

Bridging the Gap from Values to Actions: A Family Systems Framework for Family-centered AAC Early-Intervention Services

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Introduction

- Over the last two decades, there has been increasing discussion of the importance of early intervention professionals providing family-centered augmentative and alternative communication (AAC) services (e.g., Cress, 2004).
- Research suggests that family-centered services in general result in:
 - greater family satisfaction with programs and services;
 - increased family involvement;
 - stronger family self-efficacy beliefs;
 - greater family empowerment;
 - improved family ratings of the helpfulness of supports & resources;
 - improved child behavior and functioning;
 - increased family and individual well-being;
 - improved parenting (Dunst, Trivette, & Hamby, 2007).
- The need for family-centered early intervention services has been highlighted in recent years because of the increasing diversity of family constellations, needs, and skills in today's society.
- Contemporary families represent multiple forms and structures, and they are diverse in terms of race, ethnicity, culture, sexual orientation, income, religion, and education (Hanson & Lynch, 2013).

Existing Research

Current practices	Existing early intervention practices lack family-centeredness and are often characterized by directive or professionally-centered services (Dunst, 2002; Iacono & Cameron, 2009).
Professionals	Professionals often intend to deliver family-centered AAC services; however, they report several challenges or barriers to successfully achieving these services (Mandak & Light, 2016). <ul style="list-style-type: none"> Professionals have noted barriers including limited time to provide training for family members, to maintain the AAC systems, and to complete funding requests (Johnson, Inglebret, Jones, & Rey, 2006). Negative attitudes of families towards the use of AAC have been noted as a barrier to effective family-centered AAC services by professionals. Families may view AAC as a last resort or feel that they can understand their child without the use of AAC. (Cress, 2004; Iacono & Cameron, 2009; Johnson et al., 2006).
Families	Families of children who require AAC have consistently reported that professionals lack interest in family involvement and may neglect to demonstrate sensitivity regarding their families' individual needs (Goldbart & Marshall, 2004; Granlund, Björck-Åkesson, Wilder, & Ylvén, 2008; Jones, Angelo, & Kokoszka, 1998; Parette, Brotherson, & Huer, 2000). <ul style="list-style-type: none"> Families from culturally and linguistically diverse backgrounds have reported feeling a lack of respect from professionals who often adopt a stereotypical, deficit view of families from diverse backgrounds (Harry, 2008).

Bridging the Gap

Clearly there is a gap between the recognition of the importance of family-centered services and actual practice in AAC service delivery. Often professionals lack the knowledge, skills, and tools to implement family-centered AAC services effectively (Mandak & Light, 2016).

In order to close this gap, professionals require supports to assist them in establishing collaborative family-professional relationships in the provision of early intervention AAC services.

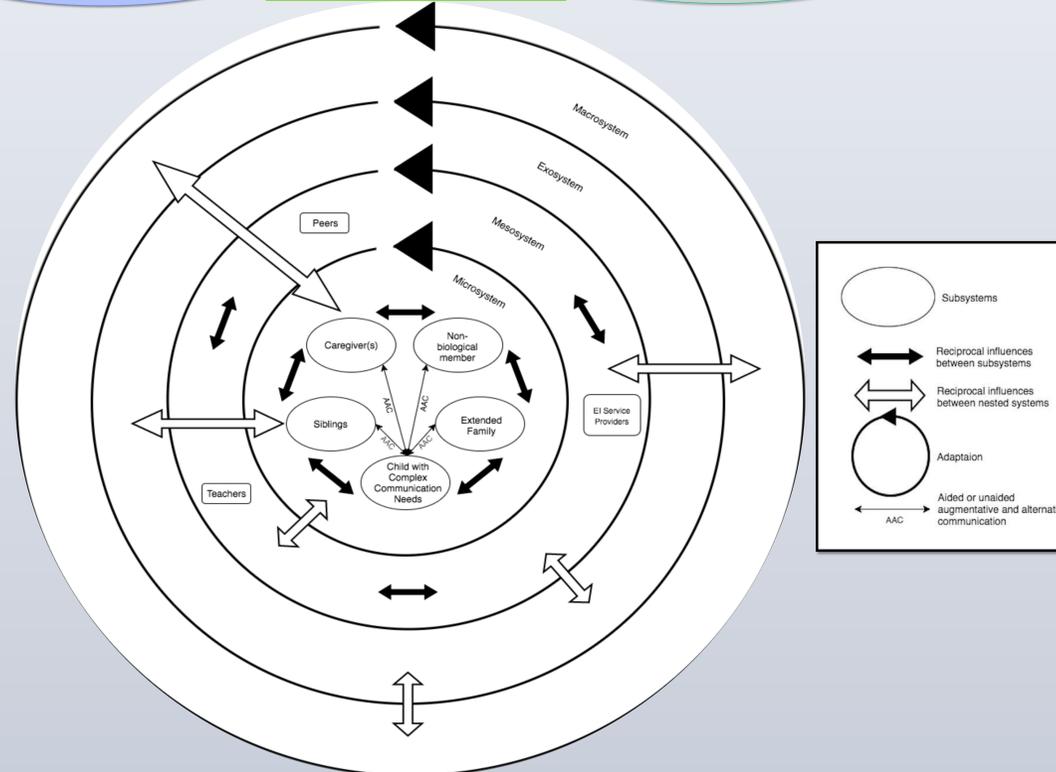
Family Systems

- Family systems theory provides a theoretical framework that views the family as an interconnected system, implying that all family members are integrally linked with each other (Minuchin, 1985; Turnbull et al., 2015)
- Family relationships can only be understood by viewing the family as a whole.
- This framework assumes that the family system affects and is affected by the environment and adjusts accordingly to maintain a sense of balance.

Ecological Systems

- Families can also be viewed within an ecological systems model, which emphasizes how families interact with their environment and accordingly adapt to change (Bronfenbrenner, 1979).
- Families do not exist in isolation, but rather they function and interact within other contexts, such as their schools, communities, and society.
- This model guides professionals in considering the range of influences on families and the interactions among the systems for families of children who require AAC (Hanson & Lynch, 2013).

Proposed Framework



Guiding Principles of Family Systems and Ecological Systems Theory

Subsystems

Relationships with other family members:
 • Parental, sibling, extended family

Adaptation

Functional responses or adjustments to demands of daily life (Gallimore et al., 2006)

Homeostasis

Maintenance of family equilibrium or constant internal environment by resistance to change from behavior that departs from typical family patterns (Minuchin, 1985).

Wholism

Families have attributes that are not reducible to characteristics of specific individuals or particular relationships (Whitchurch & Constantine, 1993).

Interdependence

Family members are integrally linked to one another and can only be considered within the context of the family system (Minuchin, 1985).

"Professionals are looking at the mother and father and not understanding that the parent is going back and asking their mothers or fathers what do you think about this." (Parette et al., 2000, p. 184)

"The hardest thing in the world is having a disabled child, being the parent of a disabled child" (Goldbart & Marshall, 2004, p. 204).

"I will go through months where it is the priority and all my energy goes into that and then something else will happen and there can be months where everything is at a stand-still" (Goldbart & Marshall, 2004, p. 203).

Nested Systems

- Microsystem: parents, relatives, friends, teachers, or others who participate in the life of a person on a regular basis over an extended period of time.
- Mesosystem: relationships between two or more settings (i.e., home and daycare).
- Exosystem: relationships between two or more settings, at least one of which does not contain the person, but in which events occur that immediately influence the life of that person (i.e., home and community).
- Macrosystem: societal and cultural beliefs and values that shape and influence lower order systems

Existing Tools and Clinical Practices to Support Family-centered AAC Interventions

SUBSYSTEMS

Clinical principle(s)	Tool(s)	Examples of clinical practices
•Recognize the family as expert; collaborative relationships	Social Networks Inventory (Blackstone & Huntberg, 2003)	<ul style="list-style-type: none"> identify family members, roles, and responsibilities; meet with and involve all relevant family members; ask family members to identify the greatest strengths and needs for the child with CCN & the family; consider interventions that include siblings

ADAPTATION

•Be sensitive to the family's unique needs	Family Resource Support Guide (Sexton & Rush, 2012)	<ul style="list-style-type: none"> acknowledge changing family roles upon the introduction of AAC; recognize that family involvement in AAC is dynamic over time as the family adapts; identify unique family supports, needs, and priorities; provide resources for community and organizational supports based on family needs and priorities; provide support and training in the use of AAC as appropriate
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HOMESTASIS

•Integrate AAC into existing routines	FACETS training (Woods-Cripe & Lindemann, 2001)	<ul style="list-style-type: none"> learn about family interactions within home environments; identify predictable and meaningful family routines for AAC intervention; provide choices of intervention contexts and activities; offer various modes of communication; offer various times and places to meet
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WHOLISM AND INTERDEPENDENCE

•Involve all relevant family members	Family Impact of Assistive Technology Scale (FIATS-AAC; Ryan & Renzoni, 2010)	<ul style="list-style-type: none"> ask the family who should be involved in the assessment and intervention process; work with the family to identify communicative situations or contexts in which they value the child's participation; gain an informant familiar with the family's culture
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Conclusion

- When families are not involved in the decision making process, there can be negative consequences for not only the child, but also the family.
- The proposed theoretical framework illustrates how family systems theory and ecological systems theory can be used to inform practice with families that include a child who uses AAC.
- The framework allows professionals to re-conceptualize AAC early intervention through a family systems lens in order to view children within their family system and to better understand the environments in which children develop and communicate.
- The framework and suggested tools can guide professionals to close the gap between knowing family involvement is necessary and successfully implementing family-centered services grounded in family systems principles.

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