Family-centered Services for Children with Complex Communication Needs: The Practices and Beliefs of School-based Speech-Language Pathologists

Kelsey Mandak, MA, CCC-SLP Doctoral Candidate, Penn State University

Janice Light, Ph.D., The Hintz Family Endowed Chair in Children's Communicative Competence, Penn State University,

Introduction

AIM OF THIS STUDY
This study aimed to examine the beliefs and practices of school-based speech language pathologists (SLPs) who serve children with complex communication needs (CCN) and their families.

Why…
- Family-centered practice?
- School-based SLPs?
- Students with CCN?
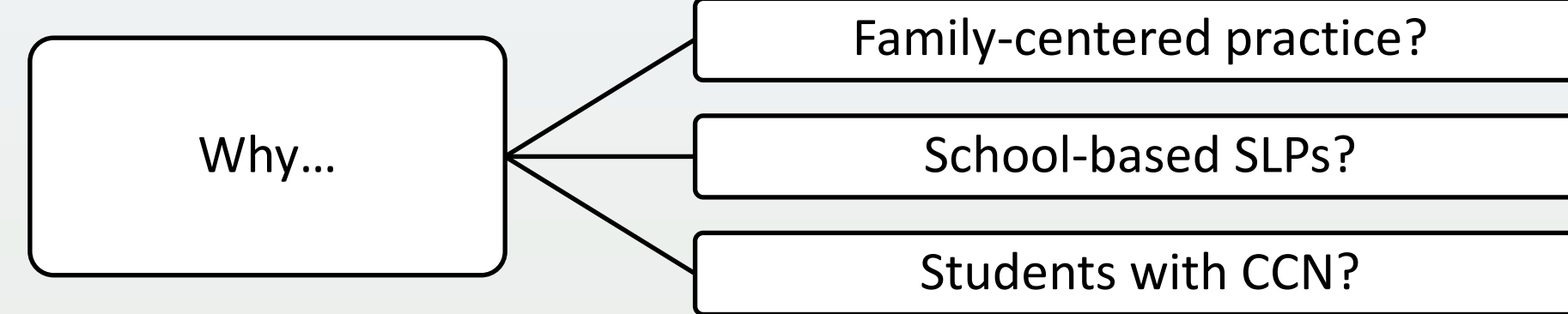
Key Research Findings

Family-centered Practice
- Family-centered practice is a partnership—characterized by trust, respect, and open communication—where families and professionals work together to make decisions in the best interest of the child (Arango, 2011).
- Allen & Petr (1998) state that family-centered service delivery "…recognizes the centrality of the family in the lives of individuals. It is guided by fully informed choices made by the family and focuses on the family's strengths and capabilities" (p. 9).
- Family-centeredness is linked to many positive outcomes:
  - greater family satisfaction
  - increased family involvement
  - stronger self-efficacy beliefs
  - greater perceptions of helpfulness of professionals and services
  - increased child and family functioning

  (Beatson, 2008; Brofenbrenner, 1990; Dunst, Johanson, Trivette & Hamby, 1991; Dunst, 2002; Horst, Werner, & Werner, 2000; Summers, Hoffman, Marquis, Turnbull, & Poston, 2005)

School-based SLPs
- Family-centered practice is highly valued in the field of speech-language pathology.
  - More than 50% of SLPs are employed in educational settings.
  - It is their ROLE and RESPONSIBILITY to engage families in planning, decision making, and program implementation for students of all ages.
- Despite the associated positive outcomes, research shows that **services within education often lack family centeredness and are often characterized by professionally-centered services.**

  (American Speech-Language Hearing Association, 2004, 2010, 2016b; Dunst, 2002)

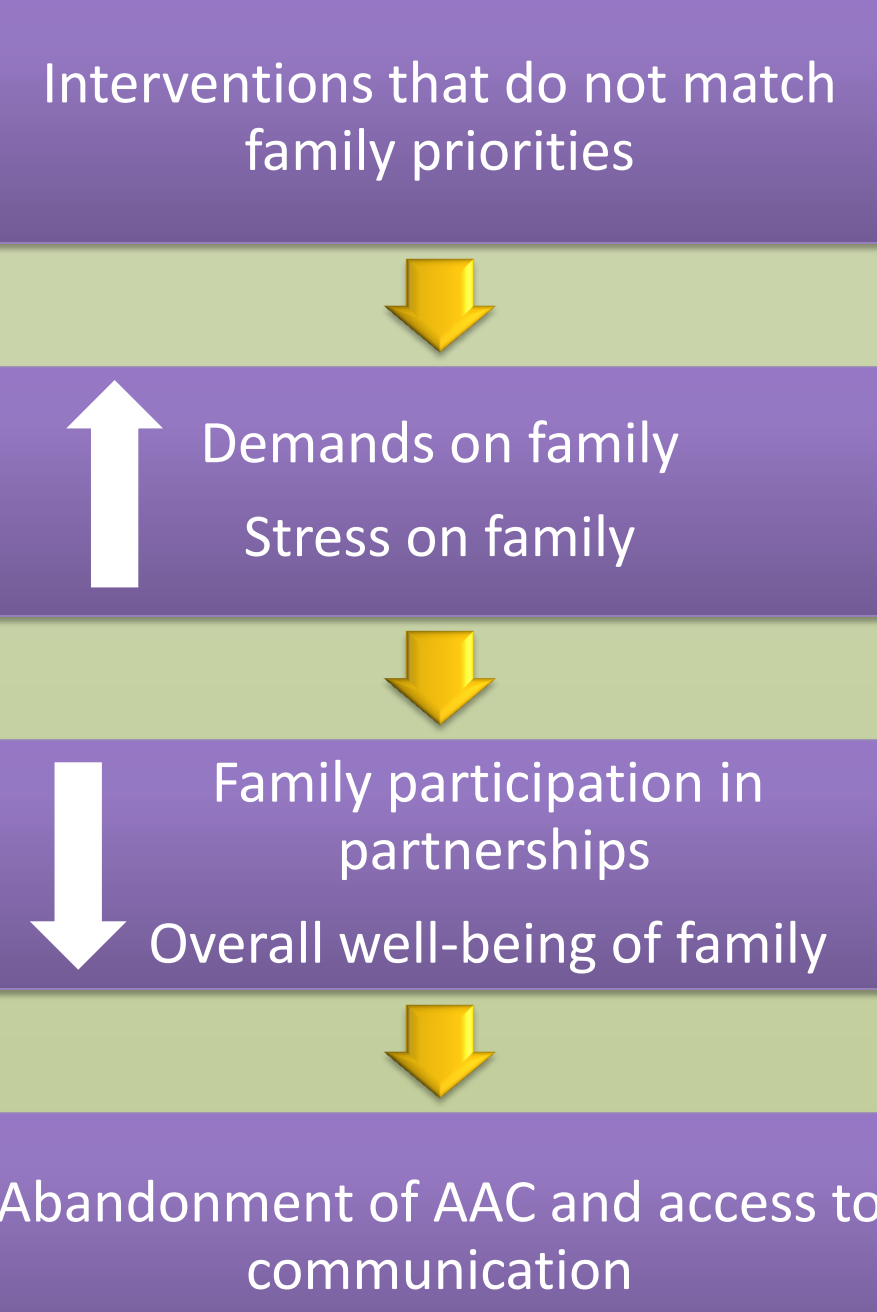**Students with complex communication needs (CCN)**
- More than 50% of the SLPs in educational settings serve students with complex communication needs that require AAC to communicate.
- Positive communication outcomes are dependent on the family's involvement, their shared commitment to the goals of intervention, and the development of a successful family-professional partnership.

  (American Speech-Language-Hearing Association, 2016a; Cress, 2004; Granlund, Björck-Akesson, Wilder, & Ylvén, 2008; Marshall & Goldbart, 2008; McNaughton, Rackensperger, Benedek-Wood, Krezman, Williams, & Light, 2008; Parette, Brotherson, & Huer, 2000)

Families report:
- A lack of interest from professionals in involving families in decision-making
- A desire for professionals to obtain a greater understanding of family demands
- Frustration with professional recommendations that are based on short term contact with their child and that differ from their own concerns, priorities, and preferences

  (Granlund et al., 2008; Jones, Angelo, & Kokoska, 1998; Marshall & Goldbart, 2008; McNaughton et al., 2008)

- Interventions that do not match family priorities
  ⬇
- ⬆ Demands on family / Stress on family
  ⬇
- ⬇ Family participation in partnerships / Overall well-being of family
  ⬇
- Abandonment of AAC and access to communication
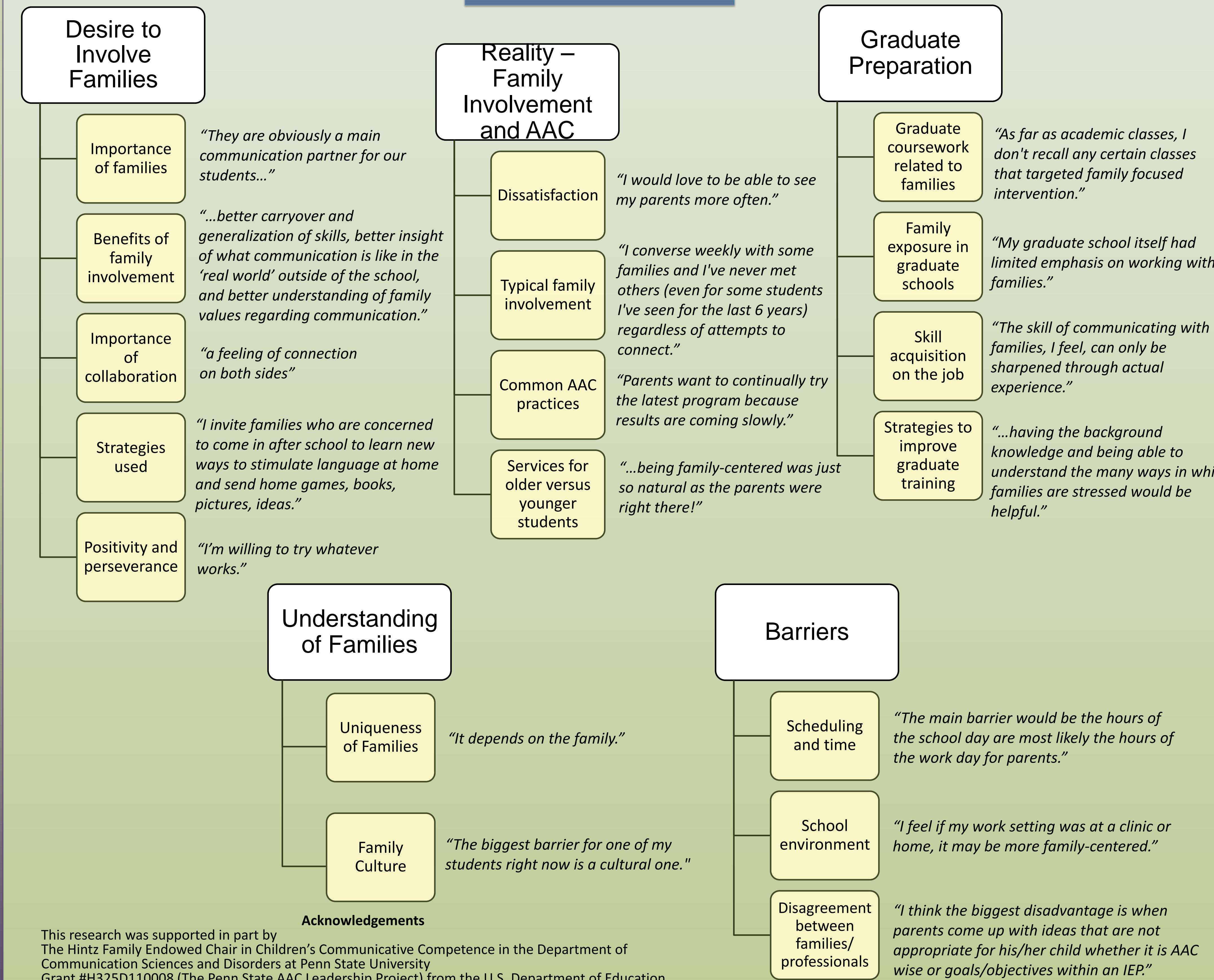
The 1st Step

Challenges still exist, despite both families and professionals believing that family involvement is necessary for AAC success.
There is currently little guidance on how SLPs can best collaborate and provide family-centered services to families of children with CCN.

It is necessary to first understand the current practices and the barriers to successful family-centered services.

Methods

Online focus group

Participants
A total of 13 school-based participants participated in an asynchronous 5-week online focus group.

Questions
The posed questions were related to:
a) beliefs about family-centeredness;
b) disadvantages and advantages of family-centered services;
c) barriers to family-centered services;
d) graduate training to work with families.

Data Analysis
- Data Analysis Spiral (Creswell, 2013)
  - Data Managing
  - Reading/Memoing
  - Describing, Classifying, Interpreting
  - Representing/Visualing
- External Audit
- Member Check

Results

Desire to Involve Families
- Importance of families — "They are obviously a main communication partner for our students…"
- Benefits of family involvement — "…better carryover and generalization of skills, better insight of what communication is like in the 'real world' outside of the school, and better understanding of family values regarding communication."
- Importance of collaboration — "a feeling of connection on both sides"
- Strategies used — "I invite families who are concerned to come in after school to learn new ways to stimulate language at home and send home games, books, pictures, ideas."
- Positivity and perseverance — "I'm willing to try whatever works."

Reality – Family Involvement and AAC
- Dissatisfaction — "I would love to be able to see my parents more often."
- Typical family involvement — "I converse weekly with some families and I've never met others (even for some students I've seen for the last 6 years) regardless of attempts to connect."
- Common AAC practices — "Parents want to continually try the latest program because results are coming slowly."
- Services for older versus younger students — "…being family-centered was just so natural as the parents were right there!"

Graduate Preparation
- Graduate coursework related to families — "As far as academic classes, I don't recall any certain classes that targeted family focused intervention."
- Family exposure in graduate schools — "My graduate school itself had limited emphasis on working with families."
- Skill acquisition on the job — "The skill of communicating with families, I feel, can only be sharpened through actual experience."
- Strategies to improve graduate training — "…having the background knowledge and being able to understand the many ways in which families are stressed would be helpful."

Understanding of Families
- Uniqueness of Families — "It depends on the family."
- Family Culture — "The biggest barrier for one of my students right now is a cultural one."

Barriers
- Scheduling and time — "The main barrier would be the hours of the school day are most likely the hours of the work day for parents."
- School environment — "I feel if my work setting was at a clinic or home, it may be more family-centered."
- Disagreement between families/professionals — "I think the biggest disadvantage is when parents come up with ideas that are not appropriate for his/her child whether it is AAC wise or goals/objectives within an IEP."
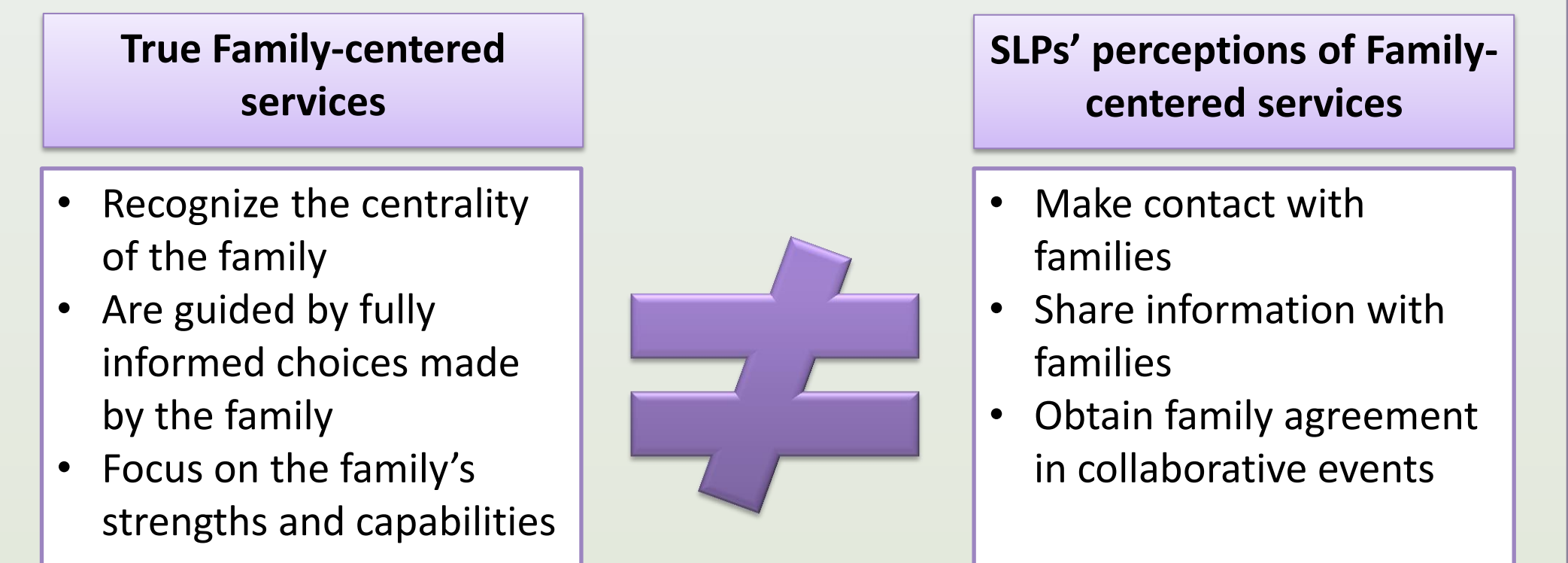
Discussion and Clinical Implications

The results demonstrated that:
- SLPs wanted to involve families
- SLPs recognized the importance and benefits of family involvement
- SLPs identified many barriers to family-centered services

BUT, the key finding was a barrier not explicitly stated by the SLPS

There was a mismatch between the SLPs' perceptions of family-centered services and true family-centered services
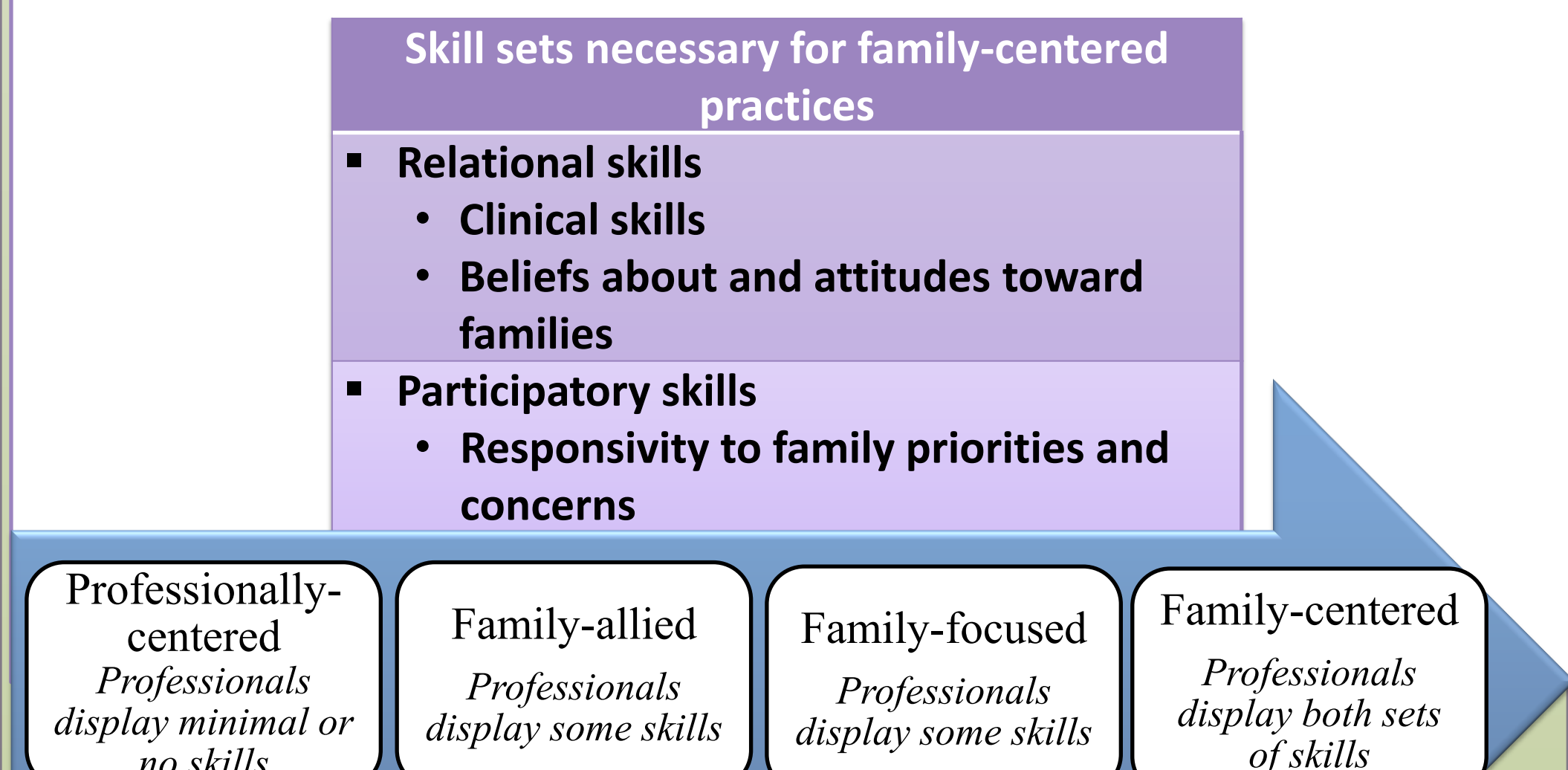
True Family-centered services
- Recognize the centrality of the family
- Are guided by fully informed choices made by the family
- Focus on the family's strengths and capabilities

SLPs' perceptions of Family-centered services
- Make contact with families
- Share information with families
- Obtain family agreement in collaborative events

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Benefits of Family-centered services ✗

Next Step
We need to change the way SLPs perceive and define family-centered services

Clinical Implications
- SLPs must reflect on current service provision and skill set
  - Which skills do they already demonstrate and which skills are lacking in their skill set?
    - Relational skills
    - Participatory skills
- SLPs must reflect on which service delivery model they are currently implementing – is it family-centered?
- SLPs may use checklists/guidelines initially to help identify their current skill set and service delivery model (Wilson & Dunst, 2005; Woodside, Rosenbaum, King, & King, 1998).

The skills necessary for family-centered practices along the continuum of family oriented models (Dunst et al., 1991; 2002).

Skill sets necessary for family-centered practices
- **Relational skills**
  - **Clinical skills**
  - **Beliefs about and attitudes toward families**
- **Participatory skills**
  - **Responsivity to family priorities and concerns**

| Professionally-centered *Professionals display minimal or no skills* | Family-allied *Professionals display some skills* | Family-focused *Professionals display some skills* | Family-centered *Professionals display both sets of skills* |

Conclusion

- This study reveals a potential reason for the lack of family-centered services provided to families of children with CCN.
- There appears to be a discrepancy between the SLPs' perceptions and definition of family-centered services and true family-centeredness.
- This mismatch could be a significant barrier as SLPs could be preventing the associated benefits of true family-centered services.
- Changes need to be made in order to improve the actual implementation of family-centered services.
- Future research is necessary at both the pre-service and in-service level.