2022

Family-centered Care for Preschool Children with Disabilities

Kaylee Athmann

Ashley Freund

Rachel Koenig

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Kaylee Athmann, OTS, Ashley Freund, OTS, & Rachel Koenig, OTS

Department of Occupational Therapy, University of North Dakota, Grand Forks, North Dakota, United States

Please direct correspondence to Rachel Koenig at r.koenig@ndus.edu

***This resource was written by doctoral-level students in fulfillment of the requirements of the Occupational Therapy course "OT 403 - Clinical Research Methods in Occupational Therapy" at the University of North Dakota School of Medicine and Health Sciences, under the advisement of Professor/Course Director Anne Haskins, Ph.D., OTR/L, Assistant Professor Breann Lamborn, EdD, MPA, Professor Emeritus Gail Bass Ph.D., OTR/L, and Research and Education Librarian Devon Olson Lambert, MLIS.

Focused Question

How does family-centered care in occupational therapy support the health management of preschool children with disabilities?

Case Scenario

Family-centered care is an innovative approach to planning, delivering, and evaluating healthcare (Eichner & Johnson, 2012). It is centered around the importance of family in the client's life and is grounded in a partnership between providers, clients, and their families (Eichner & Johnson, 2012). Some benefits of implementing family-centered care include an increase in client and family's adherence to care plans, improved satisfaction, and reduced healthcare costs (Eichner & Johnson, 2012; McCoy et al., 2020; Nickel et al., 2018). In addition to these benefits, family-centered care has been recognized as a crucial way to improve stress and self-efficacy in parents of children with disabilities (Ahmadi et al., 2019; Kuhaneck et al., 2015; Mas et al., 2019). In addition to the previously cited benefits, Kuhaneck et al. (2015) found that a child's health management skills and family functioning have been positively impacted by the implementation of family-centered care.

Family-centered care is a way to place the child's needs in the context of their family at the center of healthcare services (Jahagirdar, 2013; Kuhaneck et al., 2015; McCoy et al., 2020; Myrhaug et al., 2016). Family-centered care has the advantages of being unique to the child, while recognizing that family plays an important part during this specific stage of a child's life. Family-centered care also acknowledges that family members are the experts in the child's abilities and needs. Therefore, occupational therapists that address family-centered care consider the child more holistically than other healthcare professions (Kuhaneck et al., 2015; McCoy et al., 2020; Myrhaug et al., 2016).

Along with the benefits, there are also barriers to family-centered care that include characteristics of the family, and characteristics of the practice setting (Almarsi & Palisano, 2018; Bhopti et al., 2014; Dick et al., 2021; Fingerhut et al., 2013; McNally et al., 2020). Characteristics of the family that are barriers to family-centered care include cultural beliefs, community support, responsibilities of family members, roles within the family, language, socioeconomic status, and personal stressors (Alsmari & Palisano, 2018; Fingerhut et al., 2013). Characteristics of the practice setting that are barriers include early intervention services ending at age three years, culture and type of practice setting (i.e. home, clinic, school setting) (Bhopti et al., 2014; Dick et al., 2021; Fingerhut et al., 2013; Jahagirdar, 2013; McNally et al., 2020).

Health management is an important occupation of all people (American Occupational Therapy Association [AOTA], 2020). Health management is defined as engaging in activities that result in, "activities related to developing, managing, and maintaining health and wellness routines, including self-management, with the goal of improving or maintaining health to support participation in other occupations." (AOTA, 2020, p. 29). This is important to preschoolers with disabilities because families are the decision makers regarding how and if a child participates in therapy, which is a part of their child's health management (Ahmadi et al., 2019; Fingerhut et al., 2013; Schor, 2003).

One of the most influential aspects of a child's development is their family (Kuhaneck, 2015). Sharma (2013) purported family structures are hard to define because they are constantly changing. Sharma (2013) provided the explanation that families are always changing because culture and societal expectations are constantly evolving. It is also important to recognize that families have different cultural values and beliefs that impact health management (Sharma, 2013). In addition to recognizing these differences, occupational therapists need to be equipped with knowledge regarding the cultures of the individuals with whom they work with and to whom they provide services for (Montgomery, 2020). Therefore, when implementing family-centered care, it is important to consider the culture and beliefs of the family receiving services (Fingerhut et al., 2013; Jahagirdar, 2013; Montgomery, 2020).

The Ecology of Human Performance (EHP) framework was chosen as a model through which to consider the focus question. The EHP framework considers the association between the person, context, task and the way in which occupational performance is affected based on these relationships. (Dunn, 2017). The EHP model assumes that each person is a unique individual and has their own distinct past experiences, personal values, interests and skills (Dunn, 2017) It is also important to note that the environment and person within the EHP model are interconnected and therefore, parents and children can be looked at simultaneously (Dunn, 2017). By using this framework, occupational therapists can incorporate family-centered care and consider unique aspects of each family in the areas of person, context, task, and task performance (Dunn, 2017). Furthermore, family-centered care fits within this model because it has social and cultural aspects included in the temporal context (Dunn, 2017). This is important to this population because preschoolers are dependent on their family, and their family’s culture plays a large role in family-centered care (Kuhaneck et al., 2015).

The EHP model promotes that an individual's context can provide both supports and barriers to performance (Dunn, 2017). The family's level of involvement in the child's interventions has been shown to directly influence their progress within occupational therapy services (McCoy et al., 2020). Greater family involvement and collaboration with the occupational therapist has been shown to lead to more positive outcomes for the child (Fingerhut et al., 2013; Jahagirdar, 2013; McCoy et al., 2020).

Population

In this paper, we reviewed the findings of articles in which the authors primarily described preschool children with autism and cerebral palsy. For the purpose of this paper, we refer to both autism and cerebral palsy by using the term disability. Autism spectrum disorder (ASD) is a growing diagnosis with almost two percent of the population diagnosed (Autism Speaks, 2018; Chi & Lin, 2022). Researchers have found that preschool children with ASD struggle more with self-care and health management skills compared to the other children their age (Chi & Lin, 2022; Hoyo & Kadlec, 2021). Additionally, children with ASD have been found to thrive off of structure and routines (Kuhaneck et al., 2015). While implementing family-centered care, it is important for occupational therapists to assist in establishing routines and norms in health management (Kuhaneck et al., 2015).

Cerebral palsy (CP) is a condition that affects one's posture, balance, and motor abilities (Centers for Disease Control and Prevention [CDC], 2021). Families who have children diagnosed with CP have also been found to benefit from family-centered care (Ahmadi et al., 2019; McCoy et al., 2020; Myrhaug et al., 2016). One study that supports this assertion found that children with CP are more likely to progress when therapy services are family-centered (McCoy et al., 2020). This is important because the health management of children with CP is dependent on their caregivers (Ahmadi et al., 2019; Fingerhut et al., 2013; Schor, 2003). Children and families affected by both ASD and CP could benefit from family-centered care because of the individualized approach to therapy (McCoy et al., 2020; Myrhaug et al., 2016; Kuhaneck et al., 2015).

Purpose Statement

The purpose of this critically appraised topic paper was to define family-centered care, to look at family-centered care through the model of EHP, and to show the unique role occupational therapy plays in family-centered care. More specifically, we aimed to find the effects of family-centered care on health management. While family-centered care has been cited as beneficial by occupational therapists, there is a gap in these services being provided to preschoolers with disabilities.

Methodology

An initial literature search was conducted from February 28th, 2022 to March 9th, 2022. Searches were completed through a variety of databases including; Pubmed, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PsychInfo. A selection of literature articles were also searched for across the American Occupational Therapy Association (AOTA) website and via google searches. When searching for articles a combination of the following terms were used such as “family-centered care,” “occupational therapy,” “preschool,” “quality of life,” “early intervention,” “disabilities,” “children,” and “health management.” Articles not written in the English language were excluded.

Types of Articles Reviewed

A total of 40 articles were reviewed. Of the 40 articles reviewed, 28 articles were selected and reviewed more in depth. Out of the 28 articles thoroughly reviewed, 8 were level I studies (Ahmadi et al., 2019; Almarsi & Palismo 2018; Dunst et al., 2007; Frolek Clark & Schlabach, 2013; Hoyo & Kadlec 2021; King & Chiarello, 2014; Kuhaneck et al., 2015; Popov et al., 2021), 1 article was a level II study (McNally et al., 2020), 2 were level III studies (Kim et al., 2016; Rosenberg et al., 2015), 5 were level IV studies (Chi & Lin 2022; Dick et al., 2021; Mas et al., 2019; McCoy et al., 2020, Myrhaug et al., 2016), and 12 were N/A (Bhopti et al., 2020; Case-Smith, 1995; Dunn, 1994; Eicher et al., 2018; Eichner & Johnson, 2012; Fingerhut et al., 2013; Ginsberg, 2007; Jahargirdar, 2021; Montgomery, 2020; Nickel et al., 2018; Schor, 2003; Sharma, 2013). Other resources reviewed were a presentation at the AOTA conference (Marini, 2022), two occupational therapy textbooks (Brown, 2019; Dunn, 2017), the Occupational Therapy Practice Framework (AOTA, 2020), one government website (CDC, 2021), and one informational occupational therapy website (Williams, 2021).

Synthesized Summary of Key Findings

Theoretical Base

The purpose of this critically appraised topic paper was to look at family-centered care in preschoolers with disabilities through the EHP model. The EHP model considers how interactions between the person, task, and context impact overall performance (Dunn, 2017). Occupational therapists can utilize EHP to find interventions that target the relationships between the family, their context, and their occupational needs (Dunn, 2017).

Person

As stated by the founder of the EHP model, Winnie Dunn, the person is unique in regards to their experiences and their overall skills (Dunn et al., 1994). As a model typically used in pediatric occupational therapy, EHP considers family to be a part of the person (Dunn, 2017). Therefore, the context and person within the EHP model are interconnected, and the parents and child must be looked at simultaneously (Dunn, 2017). This is important to preschoolers because they depend on their families to care for their psychosocial, cognitive and sensorimotor needs (Ahmadi et al., 2019; Fingerhut et al., 2013; Schor, 2003). It is also important to remember that not all cultures within families look the same when implementing EHP into the family-centered care plan (Fingerhut et al., 2013; Kuhaneck et al., 2015).

Psychosocial

The psychosocial part of the person focuses on the interactions of the person's behaviors related to their immediate environment (Dunn et al., 1994). Children's physical, social, cognitive, and social health are shaped by their families (Schor, 2003). In a non-systematic narrative review, Popov et al. (2021) suggested that attending to parents' mental health needs will improve the health, development, and well-being of the whole family. In this review, Popov et al. (2021), recommended screening for parental mental health concerns and referring out to mental health professionals if the screening results indicated potential problems.

In addition to considering parents and children, it is also important to take siblings into consideration (Marini, 2022). This is important because Marini (2022) found that many siblings will step into the caretaker role as they get older. Furthermore, medical providers have a direct effect on the psychosocial component of the family (Dick et al., 2021). Dick et al. (2021) found that with the help of family-centered care, parents were willing to communicate more effectively with medical providers once trust had been established. In order to gain this trust, medical providers must respect the culture of the family (Sharma, 2013). As previously stated, parents are the decision makers in their child's life, therefore effective communication with providers is of the utmost importance (Ahmadi et al., 2019; Fingerhut et al., 2013; Schor, 2003).

Sensorimotor

Occupational therapy has been considered to be driven by foundational sensorimotor skills (Case-Smith et al., 1995). Sensorimotor skills are the basis of a child's ability to function in their given context and have the ability to be meaningful predictors of functional performance for preschool children (Case-Smith et al., 1995). Furthermore, Case-Smith (1995) stated that

children with disabilities may express functional play skills at home with siblings but experience difficulty when transferring those skills into a school setting with peers. This is supported by Eicher et al. (2018) who found that parents of children with sensorimotor impairments reported their children having difficulty in social participation at school due to impaired motor skills. Social participation is a component of health management under the sub-category of social and emotional health promotion and maintenance (AOTA, 2020). It is important that healthcare providers utilize parents' extensive knowledge of their child's sensorimotor needs to be used in developing and implementing interventions (Case-Smith, 1995; Eicher et al., 2018; Myrhaug et al., 2016).

Cognitive

One way that families play a crucial role in their child's development is by giving them the ability to learn, develop, engage in occupations, and participate in routines (Kuhaneck et al., 2015). A preschooler's ability to learn and the cognitive part of the person have been cited as critical components for preschool readiness, as cognition provides the foundation for learning and interacting with others (Frolek Clark & Schlabach, 2013; Kim et al., 2016). Poor cognitive function has been linked to poor social participation impacting health management outcomes for preschoolers with disabilities (Rosenberg et al., 2015). This is important in preschool children because play, learning, and interacting with others is a large portion of their day (Ginsburg, 2007).

Context

Environment through the lens of the EHP model is referred to as context (Dunn, 2017). The context in this model consists of interrelated conditions that surround the person and includes four sub areas: temporal, social, physical and cultural (Dunn, 2017). An individual's context can provide both supports and barriers to performance, as stated by Winnie Dunn in the EHP model (Dunn, 2017). While using EHP, it is important for occupational therapists to consider contexts to the same degree of importance as the person (Brown, 2019; Dunn, 2017).

Temporal

Temporal aspects include the person's chronological age, developmental stage, life cycle, health status, and amount of time that it takes to complete a task (Dunn, 2017). An important temporal context to take into consideration is the life cycle of the person (Dunn, 2017). Preschoolers are in the early childhood education phase of the life cycle (Ginsburg, 2007). The lifecycle phase of being a preschooler involves children taking on many new roles (Williams, 2021). These roles include looking after themselves, being a student, playing with others, and being a friend (Williams, 2021). In addition, it is important for occupational therapists to recognize that these roles may look different based on a client's culture (Jahagirdar, 2013).

Social

Social contexts in the EHP model include the people and places that individuals engage with such as their family, friends, churches, governments, and social institutions (Dunn, 2017). For the purpose of this paper, we focused on the social context of family. Fingerhut et al. (2013) found many family characteristics to be barriers to family-centered care including language,

socioeconomic status, culture, and personal stressors. Cultural differences in the use of verbal and non-verbal language can be a barrier between therapists and the family in family-centered care (Fingerhut et al., 2013). Furthermore, low socioeconomic status has been shown to be a barrier to family-centered care, as the parents often spend much of their time working (Fingerhut et al., 2013). One way researchers have suggested to reduce these barriers was by establishing a care plan to help families understand their child's diagnosis through the use of a care coordinator (McNally et al., 2020).

Physical

Physical aspects of the context include an individual's natural and fabricated environments as well as the objects that surround them (Dunn, 2017). The setting in which occupational therapy takes place has been shown to impact family-centered care (Bhopti et al., 2014; Fingerhut et al., 2013). Fingerhut et al. (2013) and Bhopti et al. (2014) found that there is a lack of family-centered care in school settings, as well as less communication between therapists and families. A possible intervention to address this issue is to create new opportunities to open communication between families and school based therapists. Further research is needed to assist occupational therapists in school settings to implement family-centered care in their practice (Bhopti et al. 2014; Fingerhut et al., 2013).

Cultural

The cultural context includes anything that contributes to what makes a person unique including their ethnicity, religion, and groups in which they participate and identify (Dunn, 2017). Almarsi and Palisano (2018) found that each family's need for information changes over time in response to their cultural beliefs, the child's changing health status, and their resources and access to services. In addition to considering the culture of the family, the culture of the healthcare setting also plays a role in the feasibility of implementing family-centered care (Fingerhut et al., 2013). For example, Jahagirdar (2013) mentioned how individuals within some Asian cultures typically view healthcare providers as superior and therefore, family leadership and active participation in the therapy process may be a challenge.

Task

Tasks are an observable set of behaviors necessary to achieve a set goal (Dunn et al., 1994). Every task is defined differently by each individual given their unique interpretation and experiences (Dunn, 2017). The feasibility of implementing tasks into family-centered care depends on the family's culture, contexts, and abilities (Dunn et al., 1994).

The context of culture plays an important role in how people view the meaning of a specific task (Dunn, 2017). What is important for one family may not be important to others, and those differences need to be recognized when implementing family-centered care (Sharma, 2013). This is supported in a case study by Jahagirdar (2013), in which a family valued bath time and it was important to them that their child learned to bathe himself. In order to make this health management task feasible, the parents and occupational therapist broke down bathing into a step by step process (Jahagirdar, 2013).

Interventions

The EHP model has various interventions that can be applied to occupational therapy services to better integrate family-centered care into the healthcare plan for preschool children with disabilities. The interventions that are unique to the EHP model include establish or restore, alter, modify or adapt, prevent, and create (Brown, 2019; Dunn, 2017).

The first intervention type that occupational therapists can utilize is modify/adapt (Dunn, 2017). In a systematic review, King and Chiarello (2014) found that family-centered care was more effective when modifying their goal setting approach to a more collaborative one and including parents in the goal setting process. Furthermore, parents were more likely to be involved in the therapy process when goals were reflective of their culture (Jahagirdar, 2013). Another way researchers have implemented family-centered care interventions into practice is by modifying the way they build their relationship with families using participatory and relational helpgiving (Dunst et al., 2007). Relational helpgiving involves listening to families' concerns and building a relationship with them, whereas participatory helpgiving requires actively involving the families into the clients healthcare process (Dunst et al., 2007).

Another intervention type that occupational therapists could utilize is establish/restore (Dunn, 2017). Family-centered care can be established by learning about a family's routine and adding new tasks into existing routines in order to avoid additional stress put on the family (King & Chiarello, 2014; Myrhaug et al., 2016). By addressing these interventions and the client's culture, occupational therapists can develop goals and further implement intervention into therapy. Rosenberg et al. (2015) also implemented the establish intervention type by using the Cog-Fun approach on preschoolers with disabilities. This approach is parent-led and emphasized family relationships (Rosenberg et al., 2015).

Summary

Overall, 40 articles were reviewed and 28 were chosen for further review. The articles included topics on family-centered care components and interventions (Brown, 2017; Dunn, 2017; Dunst et al., 2007; King & Chiarello, 2014; Myrhaug et al., 2016; Rosenberg et al., 2015), advantages and barriers to family-centered care (Almarsi & Palisano, 2018; Bhopti et al., 2014; Dick et al., 2021; Fingerhut et al., 2013; McNally et al., 2020), preschoolers with disabilities (Ahmadi et al., 2019; Fingerhut et al., 2013; Frolek Clark & Schlabach, 2013; Ginsburg, 2007; Kim et al., 2016; Rosenberg et al., 2015; Schor, 2003; Williams, 2021), and family-centered care in preschoolers (Ahmadi et al., 2019; Fingerhut et al., 2013; Frolek Clark & Schlabach, 2013; Ginsburg, 2007; Kim et al., 2016; Rosenberg et al., 2015; Schor, 2003; Williams, 2021). The following main points were found:

- Some benefits of implementing family-centered care include an increase in adherence to care plans, improved satisfaction in patients and families, and reduced healthcare costs (Eichner & Johnson, 2012; McCoy et al., 2020; Nickel et al., 2018).

- Barriers to implementing family-centered care are characteristics of the family, and characteristics of the practice setting (Almarsi & Palisano, 2018; Bhopti et al., 2014; Dick et al., 2021; Fingerhut et al., 2013; McNally et al., 2020).
- Family-centered care has the advantages of the practitioner looking at the child holistically and has the flexibility to look at each child as unique with differences in family dynamics and cultures (Dunn, 2017; Myrhaug et al., 2016; Sharma, 2013).
- EHP is a useful frame of reference when implementing family-centered care because it facilitates the practitioners in looking at the person as being interconnected to the family and how family interactions can support or hinder the health management of the child (Dunn, 2017; McCoy et al., 2020).
- Interventions useful in family-centered care include modifying goal settings and modifying relationship building between families and providers (Dunst et al., 2007; King & Chiarello, 2014)
- Other interventions observed to be useful in family-centered care include establishing new family-centered routines into existing routines and establishing the Cog-Fun approach within therapy (King & Chiarello, 2014; Myrhaug et al., 2016; Rosenberg, 2015).

The aim of researching these topics was to see how family-centered care in occupational therapy can support or hinder health management of preschool children with disabilities. After thoroughly reviewing the research, we concluded that there was an adequate amount of evidence regarding the usefulness and benefits of family-centered care. However, more research is needed on how occupational therapists can use specific interventions with family-centered care to support health management.

Clinical Bottom Line

How does family-centered care in occupational therapy support the health management of preschool children with disabilities?

To understand how family-centered care in occupational therapy supports the health management of preschool children with disabilities, the Ecology of Human Performance model (EHP) was utilized. This model focuses on the relationship between person, context, and task (Dunn, 2017). In this case, the person refers to both the preschoolers and their parents (Ahmadi et al., 2019; Fingerhut et al., 2013; Schor, 2003). The preschoolers researched in this paper are between the ages 3 and 5 years old, with the majority having been diagnosed with cerebral palsy or autism. Preschool children and their parents should be viewed cohesively because parents are the main decision makers for their children (Ahmadi et al., 2019; Fingerhut et al., 2013; Schor, 2003). Given this, the family as a whole are important stakeholders of family-centered care and should be included in the therapy process (Marini, 2022; Montgomery, 2020; Sharma, 2013). Furthermore, the parent's values and culture have a major influence on the child and therefore, on the feasibility of family-centered care in health management (Montgomery, 2020; Sharma, 2013).

Preschool children's main tasks consist of learning and play (Ginsburg, 2007). Given this, it is essential for occupational therapists to take the child's psychosocial, sensorimotor and cognitive skills into consideration when using family-centered care (Ahmadi et al., 2019; Fingerhut et al., 2013; Schor, 2003). Psychosocial and sensorimotor skills should be addressed within occupational therapy because these skills have a direct impact on the child's abilities to function in a given context (Case-Smith et al., 1995; Schor, 2003). Cognitive skills should be viewed with a great deal of importance, as cognition provides the foundation for learning and interacting with others, which are both important components of health management (Frolek Clark & Schlabach, 2013; Kim et al., 2016).

In addition, the context that surrounds a person has a large influence on occupational performance (Dunn, 2017). Occupational therapists must take temporal, social, physical and cultural contexts into thought when providing care to preschool children with disabilities (Brown, 2019; Dunn, 2017). A child's temporal context is important to consider because their roles will shift based on their changing life cycle or in other terms, what stage of development they are in (Gingsburg, 2007; Williams, 2021). It is also important for occupational therapists to acknowledge a child's social and cultural context when collaborating with the family because each family is different and their level of involvement with their child will have a direct impact on family-centered care and health management (Almarsi & Palisano, 2018; Fingerhut et al., 2013; Kuhaneck, 2015). The social and cultural context of the families can be acknowledged by listening to the families concerns and attempting to understand differences (Almarsi & Palisano, 2018). Lastly, the physical context needs to be addressed when implementing family-centered care as some settings such as schools do not currently have the means to establish family-centered care (Bhopti et al. 2014; Fingerhut et al., 2013). Occupational therapists could address the physical context by creating new opportunities for families and school-based therapists to have more open communication.

After thoroughly researching the area of interest, we found that there is a great deal of information regarding the potential usefulness of family-centered care in occupational therapy (Almarsi & Palisano, 2018; Dunn, 2017; Fingerhut et al., 2013; Jahagirdar, 2013; King and Chiarello, 2014; Kuhaneck, 2015; Myrhaug et al., 2016; Rosenberg et al., 2015). Occupational therapy can teach parents various strategies and techniques that they can implement at home to benefit their child's progress (Hoyo & Kadlec, 2021; Jahagirdar, 2013). For example, parents were taught how to break down tasks one step at a time in order for them to better implement them at home (Jahagirdar, 2013). On the other hand, there was not enough information or data pertaining to the specific interventions of create, alter, and prevent (Dunn, 2017), which occupational therapists could use in family-centered care. Biases may have been present in the process of creating this critically appraised topic paper. These biases include the availability of articles, author bias from the perspective of an occupational therapist, and the different countries in which the articles were published.

The role of occupational therapy in family-centered care is to focus on the family as a dynamic unit and to include each member within the therapy process (Hoyo & Kadlec, 2020;

Marini, 2022). However, there are existing barriers to family-centered care. Some of these barriers include the setting in which therapy is taking place, the culture of that setting and specific characteristics of the family. Furthermore, cultural differences between the interprofessional healthcare team, therapist, and the family can be a barrier (Almarsi & Palisano, 2018; Fingerhut et al., 2013). One of these barriers includes how different cultures view healthcare providers as superior and therefore participation within family-centered care would be challenged (Jahagirdar, 2013). It is recommended that occupational therapists address these barriers by acknowledging differences and being equipped with knowledge regarding the cultures of their clients (Jahagirdar, 2013; Montgomery, 2020).

References

Ahmadi Kahjoogh, M., Kessler, D., Hosseini, S. A., Rassafiani, M., Akbarfahimi, N., Khankeh, H. R., & Biglarian, A. (2019). Randomized controlled trial of occupational performance coaching for mothers of children with cerebral palsy. *British Journal of Occupational Therapy*, *82*(4), 213–219. https://doi.org.ezproxylr.med.und.edu/10.1177/0308022618799944

Almasri, A. M., & Palisano, R. J. (2018). Parents' perception of receiving family-centered care for their children with physical disabilities: A meta-analysis. *Physical & Occupational Therapy in Pediatrics, 38*(4), 427– 443. https://doi.org/10.1080/01942638.201 7.1337664

American Occupational Therapy Association. (2020). Occupational therapy practice framework: Domain and process (4th ed.). *American Journal of Occupational Therapy*, *74*(Suppl. 2), 7412410010. https://doi. org/10.5014/ajot.2020.74S2001.

Autism Speaks. (2018). *Autism and health: A special report.* Autism Speaks. https://www.autismspeaks.org/sites/default/files/2018-09/autism-and-health-report.pdf

Bhopti, A., Brown, T., & Lentin, P. (2020). Opportunities for participation, inclusion and recreation in school-aged children with disability influences parent occupations and family quality of life: A mixed-methods study. *British Journal of Occupational Therapy, 83*(4), 204–214. https://doi.org/10.1177/0308022619883480

Brown, C. E. (2019). Ecological models in occupational therapy. In B.A Boyt & G. Gillen (Eds.), *Willard and Spackman's occupational therapy* (pp. 622-632). Wolters Kluwer.

Case-Smith, J. (1995). The relationships among sensorimotor components, fine motor skill, and functional performance in preschool children. The *American Journal of Occupational Therapy*, *49*(7), 645–652. doi: https://doi.org/10.5014/ajot.49.7.645

Centers for Disease Control and Prevention (2021). *What is cerebral palsy?* Centers for Disease Control and Prevention. https://www.cdc.gov/ncbddd/cp/facts.html#:~:text=Cerebral%20palsy%20(CP)%20is%20a,problems%20with%20using%20the%20muscles.

Chi, I. J., & Lin, L. Y. (2022). Using the assessment of motor and process skills and the pediatric evaluation of disability inventory to assess self-care performance among preschool children with autism spectrum disorder. *The American Journal of Occupational Therapy, 76*(2), 1-8. https://doi.org/10.5014/ajot.2022.046326

Dick, C. C., Ibañez, L. V., DesChamps, T. D., Attar, S. M., & Stone, W. L. (2021). Brief report: Perceptions of family-centered care across service delivery systems and types of caregiver concerns about their toddlers' development. *Journal of Autism and Developmental Disorders*. Online ahead of print. https://doi.org/10.1007/s10803-021-05248-6

Dunn, W. (2017). The Ecological Model of Occupation. In J. Hinojosa et al. (Eds.), *Perspectives on human occupation: Theories underlying practice* (2nd ed., pp. 207-235). F.A. Davis.

Dunn, W., Brown, C., & McGuigan, A. (1994). The ecology of human performance: a framework for considering the effect of context. *The American Journal of Occupational Therapy, 48*(7), 595–607. https://doi.org/10.5014/ajot.48.7.595

Dunst, C.J., Trivette, C. M., & Hamby, D. W. (2007). Meta-analysis of family-centered helpgiving practices research: Families of children with developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(4), 370–378. https://doi.org/10.1002/mrdd.20176

Eicher, E. A., Skubik-Peplaski, C., O'Brien, S. P., & Fleischer, A. (2018). Exploring parents' experiences of raising a child with sensorimotor impairments and expectations for leisure participation. *The Open Journal of Occupational Therapy, 6*(4), 1-13. https://doi.org/10.15453/2168-6408.1364

Eichner, J.M., & Johnson, B.H. (2012). Patient- and family-centered care and the pediatrician's role. *Pediatrics, 129*(2), 394–404. https://doi.org/10.1542/peds.2011-3084

Fingerhut, P. E., Piro, J., Sutton, A., Campbell, R., Lewis, C., Lawji, D., & Martinez, N. (2013). Family-centered principles implemented in home-based, clinic-based, and school-based pediatric settings. *The American Journal of Occupational Therapy, 67*(2), 228–235. https://doi.org/10.5014/ajot.2013.006957

Frolek Clark, G. J., & Schlabach, T. L. (2013). Systematic review of occupational therapy interventions to improve cognitive development in children ages birth–5 years. *The American Journal of Occupational Therapy, 67*, 425–430. http://dx.doi.org/10.5014/ajot.2013.006163

Ginsburg, K. R. (2007). The importance of play in promoting healthy child development and maintaining strong parent-child bonds. *Pediatrics, 119*(1), 182–191. https://doi-org.ezproxylr.med.und.edu/10.1542/peds.2006-2697

Hoyo, V., & Kadlec, M. B. (2021). From syringe to spoon feeding: A case report of how occupational therapy treatment successfully guided the parents of a child with autism spectrum disorder and prematurity in an outpatient clinic. *Journal of Autism and Developmental Disorders, 51*(7), 2561–2565. https://doi.org/10.1007/s10803-020-04713-y

Jahagirdar, S. (2013). Together we can! Working with family and caregivers of children with developmental disability. *World Federation of Occupational Therapists Bulletin, 67*(1), 33-36. https://doi.org/10.1179/otb.2013.67.1.008

Kim, H., Carlson, A. G., Curby, T. W., & Winsler, A. (2016). Relations among motor, social, and cognitive skills in pre-kindergarten children with developmental disabilities. *Research in Developmental Disabilities, 53-54*, 43–60. https://doi.org/10.1016/j.ridd.2016.01.016

King, G., & Chiarello, L. (2014). Family-centered care for children with cerebral palsy: conceptual and practical considerations to advance care and practice. *Journal of Child Neurology, 29*(8), 1046–1054. https://doi.org/10.1177/0883073814533009

Kuhaneck, Madonna, S., Novak, A., & Pearson, E. (2015). Effectiveness of interventions for children with autism spectrum disorder and their parents: A systematic review of family outcomes. *The American Journal of Occupational Therapy, 69*(5), 1–14. https://doi.org/10.5014/ajot.2015.017855

Marini, G. (2022, March 31). Looking through the eyes of the well-sibling [Conference Session] American Occupational Therapy Association Conference, San Antonio, TX, United States.

Mas, J. M., Dunst, C. J., Balcells-Balcells, A., Garcia-Ventura, S., Giné, C., & Cañadas, M. (2019). Family-centered practices and the parental well-being of young children with disabilities and developmental delay. *Research in Developmental Disabilities, 94*, 1-13. https://doi.org/10.1016/j.ridd.2019.10 3495

McCoy, S. W., Palisano, R., Avery, L., Jeffries, L., Laforme Fiss, A., Chiarello, L., & Hanna, S. (2020). Physical, occupational, and speech therapy for children with cerebral palsy. *Developmental Medicine and Child Neurology, 62*(1), 140-146. https://doi.org/10.1111/dmcn.14325

McNally Keehn, R., Enneking, B., Ramaker, M., Goings, M., Yang, Z., Carroll, A., & Ciccarelli, M. (2020). Family-centered care coordination in an interdisciplinary neurodevelopmental

evaluation clinic: Outcomes from care coordinator and caregiver reports. *Frontiers in Pediatrics, 8*, 1-12. https://doi.org/10.3389/fped.2020.538633

Montgomery, B. (2020). *Developing cultural competence in paradise.* American Occupational Therapy Association. https://www.aota.org/publications/student-articles/fieldwork/cultural-competence-paradise

Myrhaug, H. T., Jahnsen, R., & Østensjø, S. (2016). Family-centred practices in the provision of interventions and services in primary health care: A survey of parents of preschool children with cerebral palsy. *Journal of Child Health Care, 20*(1), 109–119. https://doi.org/10.1177/1367493514551312

Nickel, W. K., Weinberger, S. E., Guze, P. A., Carney, J., Ende, J., Hoy, E., Myerson, S., Rothholz, M., Sands, D., Schneider, D., Sweeney, J. M., & Sweet, D. E. (2018). Principles for patient and family partnership in care: An American college of physicians position paper. *Annals of Internal Medicine, 169*(11), 796–799. https://doi.org/10.7326/M18-0018

Popov, N., Phoenix, M., & King, G. (2021). To screen or not to screen? Exploring the value of parent mental health screening in children's rehabilitation services. *Disability and Rehabilitation, 43*(5), 739–745. https://doi.org/10.1080/09638288.2019.1635657

Rosenberg, L., Maeir, A., Yochman, A., Dahan, I., & Hirsch, I. (2015). Effectiveness of a cognitive-functional group intervention among preschoolers with attention deficit hyperactivity disorder: A pilot study. *The American Journal of Occupational Therapy, 69*(3), 1–8. https://doi.org/10.5014/ajot.2015.014795

Schor, E. L. (2003). Family pediatrics: Report of the task force on the family. *Pediatrics*, *111*(2), 1541–1571. https://doi.org/10.1542/peds.111.S2.1541

Sharma, R. (2013). The family and family structure classification redefined for the current times. *Journal of Family Medicine and Primary Care, 2*(4), 306-310. https://doi: 10.4103/2249-4863.123774

Williams, A. (2021). *The roles of Preschool Children*. Sounds good to me. https://soundsgoodtome.com.au/the-roles-of-preschool-children/