# CHILD-CENTEREDNESS AND PARENT COUNSELING IN FAMILY-CENTERED CARE

**Kris English**

The terms in this title are simultaneously very familiar and also used in different ways. To establish a shared context, a brief history and related concerns about family centered care and child centeredness will be presented, and then integrated into the topic of parent counseling.

**Family Centered Care** (FCC) is described as a way of caring for children and their families that ensures health care is planned around the whole family. In a family centered approach, all family members are recognized as care recipients and active members.

The development of Family Centered Care emerged in response to practices of the times, notably brought to light by a British Ministry of Health report (Platt, 1959), which described the adverse impact of hospitalization on both children and parents. Parents were expected to defer to medical experts who restricted hospital visiting hours, withheld permission to accompany their child during testing, and denied access to their child's medical records (Wells, 2011). Family advocates successfully affected changes such as access to records, shared decision-making, open visiting hours and sibling visits, and later extended its philosophy into the development of early intervention in the education system.

As we now know, Family Centered Care values information sharing, partnership and collaboration, negotiation, and care in the context of family and community (Carter et al., 2014; Shields, 2015). However, although routinely cited in mission statements, FCC is often misunderstood and unevenly executed (Kuo et al., 2012). Generally, health care providers working within the FCC model do strive to collaborate with the family unit, which would assume the inclusion of the pediatric patient, but in reality usually focuses only on parents. The "child as person" is not actively recognized (Majamanda et al., 2015).

Unintentionally, FCC can result in the child or young person being assigned a passive role regarding their health care, even when more active engagement could be possible. By school age, children have an

emerging capacity for logical thought and understanding others' perspectives. Developmentally, children want to develop competence and participate in decision making; when children's preferences for inclusion are not met or impeded, they feel powerless and depersonalized (Coyne et al., 2018).

**Child Centeredness**

Over the past decade, the concept of Child Centered Care (CCC) has been proposed as an alternative approach in health care settings (Söderbäck et al., 2011). Nurses and other providers of in-patient hospital care consider the term relatively new (Carter et al., 2014), but in fact "child centeredness" is standard practice for professionals who work directly and only with children, such as speech language pathologists and hearing therapists. Family is certainly included in treatment plans, but the "center of care" is always the child (Ford, 2018).

Discussions on the principles of child centeredness usually start with the United Nations Convention on the Rights of the Child (1989), specifically the following articles:

- Article 12 (respect for the views of the child): Every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously. This right applies at all times, for example during immigration proceedings, housing decisions or the child's day-to-day home life.
- Article 13 (freedom of expression): Every child must be free to express their thoughts and opinions and to access all kinds of information, as long as it is within the law.

Child centered rights as applied to health care means the child is supported in becoming an active participant in the healthcare partnership (James et al., 1998). Once children start communicating, they certainly express opinions and preferences; providing the opportunity to express themselves, and be listened to, is not only a protected right but also supports their development as persons in healthy, productive ways. Note: listening and taking children seriously does not mean giving children permission to be demanding or insolent, or have free rein over situations; rather, it means actively acknowledging that, as persons, their experiences matter to us.

As mentioned above, the recognized active members of the FCC model have been adults (parents/carers and health care professionals), with the child or young person allocated to a passive role. Child centeredness, then, is seen as an evolution in children's health care. As described above, Child Centered

Care firstly recognizes the child's "personness," and secondly his or her "familyness:" in other words, repositions the child from the sidelines to the "heart" of attention, and honors the child's voice. (Here, we are not referring to the development of speech and language skills but rather, self expression and communicative engagement.)

These two concepts (Family Centered Care and Child Centeredness) are not intended to be mutually exclusive. The professional challenge is to keep both models of centeredness in mind over the course of a child's continuum of care. Family centered care is highly appropriate, for example, when our patient is an infant or toddler; when the child starts to express him/herself, we are challenged to find ways to expand our care from traditional (adults only) FCC to a blend of Family and Child centeredness, to continue involving family while adding the child's right to participate in their hearing care.
How to support this right within the family context? The theory of self determination directly relates to this right of self expression and participation (Deci et al, 1994; Deci & Ryan, 2012). Self determination has been defined as "the ability of individuals to live their lives as they choose, consistent with their own values, preferences, and abilities" (Luckner & Sebald, 2013, p. 377) and involves attitudes, knowledge and skills such as:

- Abilities to set goals, take the steps to reach these goals
- Making one's own choices, learning to effectively solve problems
- Taking control and responsibility for one's life
- Accepting consequences of making choices

Learning how to set goals and make choices requires practice in self awareness, self expression, and opportunities to test out options and evaluate the outcomes. Like most growth, self determination needs support from the adults in the child's life (Erwin & Brown, 2003). Promoting growth as a self-determined person within the family context can help us address both types of centeredness.

**Parent Counseling**

Now let us apply our two centeredness models to parent counseling. In audiology, parent counseling involves emotional support as well as information about diagnoses and devices (Clark & English, 2019). Throughout, we strive to assure parents that we are attending to their current needs, while also looking ahead to the future. This dual mindset parallels parents' experiences, as they report not only wanting to

know “What do we do now?” (their family centered question) but also “How do we prepare our son or daughter for adult life?” (Their child centered question).

At some point in the clinical relationship, it behooves to us to mention the future as it relates to their child’s development as active participants in their hearing care. This transition is best started sooner than later: whether ready or not, one day their child will be a young person who will discharged from pediatric care to adult services, with dramatic differences in expectations and responsibilities. A partial “readiness” list includes being able to (English & Pajevic, 2016):

- Explain the degree and functional impact of one’s hearing loss
- Describe and apply assistive technologies and communication repair strategies
- Provide case history information: etiology and family history of hearing loss, plus history of injuries, illnesses, surgeries, additional health concerns; current and past medications
- Provide names, contact info of health care providers, emergency contacts
- Fill out intake, self-assessments
- Maintain health records
- Keep health information and other private data secure
- Accurately use basic health terminology (diagnosis, nausea, prescription, antibiotic, etc.)
- Schedule and keep track of appointments

Responsibility for developing a child’s self determination skills is the family’s purview, but we in support roles can be of assistance. During audiology appointments, for instance, parent counseling might begin with basic information about self determination (e.g., handouts, guest speakers, links to websites) if it hasn’t been shared elsewhere, as well as research correlating self determination to positive adult outcomes (e.g., Cobb et al., 2009; Shogren et al., 2015). If our suggestions are consistent with family values, we should engage each child directly as soon as they are capable, requesting and factoring in his or her input regarding options, preferences, and choices, and eventually expanding to private conversations as parents step out for a few minutes. These actions may already be routine practice, but perhaps may not be actively recognized as our small but intentional efforts to nurture a child’s personness.

## Conclusion

The challenge to professionals who serve children with hearing loss and their families seems to be three-fold: to evaluate the actual practices of family centered care in one's setting (i.e., are children's voices actively included?); to analyze interactions with pediatric patients to quantify the level of their input and impact on their own care, and make changes as needed; and to routinely include self-determination goals in parent counseling moments, to support carry-over to home life if they choose to do so.

KIRJALLISUUTTA


Carter, B., Bray, L., Dickinson, A. & Ford, K. (2014). Child centered nursing: Promoting critical thinking. Thousand Oaks, CA: SAGE Publications.

Clark, J.G. & English, K. (2019). Counseling-infused audiologic care (3. ed.). Cincinnati, OH: Inkus Press. Saatavilla osoitteessa: https://www.audiology-counseling.com

Cobb, B., Lehmann, J., Newman-Gonchar, R. & Alwell, M. (2009). Self-determination for students with disabilities: A narrative metasynthesis. Career Development and Transition for Exceptional Students, 32, 108–114.

Coyne, I., Holmström, I. & Söderbäck, M. (2018). Centeredness in healthcare: A concept synthesis of family centered care, person-centered care, and child centered care. Journal of Pediatric Nursing, 42, 45–56.

Deci, E. L. & Ryan, R. M. (2012). Self-determination theory. Teoksessa P. A. M. Van Lange, A.W. Kruglanski, & E.T. Higgins (Eds.), Handbook of theories of social psychology (p. 416–436). Newbury Park, CA: Sage Publications.

Deci, E.L., Eghrari, H., Patrick, B. C. & Leone, D. R. (1994). Facilitating internalization: The Self-Determination Theory perspective. Journal of Personality, 62, 119–142.

English, K. & Pajevic, E. (2016). Adolescents with hearing loss and the International Classification of Functioning, Health and Disability: Children & Youth version. Seminars in Hearing, 37, 235–244.

Erwin, E. J. & Brown, F. (2003). From theory to practice: A contextual framework for understanding self-determination in early childhood environments. Infants & Young Children, 16, 77–87.

Ford, K., Dickinson, A., Water, T., Campbell, S., Bray, L. & Carter, B. (2018). Child centred care: Challenging assumptions and repositioning children and young people. Journal of Pediatric Nursing, 43, e39–e43.

James, A., Jenks, C. & Prout, A. (1998). Theorizing childhood. Cambridge: Polity Press.

Kuo, D., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M. & Neff, J. M. (2012). Family centered care: Current applications and future directions in pediatric health care. Maternal and Child Health Journal, 16, 297–305.

Luckner, J. L. & Sebald, A. M. (2013). Promoting self-determination of students who are deaf or hard of hearing. American Annals of the Deaf, 158, 377–386.

Majamanda, M. D., Munkhondya, T. E. M., Simbota, M. & Chikalipo, M. (2015). Family centered care versus child centered care: The Malawi context. Health, 7, 741–746.

Platt, H. (1959). The welfare of children in hospital. Ministry of Health Services Council, London.

Shields, L. (2015). What is "family centered care"? European Journal for Person Centered Healthcare, 3, 139–144.

Shogren, K A., Wehmeyer, M. L., Palmer, S. B., Rifenbark, G. G. & Little, T. D. (2015). Relationships between self-determination and postschool outcomes for youth with disabilities. Journal of Special Education, 48, 256–267.

Söderbäck, M., Coyne, I. & Harder, M. (2011). The importance of including both a child perspective and the child's perspective within health care settings to provide truly child-centred care. Journal of Child Health Care, 15, 99–106.

United Nations (n.d.). A summary of the UN Convention on the Rights of the Child. Saatavilla osoitteessa: https://www.unicef.org.uk/rights-respecting-schools/wp-content/uploads/sites/4/2017/01/Summary-of-the-UNCRC.pdf

Wells, N. (2011). Historical perspectives of family centered care. Academic Pediatrics, 11, 100–102.