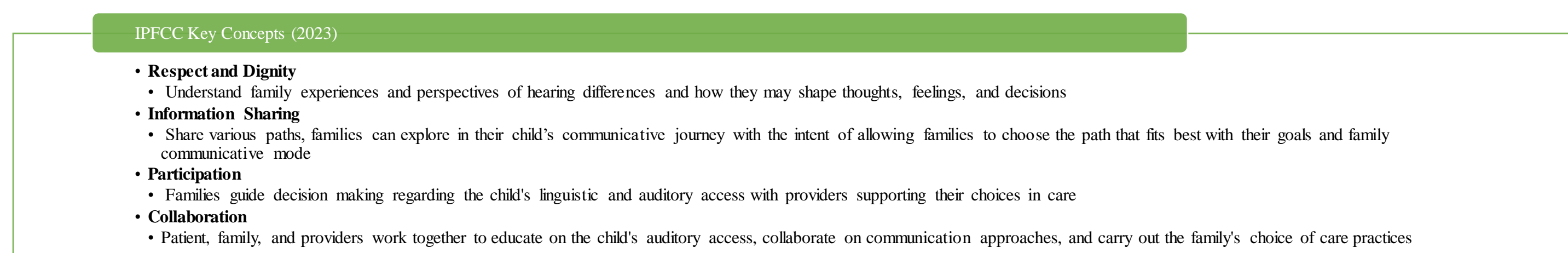


Figure 8. Descriptive Statistics of Quantitative Participant Responses.

FUTURE DIRECTIONS

Future Directions for Clinical Care



It is vital to adopt these practices at the root of family-centered care to honor patient and family needs throughout their journey.

Figure 10. IPFCC Key Concepts (2023) and how they can be implemented.

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METHODS

Recruitment

Methods mirrored that of Woodruff-Gautherin & Cienkowski (2023). There was an effort to include a wide variety of communication approaches as well as inclusion of individuals who identified as D/deaf or hard of hearing and parents of individuals who are D/deaf or hard of hearing. Those included in the study:

- Presenter lists from previous EHDI Conferences
- Directories from research publications and groups
- National and local parent support, advocacy, and educational groups
- State-level employees from states with both less than 50% and over 90% enrollment in early intervention following identification via EHDI

Survey

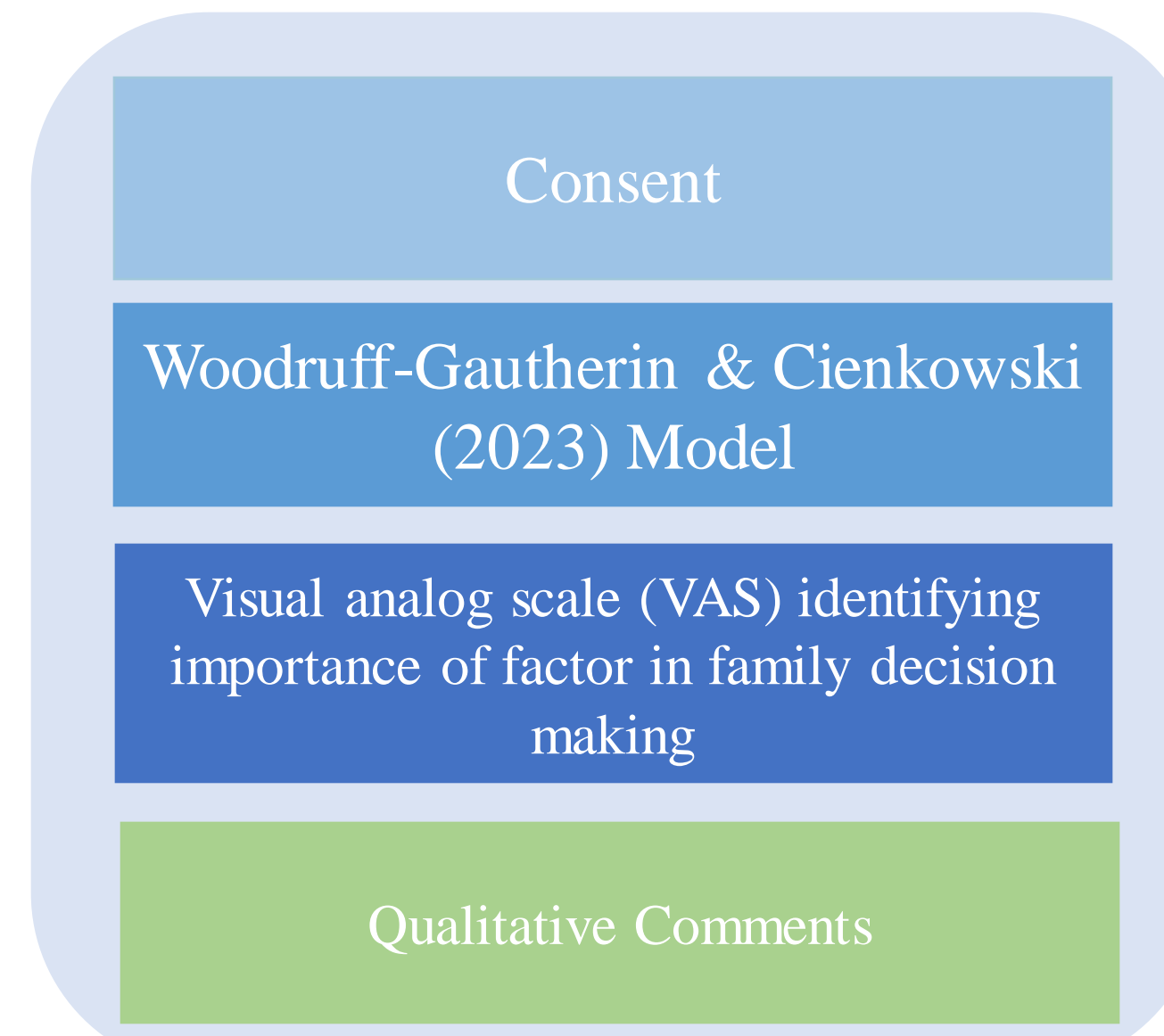


Figure 3. Process of survey presented to participants.

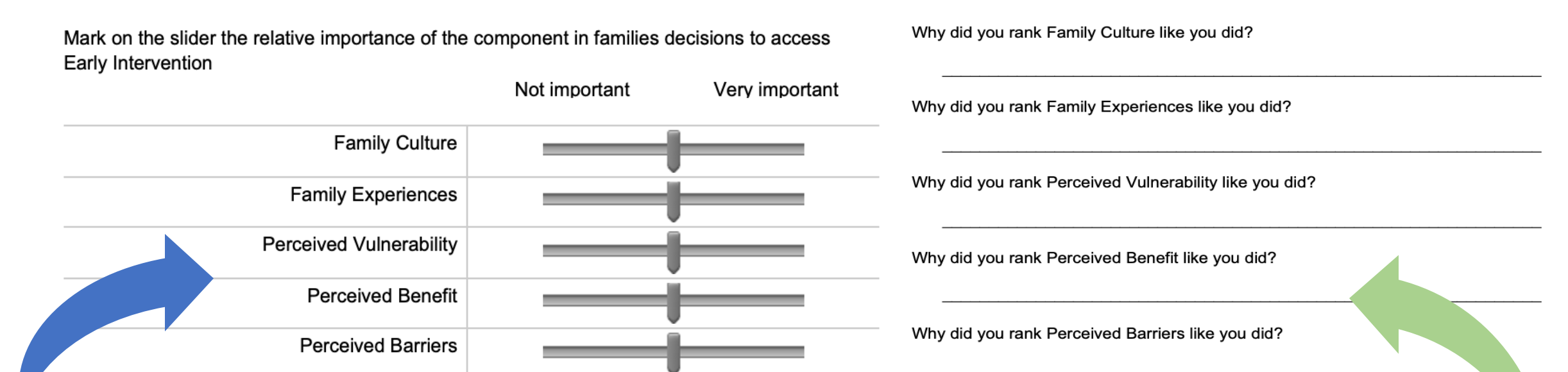


Figure 4. (VAS) and qualitative comment space presented in Weighted Factors survey.

Slider placement converted to value from 1 (not important) to 100 (very important) representative of quantitative data

Qualitative comments reviewed and used as examples

Figure 5. Identification of analysis method used for each section of the survey.

DISCUSSION

Family Culture
<ul style="list-style-type: none"> Building the trust with the family, begins with understanding their cultures (values, culture, traditions, where they are from) and more. Will lead to respecting one each another. Each component of the model can have an impact on steps families take. How providers interact with families to align with their unique characteristics, needs, barriers, fears, etc. can make a difference. Families need individualized support, for each of these components to help them take intervention steps/purposeful actions.
Family Experience
<ul style="list-style-type: none"> Research has shown that families who are lost to follow-up often report having negative family experiences with the professionals within the system. We must be able to meet families where they are at in order to mitigate loss to follow up. [Families enter the EHDI system through a medical model, one that is not typically family-centered; they are fortunate if they eventually connect with a professional with a background and expertise in deafness AND family-centered practices.]
Perceived Vulnerability
<ul style="list-style-type: none"> The manner in which diagnosing audiologists deliver results from the hearing screening ("it's probably fluid") to how diagnosing audiologists deliver the message of a confirmation of hearing loss (we hear time again that audiologists need training in how to do this sensitively but also with encouragement to follow-up) to pediatricians sometimes indicating "it's probably fluid"...families end up in very vulnerable positions and not getting the information they need to make informed decisions. This translate into pure fear, and as a Mom there is nothing more paralyzing that the fear of your child failing.
Perceived Benefit
<ul style="list-style-type: none"> We hear many families talk about the feeling over overwhelm that is more urgent than the hearing differences as reasons to decline EI services. Also, the EI system sometimes deemphasizes the importance of immediate access to EI or prioritizes family choice without assuring that the choice is truly informed decision making[.] I think we do not share with families the clear positive outcomes of early intervention on language and academics later in life[.]
Perceived Barriers
<ul style="list-style-type: none"> [The barriers to moving through the EHDI system are great, and they are complex; state EHDI systems sometimes involve multiple state agencies creating "friction" for families in terms of getting a timely diagnosis and connecting with a hearing-specific EI provider; oftentimes, state EHDI programs are not family-friendly, demonstrated by a lack of formal parent-to-parent support structures[.] Educational materials and resources need to be accessible to all families[.]

Note. The responses presented in the table above were taken directly from participant responses, brackets indicate grammatical edits.

Table 1. Participant Responses of the Significance of each Weighted Factor.

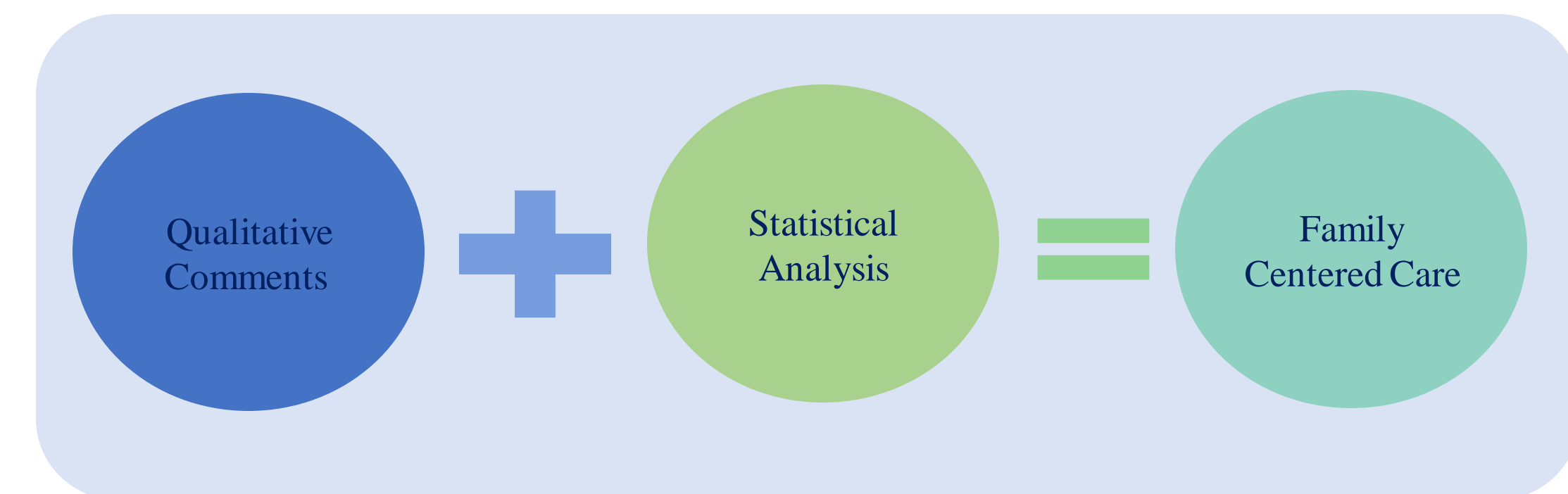


Figure 9. Analysis of qualitative and quantitative results emphasized need for family centered care.

Furthering the Model

- Primary target for further work will be to increase the buy-in of those invited to participate
- Prime opportunity to forge research partnership with implementation and technical assistance programs around the United States that support EHDI services
- Another area for further inquiry is to look at qualitative comments across stakeholder groups

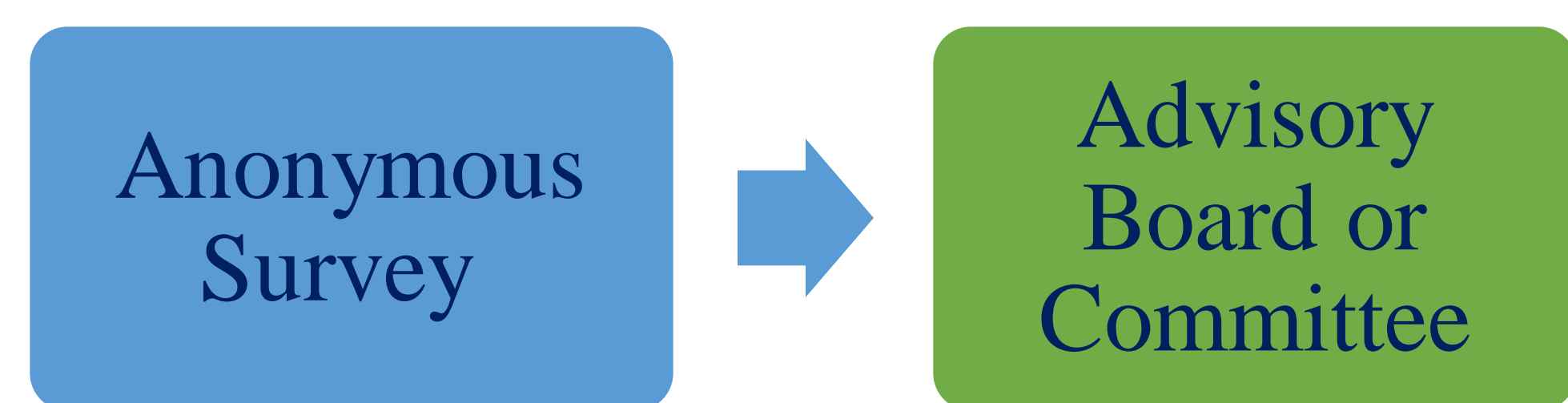


Figure 11. Progression identifying prospective future directions furthering Woodruff-Gautherin & Cienkowski (2023) model.

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