An Integrative Framework for Working with Families of Children with Complex Communication Needs (CCN)

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Introduction

- There are nearly one million children with complex communication needs in the United States (Binger & Light, 2006; Light & McNaughton, 2012).
- Augmentative and alternative communication (AAC) offers children with autism spectrum disorders, cerebral palsy, Down syndrome, and other disabilities a way to participate in these environments.
- AAC includes aided and unaided communication systems (e.g., symbols, symbol boards, speech generating devices and gestures, signs, and vocalizations) (Light & McNaughton, 2012).
- Interventions that consider family routines are more effective in providing opportunities for children to participate in home and school environments (Granlund et al., 2008; Parette & Angelo, 1996).
- Professionals are often unprepared to work with families (Snell & Janney, 2005; Hunt et al., 2002).
- This poster provides an integrative framework for working with families of children with CCN in speech-language pathology.
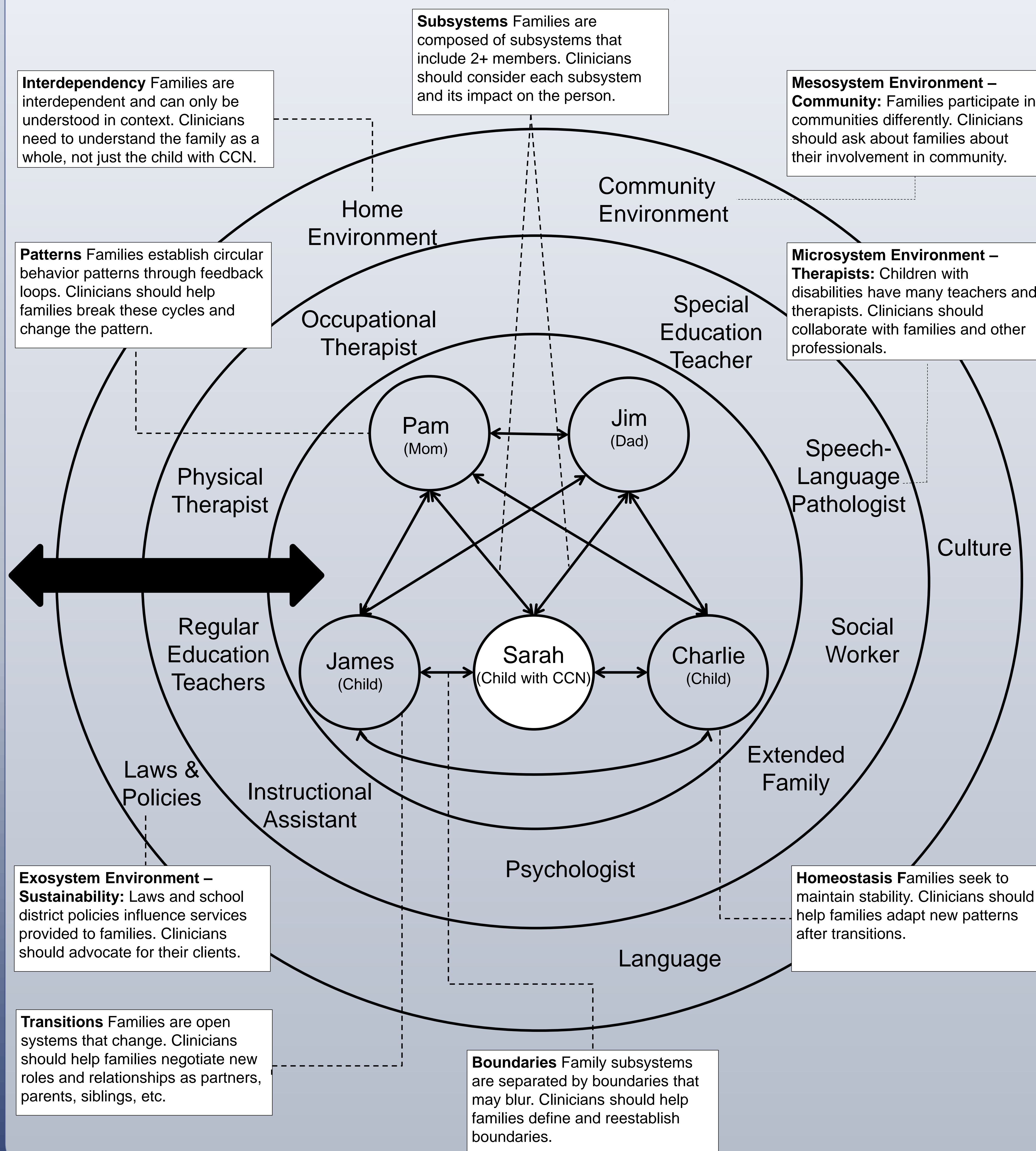
Families

- Children with CCN and their families are the most important members of the AAC team (Beukelman & Mirenda, 2013; Parette, Huer, & Brotherson, 2001).
- Families of children with CCN describe their roles as caregivers, teachers, playmates, technical support personnel, and advocates (Parette & Angelo, 1996).
- Families of children with CCN report that they are not involved in AAC assessment and intervention (e.g., Granlund et al., 2008; McNaughton et al., 2008; Parette & Angelo, 1996).
- Parents have little or no input in AAC device selection (McNaughton et al., 2008).
- Parents' roles and responsibilities increase when their children receive an AAC device (McNaughton et al., 2008).
- Parents do not receive enough training about AAC devices and strategies (McNaughton et al., 2008; Parette & Angelo, 1996).
- Parents' priorities are not acknowledged by professionals (Granlund et al., 2008).

Professionals

- It is important for professionals to understand the family structures and contexts available to support children with CCN (Alant, 1996).
- The American Speech-Language-Hearing Association (ASHA) recommends family-centered practice (2002).
- The Individuals with Disabilities Education Act and Section 504 of the Rehabilitation Act (2004) require schools to involve families in developing individualized education plans.
- Professionals report that families are not involved in assessment and intervention (Birmingham & Light, 2014).
- Professionals are unable to gather enough information about children's communication, their current and future communication needs, and appropriate strategies for intervention from families (Birmingham & Light, 2014; DeBortoli et al., 2014).
- Professionals need knowledge and skills in collaborative teaming with families (Soto et al., 2001; Hunt et al., 2002).

Description of Model

This model combines family systems theory (Minuchin, 1985; Cox & Paley, 1997) with ecological systems theory (Bronfenbrenner, 1979) to provide a framework for working with families in speech-language pathology, specifically during AAC assessment and intervention. Families are part of an interactive system composed of subsystems with individual family members who are interconnected and linked to each other (Minuchin, 1985; Cox & Paley, 1997) within a broader social context (Bronfenbrenner, 1979). Speech-language pathologists need to consider the interdependency of families and the social environment in which the family partakes in order to provide inclusive, family-centered practice and improve the family-professional relationships and the child's communication and participation in the home, school, and community.

Subsystems Families are composed of subsystems that include 2+ members. Clinicians should consider each subsystem and its impact on the person.

Interdependency Families are interdependent and can only be understood in context. Clinicians need to understand the family as a whole, not just the child with CCN.

Patterns Families establish circular behavior patterns through feedback loops. Clinicians should help families break these cycles and change the pattern.

Mesosystem Environment – Community: Families participate in communities differently. Clinicians should ask about families about their involvement in community.

Microsystem Environment – Therapists: Children with disabilities have many teachers and therapists. Clinicians should collaborate with families and other professionals.

Exosystem Environment – Sustainability: Laws and school district policies influence services provided to families. Clinicians should advocate for their clients.

Homeostasis Families seek to maintain stability. Clinicians should help families adapt new patterns after transitions.

Transitions Families are open systems that change. Clinicians should help families negotiate new roles and relationships as partners, parents, siblings, etc.

Boundaries Family subsystems are separated by boundaries that may blur. Clinicians should help families define and reestablish boundaries.

Case Study

Sarah is a 14-year-old girl with cerebral palsy and CCN who uses AAC. She receives special education services at her middle school and participates in adapted dance classes in the community. Sarah lives with her parents and brothers. Her dad, Jim, is an accountant and her mom, Pam, is a teacher. Her brothers, James and Charlie, are 18- and 12-years-old. James plans to attend college next year.

Interdependency Sarah's speech-language pathologist interviews the family to determine her communication, current and future communication needs, and appropriate intervention strategies based on their priorities.

Patterns Parents report that Sarah "never talks at home". The speech-language pathologist observes the family and notices that Sarah needs more time to compose messages. The speech-language pathologist and the family develop strategies for conversation at home (e.g., providing opportunities for Sarah to communicate and wait time for Sarah to compose messages).

Homeostasis Charlie dominates conversation with Sarah. The speech-pathologist interviews him with inclusive wording (e.g., "How can we make sure Sarah gets a turn to talk?").

Transitions James reports that he cares for Sarah every afternoon. Because he plans to attend college in another state, the speech-language pathologist and other professionals ask the family about their plans for next year.

Subsystems Each family member has a different relationship with Sarah (e.g., parent-child, sibling, etc.). The speech-language pathologist recognizes the differences and recommends interventions that are appropriate for each subsystem.

Boundaries James' parents rely on him to care for Sarah every afternoon. This co-parenting role is uncomfortable for James and annoy for Sarah. Professionals ask the family about maintaining the sibling subsystem.

Mesosystem Environment: Community Professionals in home, school, and community environments communicate to adapt dance classes (e.g., The physical therapist consults with the dance instructor).

Exosystem Environment: Sustainability Professionals discuss requirements for family-centered practices and approaches to managing workloads with school administration.

Micro-Level Environment: Therapists Jim works long hours during the spring to prepare tax returns for his clients. Sarah's school team schedules her annual IEP meeting after April 15th.