

Critical Literature Review: Child and Family Focused Care

Commissioned by Macaulay Child Development Centre

December 17, 2017

Caitlin Wood

Critical Literature Review: Child and Family Focused Care

Introduction

The notion of child and family focused care (CFFC) emerged in the 1960's as a strong advocacy movement led predominantly by parents of children living with disabilities or chronic illnesses (MacKean, Thurston, & Scott, 2005). The movement demanded a greater role for parents and families in the dominant expert-model of children's health and service delivery (MacKean, Thurston, & Scott, 2005). The rationale for CFFC is two-fold: i) that families have expertise, additional resources and insights into their child that will result in greater outcomes for the child; and ii) that family well-being is an important outcome for professionals to consider (Summers, et al., 2007).

Over the years CFFC has been integrated in many major policy changes in children's health and service sectors on international, national and local scales (MacKean, Thurston, & Scott, 2005) - including many legislative documents governing Ontario's Early Years Sector. *Building a Better Future* (2016) states that, "Our goal is to create a renewed early years and child care policy framework and a child care expansion strategy that takes a child and family-centred approach that respects equity, inclusiveness and diversity" (p. 11); *How Does Learning Happen* (2014) notes that "We must engage with families and support each child within the context of her family, recognizing that family and child well-being are inextricably linked" (p. 11); and the *Ontario Early Years Policy Framework* (2013) states the first principle to support Ontario's vision for the early years is that "programs and services are centred on the child and the family" (p. 7).

Great strides have undoubtedly been made to recognize and accept the necessity of the inclusion of families in the care and service delivery provided to young children. However, there

remains a great difficulty in genuinely implementing CFFC into action and will be elaborated further within this paper. The following critical literature review has been commissioned by the Macaulay Child Development Centre. The goal will be to “articulate a full description of what it would mean for an agency like Macaulay to be child and family focused” (Macaulay Child Development Centre, 2017).

Theoretical Frameworks

Macaulay Child Development Centre stressed the importance of framing this literature review within a trauma and poverty informed frameworks.

Trauma-Informed Framework

A trauma informed framework is designed to recognize the widespread impact of trauma on individuals, families and communities. It should recognize the signs and symptoms of trauma in staff, clients, children, and families, and respond by fully integrating knowledge about trauma into all policies, procedures, practices and all settings (Australian Government Department of Families, Community Services and Government Affairs, 2002; Klinic, 2003). The core principles of trauma informed practice include: trauma is a pervasive problem; that practice must always prioritize the safety of all partners; that professionals must provide honest explanations and genuine care to foster trust; that partners must have choice and control over the services and care provided to them; and that all care must be provided in a compassionate manner (Klinic, 2003).

Poverty Informed Framework

Families exposed to urban poverty are disproportionately affected by trauma (Family-Informed Trauma Treatment Centre, 2000). Among the factors associated with urban poverty include low neighbourhood safety, racial discrimination, and daily hassles that negatively impact family functioning. It is therefore imperative that family support services and programs be

reflective and sensitive to the traumatic context of poverty. Furthermore, programs designed with poverty informed frameworks must include engagement strategies that incorporate partnerships with primary and extended family systems, that build family coping skills, and that acknowledge cultural variations in family roles and functions (Family-Informed Trauma Treatment Centre, 2000).

Method

Identification and Selection of the Literature

For the purpose of this study a computerized search of the electronic bibliographic databases PubMed, ProQuest, Scholars Journal, ERIC, and Google Scholar Research Library was made from 2001 until 2017. Using appropriate terms for the database I searched ‘child and family centred’ and ‘child and family focused’ in peer-reviewed journals. To refine the search results, I surveyed the article titles and abstracts for fit with the search criteria. After screening for the eligibility of these articles, 42 appeared appropriate and therefore retained. The third stage of the data collection process involved reading all articles and selecting all potentially relevant literature using the inclusion and exclusion criteria. This further refined the literature to 16 articles.

Inclusion and Exclusion Criteria

For the purpose of this literature review, I created inclusion and exclusion criteria to determine the relevance of a given article to my study. The inclusion criterion was co-developed by myself, Sherri Ernst, and Ruth Gayle of Macauley Child Development Centre, and further informed by personal communication with Dr. Kathryn Underwood of Ryerson University, and Glory Ressler of Mothercraft. The inclusion criterion included the terms ‘child and family focused’, ‘child and family centred/centered’, ‘professional and family

collaborations/partnerships', 'family focused care'. Only peer-reviewed articles were selected to guarantee the quality of the material (with the exception of a grey literature search completed using Google Scholar). Only English articles were included because I am only able to read English. Additionally, all articles were published between 2001-2017. Searches were not limited by geographic location.

The initial database search yielded 1,938 potentially relevant publications. After titles and abstracts were screened and duplicates excluded, only 42 articles were deemed as potentially relevant and retrieved in full text. After reading and utilizing the inclusion and exclusion criteria, 16 publications were found relevant to the topic. Of the 16 articles selected, 9 were original research papers, 4 were perspective pieces, and 4 were literature reviews. It is important to note that of the 16 articles, 9 were related to providing services to children with disabilities, 3 were related to hospital service provision, 2 were related to mental health service provision, 1 was related to service provision in the early years, and 1 was related to the provision of welfare services.

To organize the findings from the critical literature review I created a table (Appendix A) that paid particular attention to principles, definitions, and critiques of CFFC, and the results/findings/positions of the paper. I then structured the findings that arose from the data into themes presented within the findings section of this paper.

Findings

The following section of this paper will discuss the findings into three sections: i) a brief theoretical background: which will include a comprehensive definition of CFFC as well as the principles CFFC as stated in the literature; ii) a critique: which will include discussion of the importance of fluidity in definition; the importance and challenges of the inclusion of multiple

perspectives, and the importance of dynamic evaluation; iii) next steps: inclusive of the critiques made in part ii.

The Theory

Child and Family Focused Care defined. A variety of definitions of Child and Family Focused Care appear in the literature. The most comprehensive definition – and the one most aligned with the specific focus and critiques of this paper – is provided by MacKean, Thurston, and Scott (2005). The authors define CFFC as:

placing the needs of the child in the context of the family and community, at the center of care and devising an individualized and dynamic model of care in collaboration with the child and family that will best meet these needs (p. 75).

This is further characterized within the literature as including mutually supportive interactions (Summers et al., 2005; Dunst & Pagat, 1991 as cited in Summers et al., 2005; Summers et al., 2007;), collaborative and respectful relationships (Summers et al., 2005; Dunst, & Pagat, 1991, as cited by Summers et al., 2005; Summers 2007; Regan, Curtin, & Vorder, 2006), and by a sense of positive communication, competence, and quality (Summers et al., 2005; Summers et al., 2007).

The principles of CFFC. Only three of the 16 articles clarified the principles of CFFC. Woods and McCormick (2002) created five principles for carrying out developmental assessments within preschool years. The authors state that CFFC must: 1) recognize that individual members of a family have preferred learning styles, unique child-rearing practices, play different parenting roles, and have distinct values and opinions; 2) recognize that families are partners in the process and are the ultimate decision makers; 3) share information in a

reciprocal, sensitive, and a timely manner; 4) view the assessment as an opportunity to teach/intervene; and 5) identify supports for family member participation.

Regan, Curtin, and Vorderer (2006) advance 4 principles of CFFC in the context of psychiatric care for young children. The authors state that CFFC must: 1) always treat people with respect and dignity; 2) communicate complete and unbiased information with patients and families in manner that is affirmative and useful; 3) support to individuals to build their strengths and participate in experiences that enhance their control and independence in the process of receiving care; 4) collaborate with patients and families in policy and program development, professional education, and in the delivery of care.

Similarly, MacKean, Thurston, and Scott (2005) identify 6 principles of CFFC in developmental services for young children in hospitals. The authors state that CFFC must: 1) recognize the importance of family as a source of stability, security, and strength in the child's life; 2) respect the diversity that exists among children and their families; 3) acknowledge the expertise of parents at the individual and care-giving level and the systems level; 4) recognize that family centred care focuses on competency enhancement rather than weakness focused; 5) encourage a true collaboration between families and health care professionals; and 6) facilitate family-to-family support networking and provide emotional and financial services that meet the needs of families. MacKean, Thurston, and Scott (2005) have observed a tendency among professionals to overlook or ignore principles 2, 5, and 6. This subsequently contributes to a lack of cohesiveness in approach and an absence of a shared understanding of the purpose of CFFC between professionals and families.

All three models of CFFC share many similarities in their design. Each model is strength based, places the child within the larger family unit, recognizes the expertise and diversity of

families, and emphasizes the importance of collaboration and partnership. Though there are many similarities between models, authors of all three articles detail the many complexities and particular shortfalls of CFFC as it is implemented into practice. The aim of the following section is to explore these complexities further.

The Critique

Regan, Curtin, and Vorderer (2006) outline some potential barriers to a cohesive approach to CFFC in early years programs. The authors identify the following 4 obstacles: 1) a lack of knowledge in regards to the principles of CFFC; 2) a lack of strong organizational support for CFFC; 3) a perceived conflict among professionals between the principles of CFFC and their professional identities and professional acknowledgement; and 4) an incongruity between the personal beliefs and/or values of professionals and the principles of CFFC. In consideration of these barriers it is argued that a comprehensive understanding of the specificities of CFFC be developed and understood by all professionals in order to be successful.

What emerged from the literature was that despite sound theoretical foundations of CFFC there were greater complexities that present themselves in the implementation phase of this practice that must be noted in order to create a model that is truly child and family focused. The specific critiques that emerged from the literature to CFFC was the importance of fluidity in definition, the importance and challenges of the inclusion of multiple perspectives, and the importance of dynamic evaluation.

The importance of fluidity in definition. Though the importance of creating a thorough definition and organizational understanding of CFFC has already been argued, this present section will suggest the need to create a fluid and flexible definition of CFFC rather than one which is operationalized. The literature presents this argument as serving two purposes: first,

because it has been noted that when a definition becomes operationalized it may cease to be relational (MacKean, Thurston, & Scott, 2005); and second, to ensure professionals remain committed and accountable to the practice of CFFC not the protocol.

MacKean, Thurston, and Scott (2005) ground their conception of CFFC in the experiences of families and those of their health providers. The authors observe an overwhelming desire among parents of children in hospital care for a greater relational component in CFFC. Though it was known that relationships are predominantly accepted to be central factors to CFFC, MacKean, Thurston, and Scott (2005), found that “when family centred care is operationalized the collaborative processes often disappear” (p. 81). The authors further noted that “the operational definition of a collaborative relationship, in the context of family-centred care, appears to be the devolution of responsibility to parents” (MacKean, Thurston, & Scott, 2005, p.81). The operationalization of CFC frequently overlooks important differences among children and families, fails to acknowledge the different desires and goals between different family partners, and may result in a belief that the professionals can meet the needs of the child if they are provided with the evidence-based protocol to follow (Hewitt-Taylor & Melling, 2004). It is therefore imperative that introducing care protocols and definitions be accomplished without compromising the recommendations that children and families should be cared for by staff that are aware of their specific needs (Hewitt-Taylor, & Melling, 2004).

Veelen, Regeer, Broerse, van de Poel, and Dinkgreve (2017), argue that professionals must remain accountable to their practice – not the protocol. Van Veelen et al., (2017) noted in their research study on the implementation of CFFC in Amsterdam’s child welfare system, that programs and services would frequently become so fragmented and internally overwhelmed by redundant bureaucracy, protocols, and definitions, that professionals would often fail to best

support the needs of children and their families. What was more was that when something went wrong in service delivery, professionals would hide behind the administrative systems arguing that they had followed protocol and therefore not responsible for the programs/and or services' failing (van Veelen, et al., 2017). This shrugging of responsibility in turn led to negative ripple effects in the quality of programs delivered to children and families as it would interrupt the necessary process of reflexive practice, and relational problem-solving while furthering the professional as expert model (van Veelen, et al., 2017). Authors instead suggest that the creation of a definition for CFFC must be bottom up, not top down (van Veelen, et al., 2017).

If the desire is to provide care that is truly child and family centred, practitioners must radically alter the way in which institutional structures, practices, and policies are formulated and carried out (Regan, Curtin, & Vorderer, 2006). Children and families must be truly seen as central to the implementation of CFFC. What is truly best practice must be derived from learning about the individual who is being provided with care and making decisions based on the specific needs and preferences of that individual, as well as using what is generally known to be the best evidence based approach to the situation (Hewitt-Taylor, Melling, 2004).

The importance and challenges of the inclusion of multiple perspectives. Within the implementation process of CFFC, it is important to consider all key players (made up of children, families and professionals) as competent, curious, and capable (G. Ressler, personal communication, December 13, 2017). As outlined in the previous section, it is not uncommon for professionals to rely too heavily on operationalized definitions – subsequently overlooking the multiple view points of families and their children and negatively impacting the integrity of CFFC. This next section will outline the views of families, children, and professionals as defined – or in some cases absent from the literature.

Parents/Families. Sheild (2010) questioned the relevance, meaning, and effectiveness of CFFC in the way it is frequently practiced and posited that it is not the best model for parents and their children. In her study specifically looking at children in hospitalized care, Shield (2010) argued that many parents are erroneously assumed to know the best way to care for the specific needs of their children; that some parents feel judged by staff if they are uncomfortable or unable to participate in their child's care in a manner determined by professionals to be correct; and that parents often experience role confusion regarding the degree of involvement in their child's care (as cited by Tallon, Kendall & Snider, 2015). This should not however mean that CFFC cease to be practiced, but rather that attention be drawn to the importance of providing care within the context of the family – understanding their individualized needs (Tallon, Kendall & Snider, 2015; Ziviani, Darlington, Feeney, Rodger, & Watter, 2014). The following section will examine how to do just that by specifically exploring themes that emerged from the data regarding how parents and families viewed CFFC.

Within the literature parents and families expressed that they were frequently dissatisfied with services and often felt disempowered (Keen, 2007). Parents often believed that professionals failed to understand and respect their cultural differences, and perceived the provision of appropriate and inclusive services for their child as “forever an ongoing struggle” (Summers, et al., 2005, p. 66). Additionally, parents reported a frequent imbalance of power which subsequently affected parents' future desire for further partnerships (Keen, 2007), and which resulted in increased parental stress (Regan, Curtin, & Vorderer, 2006).

Though parents greatly valued the knowledge and expertise of professionals (MacKean, Thurston & Scott, 2005), they often reported feeling that they were being treated as clients and consumers, rather than key decision makers (Mackean, Thurston, & Scott, 2005; Keen, 2007).

Parents stated that they desired a harmonious interpersonal relationship (Wang, Petrini, & Guan, 2014) in which they would receive greater input from professionals regarding defining their respective roles, support in making decisions about what services would best meet their child's needs, guidance in the ongoing management of their child's care, and advocating for their child's best interest. (Terweil et al., 2017; MacKean, Thurston & Scott, 2005). In a study by Regan, Curtin, and Vorderer (2006), parents identified characteristics of communication, responsiveness, honesty and emotional support as being central to the effective delivery of CFFC.

Children. What seemed to be overwhelmingly lacking from the literature was the perspectives of children and youth regarding their role within the CFFC partnerships. Article 12 and 13 of the United Nations Conventions of the Rights of the Child (UNCRC) (UN General Assembly, 1989), state that children have the right to form opinions and the right to be heard in matters that affect them (UN General Assembly, 1989). Yet, of the 16 articles selected only three gave mention to the role of children in their care. In the provision of services to children, the rationale for providing children specialized care are often considered in light of the "best interests of the child" (Article 3, UNCRC) (UN General Assembly, 1989), but may not always take into account the "rights of the child" (Regan, Curtin, & Vorderer, 2006, p. 32). In light of this it is not surprising that when children do make contributions to their own care, their involvement tends to be regarding social rather than health issues (Callery, 2005). Though it is difficult however, should not mean that it is not done.

Regan, Curtin, and Vorderer (2006), suggested characteristics required to build strong relationships with children. They included: establishing trust with the child, providing honest explanations, getting to know the child as a person, conveying a sense of genuine like and

respect for the child, sharing one's self (i.e. personal stories or anecdotes), resisting emotional detachment as a protective measure, and recognizing the essential importance of physical touch as evidence of a reciprocal process in forming a trusting bond. It is clear that more research is necessary in this category. Though these characteristics present an important first step towards the partnership and inclusion of young children to determine their own care, further research and practice into the involvement of children within their own care is necessary.

Professionals. Professionals have no easy job juggling their many day-to-day tasks that may involve specific budgeting, reporting, tracking, and ministry compliance demands. However, it is important to recognize that these protocols are simply one part of the role, and should not overtake the importance of a genuine relational approach with children and their families. Within the literature, three main themes arose: the importance of viewing families as unique, the importance of supporting parents and children in the process of partnership, and the suggestion to see partnership in CFFC as having two components: relationships and child outcomes.

Professionals must be sensitive and aware of the specific needs of family members but should not necessarily assume responsibility or direct involvement in meeting these needs (Keen, 2007). Demonstrated in a study by Knox and Bigby (as cited by Keen, 2007), researchers found through in-depth interviews with families of children receiving developmental supports, that family members frequently work together to ensure the well-being of the family as a whole. Keen (2007) therefore cautions that these relationships are at risk of being undermined if professionals fail to recognize the complex dynamics and critical roles each family member plays. Therefore, the terms of partnership and professional boundaries must be co-determined with families, and not assumed that because there is a need, it is the professional's role to fill it.

Similarly, Regan, Curtin and Vorderer (2006), demonstrated that parents identified a variety of significant people in their lives and ways in which they assisted them in making important decisions about the care of their children. Thus in delivering CFFC the structure of the providing care must allow for a variety of family and support systems to be involved.

Terweil et al., (2017), noted that family focused care is largely associated with parental well-being, psychological health, children's healthy development, adaptive behavior, as well as socio-emotional competence and functioning. But further noted that the implementation of such an approach is often found to be challenging. In their research study, authors sought to understand this difficulty. Using the Measure of Processes of Care questionnaire to gauge parent satisfaction with the delivery of services to their children who had cerebral palsy, authors noted considerable variation in satisfaction scores among parents – indicative of the great diversity of beliefs and experiences amongst families. However, one area in which parents overwhelming reported dissatisfaction was related to the degree of input they had in their child's care. Parents indicated they were unsure of how to become more involved, what specific questions to ask, and how to express their desires and goals to professionals freely. Keen (2007) further demonstrated in parent-professional partnerships, families often have little control over the type of partnership they entered into, when the partnership begins or ends, as well as the interpretation of goals is different between parents and professionals. In light of this, Terweil et al., (2017) posit that professionals must support parents to express what they find important and support them throughout the partnership.

Within this area greater research is needed to understand how to identify and prioritize diverse and potentially competing needs of key partners. One approach may be to conceptualize CFFC as having two main components: i) relationships (between professionals, parents, families,

children); and ii) service delivery (that may promote specific child outcome goals) (Keen, 2007; Terwiel et al., 2017; Summers et al., 2007). This conceptualization, allows for recognition and commitment of the separate goals included in the *process* of providing care, as well as the *product* of care provided (MacKean, Thurston, & Scott, 2005). What is known however, is that the contributions of all partners are key to the successful delivery of CFFC.

The importance of dynamic evaluation. Related to the importance of having a flexible definition, as well as including all key partners, is the importance of having dynamic evaluation. Parents, children, and professionals have important respective roles to play, not only in the identification of goals but also in the measuring of impact (Green & Wilson, 2008). Summers et al., (2005), suggest two key components of CFFC to be measured: i) measure of child and family centred practice: specifically how included and supported the family was in the process of care; and ii) measure of satisfaction with the instrument or outcome of service (was the service or prescribed tool helpful). This however, can be a complicated task. Pertaining to the evaluation of CFFC there is no ‘one-size-fits-all’ evaluative approach, but rather evaluation must remain dynamic and on-going.

In recognition of the various key partners, it is necessary to create evaluation instruments that are reflective of the participants they are aimed to serve. Summers, et al., (2005) identified that the evaluation of services for children and the evaluation of the services provided to their families required different approaches, thus they developed different evaluations. Similarly, Green and Wilson, (2008) developed different evaluation methods for children and their families. They found however, that frequently the satisfaction levels, goals, and desired impacts of services different greatly between evaluations. This lack of relationship between the opinions of

parents and children raises some ethical issues regarding how to determine partnership, how to set goals, and how to facilitate compromise between key partners (Green & Wilson, 2008).

Additionally, different types of evaluations must be employed. Though self-report questionnaires are often desirable due to their ease of use, they provide only a brief snapshot into the successfulness of CFFC at the time of questionnaire delivery. Instead, evaluation should be continuous. This can be done in on-going discussions, and check ins, pre-discharge interviews, satisfaction surveys, suggestion boxes, and a myriad of other approaches (Heywood, 2002). This is important because if parents, families and children are consulted and their involvement evaluated throughout the process, there is a higher likelihood that their felt needs line up with their needs as perceived by staff.

Next Steps

In section i) this paper identified a definition that is open ended, and comprehensive enough to include all elements of the theory and the critique. It was that CFFC is:

placing the needs of the child in the context of the family and community, at the center of care and devising an individualized and dynamic model of care in collaboration with the child and family that will best meet these needs (MacKean, Thurston, & Scott (2005). p. 75).

Next, by comparing principles of CFFC as identified in the literature, the similarities between models were outlined. These were that CFFC must be strengths-based model, must place the child within the larger family unit, must recognize the individual expertise and diversity of families (and their children) and are must be based on true collaboration and partnerships.

Section ii) outlined that despite comprehensive definitions and principles of CFFC greater difficulties frequently present themselves in the implementation phase. The specific critiques

made in this paper – as they emerged from the literature, was the importance of fluidity in definition, the importance and challenges of the inclusion of multiple perspectives, and the importance of dynamic evaluation.

Section iii) is currently left open so it can include feedback gained through consultation with Macaulay Child Development Staff.

References

- Australian Government Department of Families, Community Services, and Government Affairs. (2002). Literature Review: A trauma sensitive approach for children aged 0-8 years. *Trauma and young children – a caring approach project Women’s Health Goulburn North East*.
- Callery, P. (2005). 'The prairie tortoise'. *Paediatric nursing*, 17(1), 12-13.
- Family-Informed Trauma Treatment Centre. (2000). Understanding the impact of trauma and urban poverty on family systems: Risks, resilience, and interventions. Retrieved from http://www.nctsn.org/sites/default/files/assets/pdfs/understanding_the_impact_of_trauma.pdf
- Green, D., & Wilson, B. N. (2008). The importance of parent and child opinion in detecting change in movement capabilities. *Canadian Journal of Occupational Therapy*, 75(4), 208-219.
- Hewitt-Taylor, J., & Melling, S. (2004). Care protocols: rigid rules or useful tools? *Paediatric nursing*, 16(4), 38-42.
- Heywood, J. (2002). Enhancing seamless care: A review: The complex issues of continuity and seamless care for children and families are examined by Jeannette Heywood. *Paediatric Care*, 14(5), 18-20.
- Keen, D. (2007). Parents, families, and partnerships: Issues and considerations. *International Journal of Disability, Development and Education*, 54(3), 339-349.
- Klinic. (2003). Trauma Informed: the trauma toolkit, second edition. Retrieved from http://trauma-informed.ca/wp-content/uploads/2013/10/Trauma-informed_Toolkit.pdf
- MacKean, G. L., Thurston, W. E., & Scott, C. M. (2005). Bridging the divide between families

and health professionals' perspectives on family-centred care. *Health Expectations*, 8(1), 74-85.

McKay, M. M., Gopalan, G., Franco, L. M., Kalogeroiannis Tallon, M. M., Kendall, G. E., & Snider, P. D. (2015). Rethinking family-centred care for the child and family in hospital. *Journal of clinical nursing*, 24(9-10), 1426-1435.

Ministry of Education (2013). Ontario early years policy framework. Retrieved from <http://www.edu.gov.on.ca/childcare/OntarioEarlyYear.pdf>

Ministry of Education (2014). How does learning happen: Ontario's pedagogy for the early years. Retrieved from <http://www.edu.gov.on.ca/childcare/HowLearningHappens.pdf>

Ministry of Education (2017). Building a better future: A discussion paper for transforming early years and child care in Ontario. Retrieved from https://files.ontario.ca/en_cc_discussion_paper_aoda.pdf

Regan, K. M., Curtin, C., & Vorderer, L. (2006). Paradigm Shifts in Inpatient Psychiatric Care of Children: Approaching Child-and Family-Centered Care. *Journal of Child and Adolescent Psychiatric Nursing*, 19(1), 29-40.

Sick Kids (2017) Model of child and Family-Centred Care. *SickKids*

Summers, J. A., Hoffman, L., Marquis, J., Turnbull, A., Poston, D., & Nelson, L. L. (2005). Measuring the Quality of Family—Professional Partnerships in Special Education Services. *Exceptional Children*, 72(1), 65-81.

Summers, J. A., Marquis, J., Mannan, H., Turnbull, A. P., Fleming, K., Poston, D. J., Wang, M. & Kupzyk, K. (2007). Relationship of perceived adequacy of services, family—professional partnerships, and family quality of life in early childhood service

- programmes. *International Journal of Disability, Development and Education*, 54(3), 319-338.
- Terwiel, M., Alsem, M. W., Siebes, R. C., Bieleman, K., Verhoef, M., & Ketelaar, M. (2017). Family-centred service: differences in what parents of children with cerebral palsy rate important. *Child: Care, Health and Development*, 43, 663-669.
- UN General Assembly. (2007). *United Nations Declaration on the Rights of Indigenous Peoples :resolution / adopted by the General Assembly*, 2 October 2007, A/RES/61/295, available at: <http://www.refworld.org/docid/471355a82.html>
- Van Veelen, J. S. M., Regeer, B. J., Broerse, J. E. W., Van de Poel, S. F. P., & Dingreve, M. A. H. M., (2017). Embedding the Notion of child-Family-Centred care into Organizational Practice: Learning from Organizational Visioning. *Journal of Public Child Welfare*, 11(2), 231-259.
- Wang, M., Petrini, M. A., & Guan, Q. (2015). Evaluation of family-centred services from parents of Chinese children with cerebral palsy with the Measure of Processes of Care. *Child: care, health and development*, 41(3), 408-415.
- Woods, J. J., & McCormick, K. M. (2002). Toward an integration of child-and family-centered practices in the assessment of preschool children: Welcoming the family. *Young Exceptional Children*, 5(3), 2-11.
- Ziviani, J., Darlington, Y., Feeney, R., Rodger, S., & Watter, P. (2014). Early intervention services of children with physical disabilities: complexity of child and family needs. *Australian occupational therapy journal*, 61(2), 67-75.

Appendix A

Citation	Type of study	Professional sector	Location	Findings
<p>Keen, D. (2007). Parents, families, and partnership: Issues and considerations. <i>International Journal of Disability, Development and Education</i>, 54(3), 339-349.</p>	<p>Literature review</p>	<p>Supporting families of children with disabilities.</p>	<p>Australia</p>	<p>Family (according to family systems theory): The family is a dynamic entity with unique characteristics and needs but is also comprised of individuals who each have their own unique characteristics and needs In parent-professional partnerships, families have little control over the type of partnership they enter into, when the partnership begins or ends, and often the interpretation of goals is different between parents and professionals</p> <p>Approaches to achieving agreement about goals: Shared planning and decision making – parents often felt disempowered and dissatisfied with services. Parents who feel they are able to take action report higher satisfaction. Parents often report an imbalance of power subsequently affecting future partnerships. Parents instead must be seen as key decision makers rather than consumers or clients</p> <p>Individual and Family Needs: - difficulty in accessing information about the family that aids in the delivery of specialized services while also protecting family rights. Professionals need to be aware and sensitive to the needs of carers and siblings but should not assume responsibility or direct involvement in meeting these needs. – study by Knox and Bigby() demonstrated through in-depth interviews with families that family members work together to ensure the well-being of the family as a whole. And caution that these relationships are at risk of being undermined or disrupted if professionals fail to recognize the complex dynamics and critical roles family members play. Therefore, professionals must determine from the family what the professional boundaries are.</p> <p>Outcomes In collaboration with families multiple outcomes are possible. – greater research is needed to understand how to identify and prioritize diverse and possibly competing needs. Dunst and Dempsey (2007) have suggested that parent-professional partnerships may be best conceptualized as comprising at least two types of practices: partnerships that promote parent and family outcomes, and partnerships that promote child outcomes.</p> <p>Evaluation of Partnership Practices: Partnerships do impact families quality of life (Summers et al., 2007). The Measure of Process of Care is an evaluative tool that can be used. It includes areas such as supportive, respectful, comprehensive care, enabling partnerships, and provision of information.</p>
<p>McKay,</p>		<p>Inner-city</p>	<p>New</p>	<p>Multiple Family Group Service (MFG) – a mental health service that involves six to eight families; b)</p>

<p>M. M., Gopalan, G., Franco, L. M., Kalogerogi annis</p>		<p>mental health</p>	<p>York, U.S.A.</p>	<p>an intervention facilitated by trained clinicians and parent advocates; c) a treatment where at least two generations for a family are present in each session; and d) pschoeducation and practice activities that foster both within family and between family learning and interaction.</p>
<p>Tallon, M. M., Kendall, G. E., & Snider, P. D. (2015). Rethinking family- centred care for the child and family in hospital. <i>J ournal of clinical nursing</i>, 24 (9-10), 1426-1435.</p>	<p>Discursive Essay/Inte grative review</p>	<p>Hospital care</p>	<p>Australia</p>	<p>Family Centred Care: a child’s mother or primary care-giver is permitted, even encouraged, to ‘room in’ with her sick child in hospital. – supported by attachment theory</p> <p>Sheild (2010) has recently questioned the relevance, meaning and effectiveness of FCC – suggesting it may not be best for mother and child. Shield argues that</p> <ol style="list-style-type: none"> 1. Many parents report a sense of being left to care for their sick child with little or no support from nursing staff 2. Some parents who are not comfortable staying at the hospital or unable to do so, feel judged by hospital staff. 3. There is often some uncertainty about what care a parent should and should not give in hospital. <p>Tallon, Kendall & Snider (2015), agree with shields that FCC as it is practiced is not appropriate and have proposed an alternative model that draws attention to the importance of caring for the child in the context of the family.</p> <p>Authors suggest other theories beyond attachment theory and research findings that are relevant:</p> <p>Bioecological theory: Brofenbrenner’s ecological module of human development – which has been extended to include biological processes has become the most popular meta-theoretical perspective with researchers as well as practitioners – the bioecological model identifies broad concepts and the relationship between these concepts</p> <p>The family and community resource framework: Provides a useful structure to consider the financial, physical, human and social capital resources that the families of children who are seriously ill have access to (Duncan et al. 2994; Zubrick et al., 2000; Kendall & Li, 2005). Human capital is understood as the totality of resources that are acquired from the time of conception to all human beings. Research confirms that the higher the parental human capital, the better child health and developmental outcomes (DeWalt & Hink, 2009). Trusting reciprocal relationships between professionals, other community members and caregivers are known as social capital and can be a significant resource for families. Research findings demonstrate that extended family support, also considered a source of social capital is associated with an increased sense of maternal confidence and mastery, particular in younger mothers. Parents also often experience</p>

				<p>higher self-esteem, parenting skills, and increased communication with children.</p> <p>Allostatic load and biological embedding: When a child has a serious illness, it is a major life stressor for parents as well as the child. Chronic exposure to both physical and psychosocial stressors, leading to prolonged activation of the systems has detrimental physiological consequences referred to as allostatic load. Children and parents that are ill experience significant stress coupled with additional stresses in their lives can easily turn to distress – leading to poor physical and mental health outcomes in the short, medium and long term.</p> <p>Nurse Family Partnership Research suggests that when parents feel listened to, valued and respected, they are better able to clarify their concerns, enhance their feelings of competency and increase their confidence (Edwards et al., 2009). Parents who feel judged or misunderstood are more likely to have difficulty developing trusting relationships with staff, and less likely to engage in information sharing (Avis & Reardon, 2008). This model uses qualities of respect, humility, reflective listening and a quiet enthusiasm as essential to developing a helping relationship with parents. This relationship is characterized by exploratory questioning, sharing information, and encouraging parents to tell their stories, and a reflective dialogue is promoted to reinforce family strengths and needs (Bidmead et al., 2002). This theory has its roots in Friere’s (1999) empowerment theory which is driven by personal experience to overcome oppression by a mutual investment in action for positive social change.</p>
<p>MacKean, G. L., Thurston, W. E., & Scott, C. M. (2005). Bridging the divide between families and health professionals’ perspectives on family-centred care. <i>Health</i></p>	<p>Qualitative Grounded Research</p>	<p>Developmental services at children’s hospital in Canada</p>	<p>Alberta, Canada</p>	<p>Family Centred Care: “placing the needs of the child, in the context of their family and community, at the center of care and devising an individualized and dynamic model of care in collaboration with the child and family that will best meet these needs. The term family-centred care encompasses the concept of the client as the child patient and their family, rather than just the patient” (p.75). In this article, authors use FCC to mean children <i>and</i> their families. 6 key elements of FCC described by MacKean, Thurston, and Scott (2000), include</p> <ol style="list-style-type: none"> 1. Recognizing the family as central to and/or the constant in the child’s life, and the child’s primary source of strength and support 2. Acknowledging the uniqueness and diversity of children and families 3. Acknowledging that parents bring expertise to both the individual and care-giving level and the systems level 4. Recognizing that family centred care is competency enhancing rather than weakness focused 5. Encouraging the development of true collaborative relationship between families and health-care providers, and partnership 6. Facilitating family-to-family support networking, and providing services that provide emotional and financial support to meet the needs of families. <p>*Frequently 2,5,6 above are missed.</p> <p>There seems to be a lack of shared understanding about the concept of FCC. The purpose of this study</p>

<p><i>Expectations</i>, 8(1), 74-85.</p>			<p>was to develop a conceptualization of family centred care grounded in the experiences of families and direct health-care providers.</p> <p>Methods: Data was collected in 1999 through focus groups, face-to-face interviews, semi-structured interviews involving 37 parents of children diagnosed with a developmental problem, and 16 frontline health care providers. Questions were asked of the families good and bad experiences with the health care system and contributing factors to these things, priority desired changes to the way the services are being administered, and information that has influenced the participants thinking about how health care should be provided to children and families.</p> <p>Findings: A concept of FCC and their interrelationships was developed as a result of this research. Three of these dimensions included relational competencies of health care providers, expectations of families, priorities for health care system change.</p> <ul style="list-style-type: none"> - What emerged strongly from data was that parents desired to work collaboratively with staff, to make decisions about and implement a dynamic care plan. - They desired a greater input from health care professionals regarding their defining their respective roles, and making decisions about what services would best meet their child’s needs, the ongoing management of their child’s care, and advocating for their child’s best interest. <p>Relational competencies of health-care providers: both health care provider and parent participants described relational competencies of health-care providers to be technically competent. It was relational competency however that dominated parents descriptions of their experiences with the health care system. The relational competencies described most frequently were caring (including being compassionate, respectful, and providing care in a personalized way); communicating with parents, and interacting with children. Health care providers with good communication skills were recorded as being: open to discussion and negotiation, communicated in an honest and direct manner, listened; sought and valued parent’s input, and were informative. Parents valued not only receiving useful information with them but those who would listen to their perspective, and continue to work collaboratively developing a plan of care that would best meet their needs of the child and family.</p> <p>Expectations of families: HCP – described roles they saw parents playing in addressing their child’s care needs Parents – expressed what they felt was expected of them by health-care providers. Parents very much respected HCP knowledge but wanted to work more closely and to gain support in how to advocate for their child’s best interests</p> <p>Priorities for health-care system change: The emphasis on wanting and needing some help and support and wanting to work collaboratively with hcp came out strongly in this category. Parents highest priority for change was help with advocacy and care coordination, followed by coordination of services and transitions, and then information about services – as well as help assessing and interpreting information.</p>
--	--	--	--

				<p>The relational value of FCC was stressed in these findings. Parents valued HCP who cared about them understood that each family and child was unique, and understood that collaborative relationships depended on open communication and negotiation of roles.</p> <p>Though the relational value of FCC is frequently cited in literature on FCC, this study illustrates that when family centred care is operationalized the collaborative processes often disappear. Specifically the process of determining the role parents want and are able to play in their child’s care and care management.</p>
<p>Terwiel, M., Alsem, M. W., Siebes, R. C., Bieleman, K., Verhoef, M., & Ketelaar, M. (2017). Family-centred service: differences in what parents of children with cerebral palsy rate important. <i>Child: Care, Health and Development</i>.</p>	<p>Quan and qual research study</p>	<p>Families of children with cp</p>	<p>Utrecht, Netherlands,</p>	<p>FCC - contains some general principles: recognition of the family as expert and source of support, acknowledgement of the uniqueness of families, partnership between family and service providers, and supporting the family’s role in decision making about services for their child. FCC has been associated with parental well-being and psychological health, childrens development, adaptive behavior, social-emotional competence and functioning. The implementation however is frequently quite challenging.</p> <p>The Measurement of Processes of care is a 56-item questionnaire that measures parents expereicens and perceptions of the extent to which they receive care.</p> <p>There was much variation in what participants rated important or less important. This demonstrates that family centred services must recognize the uniqueness of families and should be tailored to what parents find important. It also implies that service providers should understand that parents perceptions about the extent to which they receive care is not enough to conclude whether or not parents need or want this type of care.</p> <ul style="list-style-type: none"> - Parents reported it was difficult for them to ask for specific info at a time when they were still quite unfamiliar with their child’s diagnosis and rehab setting. - Findings demonstrate staff must support parents to express what they find important at this moment knowing that this might change over time as it is crucial in family centred services. - Tools could be developed to help parents make clear what they find important and how to ask questions.
<p>Summers, J. A., Hoffman,</p>	<p>Research Study</p>	<p>‘special education’</p>	<p>U.S.</p>	<p>Parent involvement is consistently related to students cognitive development and academic achievement.</p>

<p>L., Marquis, J., Turnbull, A., Poston, D., & Nelson, L. L. (2005). Measuring the Quality of Family—Professional Partnerships in Special Education Services. <i>Exceptional Children</i>, 72(1), 65-81.</p>				<p>Partnerships: encompass the overlapping concepts described in the literature: collaboration, service integration, multidisciplinary teams, family or parent involvement and to some extent family-centred services. Definition: mutually supportive interactions between families and professionals, focused on meeting the needs of children and families, and characterized by as sense of competence, commitment, equality, positive communication, respect and trust. Dunst and Pagat (1991) list six similar characteristics of partnerships: mutual contributions, shared responsibility, desire to work together, loyalty and trust, full disclosure, and agreement that parents are the final decision makers.</p> <p>Frequently partnerships between families and professionals fall short of recommended practice resulting in stress for both parties. Parents often describe problems communicating with teir child’s teacher, believe that professionals fail to understand and respect cultural differences, and perceive that getting appropriate and inclusive services for their child is ‘forever an ongoing struggle’ and feel blamed and//or judged for their child’s needs.</p> <p>Two important steps towards addressing these issues:</p> <ol style="list-style-type: none"> 1. A better understanding of the skills and behaviours professionals need for a collaborative helping style leading to partnerships with families 2. The development of appropriate measure to evaluate these skills and behaviours. <p>Dinnebeil, Hale and Rule (1996) identified personal characteristcs required by professionals central to successful collaborations such as friendliness, family-centred beliefs, integrity, commitment, and communication skills.</p> <p>Two main components of partnership</p> <ol style="list-style-type: none"> 1. Measure of family-centred practice- how involved, included, and supported was the family in the process 2. Measure of satisfaction with the instrument of outcome of service (was the service or tool prescribed helpful to the child). <p>Family-centred service: respectful treatment of families, individualized and responsive practice, family choice, family-professional collaboration, and provision of supports to families and children in order to produce optimal child and family outcomes.</p> <p>Study found that there should be two scales for evaluation – one for child-focused relationships, and one for family-focused relationships. That they require different approaches and therefore different evaluations.</p>
<p>Sick Kids – Model of child and Family – Centred</p>	<p>Brief description of model</p>	<p>hospital</p>	<p>Toronto, Ontario</p>	<p>Created a model with the Centre for Innovation and excellence in child and family centred care.</p> <p>Systems:</p> <ul style="list-style-type: none"> - The child is at the core and is of primary importance, - the family is central to everything they do,

Care				<ul style="list-style-type: none"> - CARE is central to SickKids and experienced through engagement in Clinical practice, Administration, and Research in Education. - The community health system- interacts locally, nationally and internationally to inform, shape an support health-care service delivery among other partner agencies and relevant stakeholders <p>Elements</p> <ul style="list-style-type: none"> - Respect – embracing unique strengths, vulnerabilities, and values of children - Communication – promoting understanding with children and families by listening, information sharing, and validating the process of CARE - Parenterships – engaging children and families, according to their preference, through authenticity, collaboration, and participation <p>Outcomes:</p> <ul style="list-style-type: none"> - Promoting Optimal health - Ensuring Patient Safety - Achieving Health Equity - Maximizing Patient Experience.
Woods, J. J., & McCormick, K. M. (2002). Toward an integration of child- and family-centered practices in the assessment of preschool children: Welcoming the family. <i>Young Exceptional</i>	Discursive Essay	Carrying out assessments of preschool children.	U.S.	<p>Family centred approach recognizes and adapts to the many roles that families fulfill. It must support the family’s roles of decision maker, team member, teacher, as it enhances the capacity of the team to develop an individualized and effective intervention process. Adequate information and support must be provided to families so they are able to make the best possible choices and informed decisions.</p> <p>Remember: Family Members Know their child Family Members know they’re child within the context of their families Family Members know their child and family within their community.</p> <p>Operating Principles for Assessments with Family Members</p> <ol style="list-style-type: none"> 1. Recognize that family members are individuals with preferred learning styles, values/opinions on education and child rearing practices and parenting roles. 2. Recognize families as partners in the process and as an ultimate decision maker 3. Share information in reciprocal, sensitive and timely manner 4. View assessment as a teaching/intervention opportunity 5. Identify supports for family member participation.

<p><i>Children, 5</i> (3), 2-11.</p>				
<p>Summers, J. A., Marquis, J., Mannan, H., Turnbull, A. P., Fleming, K., Poston, D. J., ... & Kupzyk, K. (2007). Relationship of perceived adequacy of services, family-professional partnerships, and family quality of life in early childhood service programmes. <i>International Journal of Disability, Development and Education,</i></p>	<p>Qual and Quan</p>	<p>Families that receive early childhood services</p>	<p>U.S.A</p>	<p>Family-centred service delivery, across disciplines and settings recognizes the centrality of the family in the lives of individuals. Guided by a fully informed choices made by the family and focuses upon the strengths and capabilities of these families. (p. 320).</p> <p>Rationale for FCC is two fold:</p> <ol style="list-style-type: none"> 1. The family is seen as a means towards achieving better outcomes for children – may have resources and skills that provide a nourishing home environment that meet the needs of children in their care. – thus a component is forging meaningful relationships with parents. 2. Family well being is an additionally important component and an appropriate outcome for FCC <p>The increasing emphasis on program accountability and the consequent focus on outcome-based program evaluation suggest that a measure of family outcomes should be included in the evaluation.</p> <p>Authors propose that an appropriate evaluation design should include, a) measurement of the family’s assessment of the adequacy of or their satisfaction with the services they have received; and b) their perceptions about the quality of their partnerships with professionals; and c) their overall family quality of life.</p> <p>Family-professional partners: mutually supportive interactions between families and professionals, focused on meeting the needs of children and families and characterized by by a sense of competence, commitment, equality, positive communication, respect and trust.</p> <p>Research questions:</p> <ul style="list-style-type: none"> • Do families perceive that they are receiving adequate levels of services for themselves and their children? • What are families ratings of satisfaction and importance of their family professional partnerships? • What are families’ ratings of satisfaction with aspects of their family quality of life? • Do services act as a predictor for family quality of life • And do partnerships mediate that relationships? <p>The results showed several different responses for child-oriented services and family oriented services. The number of families indicated a need for family services was smaller than the number of families indicating a need for child services; 124 families compared with 176.</p> <p>Families reported the need for more information about their child’s disability and also reported having difficulty assessing that information. Respite care and sibling support programs were among those services that families judged least adequate.</p>

54(3), 319-338.				Family professional partnerships- parents expressed a great deal of satisfaction with their professional partners. Partners however wish professionals were better able to meet individual child’s needs and advocate for the child with other providers which suggests that some of these components of partnerships should be examined and incorporated into pre-service and in-service training.
Embedding the Notion of child-Family-Centred are into Organizational Practice: Learning from Organizational Visioning	Case-study	Welfare Organizational	The Netherlands	<p>Sometimes programs/services become so fragmented and internally overwhelmed by redundant bureaucracy that they fail to best support children and families. Additionally, when something went wrong in service delivery, professionals would hid behind the administrative systems arguing that they had followed protocol. For this reason, scholars have pleaded for rethinking the child protective services system, its child-centred approaches and its ‘expert perspective.’</p> <p>Scholars argue that to improve organizational change, they should start from a bottom up approach rather than a top down approach.</p> <p>Research Question: How can the emergent organizational vision of the new child-and family-centred case management approach be understood at the <i>operations and structures</i> level the <i>values</i> section, and the <i>organizational structure</i>?</p> <p>Results</p> <p>Strategy: managers noted the following changes in the IFCM (intensive family case management):</p> <ol style="list-style-type: none"> 1. From problem-driven to pattern-oriented care; 2. From standardized to tailor-made care 3. From protection oriented to strength based care; 4. From process-oriented to purpose oriented care. <p>Artifacts: Operations and structure: the most prominent implications:</p> <ol style="list-style-type: none"> 1. From protecting the child through coercive 2. From following prescribed protocols to constructing a family plan; 3. From specialized to generic case management <p>Organizational Structure</p> <ul style="list-style-type: none"> - From top down control to ownership
Green, D., & Wilson, B. N. (2008). The importance of parent and child opinion in detecting change in	Research study	Supporting children with Developmental Coordination Disorder (DCD) and their families	England	<p>The study explored the appropriateness of using parent and child questionnaires to measure progress.</p> <p>Specific objectives included:</p> <ol style="list-style-type: none"> 1. Analysis of parent’s perspectives of progress in movement tasks compared to standardized measures 2. Analysis of children’s perspectives of progress in movement tasks compared to standardized measures. 3. Exploration of factors potentially influencing children’s opinions of motor capabilities; and 4. Contrast of parents and children’s opinions of movement ability. <p>The results of the evaluations by children and those of their parents did not line up. The low relationship between parents’ and children’s perspectives of progress line up with Dunford et al.,</p>

<p>movement capabilities . <i>Canadian Journal of Occupational Therapy</i>, 75(4), 208-219.</p>				<p>(2015), who found low correlations between a parent’s report and the child’s self-report of movement skills.</p> <p>The lack of relationship between the opinions of parents and children raises some ethical issues regarding how to determine the need to begin or when to terminate the intervention. Both parents and children have an important role to play, not only to identify goals but also to measure impact. As such both opinions are integral to the process of intervention and the evaluation outcomes.</p>
<p>Callery, P. (2005). 'The prairie tortoise'. <i>Paediatric nursing</i>, 17(1), 12-13.</p>	<p>Monthly column</p>		<p>Manchester, England</p>	<p>All staff working with children and young people must receive training and be skilled to communicate with children and young people and their parents.</p> <p>Communication with children in health care is woefully inadequate however there is a huge lack of research within this area. Subsequently there have been few studies about children being consulted in their own care. Children often make limited contributions to discussions about their care and their involvement tends to be about social rather than health issues. – more research is needed regarding good communication and involving and informing children of their own care.</p> <p>Communication with parents is as important as it is with children. It is easy to make assumptions that we share the same meaning because we use the same words however this is not the case. It is therefore important that we use language in a careful and thoughtful way and that we do more research to determine how to best communicate goals with children and adults.</p>
<p>Hewitt-Taylor, J., & Melling, S. (2004). Care protocols: rigid rules or useful tools? Jaquelina Hewitt-Taylor and Sue Melling discuss the need to</p>	<p>Literature review</p>	<p>Healthcare</p>	<p>England</p>	<p>The development of care protocols and operationalized definitions may result in a belief that any healthcare professional can meet the needs of the child/young person if they are provided with the evidence-based protocol to follow. – this is not true.</p> <p>Increasing the flexibility of professional boundaries and introducing care protocols must be achieved without compromising the recommendation that children and young people should be care for by staff that are aware of their specific needs.</p> <p>What is truly best practice is derived from learning about the individual who is being provided with care and making decisions based on their specific needs and preferences as well as what is generally known to be the best approach given to the situation.</p>

<p>balance the benefits of using evidence-based care protocols with the need to maintain holistic child and family-focused care delivered by appropriately qualified professionals. <i>Paediatric nursing</i>, 16 (4), 38-42.</p>				
<p>Heywood, J. (2002). Enhancing seamless care: A review: The complex issues of continuity and seamless care for children and families</p>	<p>Literature review</p>		<p>Preston, England</p>	<p><i>“a good quality service for children is child and family centred, with children, their siblings and their carers experiencing a ‘seamless web’ of care, treatment and support, as they move through the constituent parts of the NHS’</i> (Department of Health, 1991). This is certainly a worthwhile goal. This article explores literature regarding ‘seamless care’ and highlights issues that need to be addressed by children’s nurses and others. The department of health identified features of seamless care as:</p> <ol style="list-style-type: none"> 1. <i>Organizational boundaries that do not get in the way</i> 2. <i>Practitioners with clear roles, responsibilities and accountability</i> 3. <i>The use of multi-professional teams.</i> <p>these and the issue of continuity create a framework to structure the discussion of this article.</p> <p>Continuity: things must be connected and continuous. If everything is organized as though it was separated and fragmented, the child and family may receive a disjointed episode of care. Therefore it is important to see it as continuous – focusing on the big picture. Also, if the child and family are involved in all care decisions and planning there is a greater chance of ensuring that their felt needs as the needs staff perceive are met. But only when effective communication and negotiation are achieved</p>

<p>are examined by Jeannette Heywood. <i>Paediatric Care</i>, 14(5), 18-20.</p>				<p>can this be done.</p> <p>Evaluating continuity: it is necessary to evaluate the child and family’s experiences of care to gain insight on its effectiveness. This can be done in an-going discussion, pre discharge interviews, satisfaction surveys, or a suggestion box. Staff need feedback on what children and families find useful and approaches they do not value.</p> <p>Organizational boundaries. Hibberd (1998): to provide seamless care: “... a new philosophy of cooperation, negotiation and a shared responsibility will be important, not only through cross-boundary teamwork, at a management level, but also through the attitudes and practices of all health care professionals.</p> <p>Clear roles, responsibilities and accountability: effective communication (jargon free) and easily understood by all disciplines is essential for ensuring clarity with regard to who is providing care and how they will go about it. Mutli-disciplinary documentation and parent-held records are ideal, with children, young people and their families being encouraged to become actively involved in their care planning and recording the care given.</p> <p>The use of multi-professional teams: to achieve care for the child and family it must be seen to be evident throughout the care experience.</p>
<p>Wang, M., Petrini, M. A., & Guan, Q. (2015). Evaluation of family-centred services from parents of Chinese children with cerebral palsy with the</p>	<p>Research study</p>	<p>Evaluation of family-centred services from parents of chines children with cerebral palsy</p>	<p>China</p>	<p>FCS Goals: are to meet the specific needs of children and their families, to promote optimal professional service delivery, and to ensure service systems are flexible, relevant and responsive to the family needs. Applying FCS improves mental well-being for parents and increases participation and feels of competency.</p> <p>FCS is a significant predictor of parents view of their child’s health related quality of life. Parents and Professionals are intended to change roles when implementing FCS. Professionals should take on the role of collaborator, advocate, team member etc. They should become familiar with the family culture and provide support for both the parents and children with CP. However, this is not always the case. Families may have different preferences about their child’s care and about their partnership within the FCS relationship. They may have different views about FCS is practiced.</p> <p>This article used the Measure of Process of Care to determine the extent of satisfaction in service provision.</p> <p>Results showed that professionals need to further plan to improve parent’s satisfaction with service</p>

<p>Measure of Processes of Care. <i>Child: care, health and development</i>, 41(3), 408-415.</p>				<p>provision. It also revealed a lack of connection among cooperation and partnership relationships of parents and professionals during service delivery. Additionally, professionals information delivery, both general and specific received poor scores.</p> <p>Results showed that holistic care and a harmonious interpersonal relationship was wanted.</p>
<p>Ziviani, J., Darlington, Y., Feeney, R., Rodger, S., & Watter, P. (2014). Early intervention services of children with physical disabilities : complexity of child and family needs. <i>Australian occupational therapy journal</i>, 61 (2), 67-75.</p>	<p>Research study/ longitudinal study</p>	<p>Early intervention</p>	<p>australia</p>	<p>Unique challenges and strengths of children and families must be considered when implementing Family centred practice (FCP) Hebbler, Spiker, Mallik, Scarborough and Simeonsson (2003) found that many children receiving EI were from culturally and linguistically diverse backgrounds, single parent or foster care households and/or have other family members with special needs. Children and families complex circumstances tend to co-occur with an average of two risk factors per family.</p> <p>Results</p> <p>Theme one: services Received 5 participants reported dissatisfaction with therapy quality. 2 reported being unhappy with goal setting, not having a therapeutic approaches adequately explained, insufficient instruction on implementation of therapy at home and inexperienced staff. Other participants were unhappy about the rarity of therapy appointments</p> <p>Family Support Many parents reported valuing these services, they thought it was helpful when they were experiencing problems to have respite, parent education/support groups and emotional support for other siblings. Some families noted deficiencies of family support. Specifically, that the amount or degree of support they received was insufficient. Theme two: Service Structure and ethos/culture Parents overall were happy with their relationships with EI staff.</p> <p>Communication: the quality for communication was closely related to parents satisfaction with parent-provider relationships.</p> <p>Continuity of staff – parents noted that high staff turnover affected their relationship with EI providers due to a lack of continuous follow up with a particular individual or team. Apart from parent-professional relationships, a key aspect of service structure and ethos/culture was responsiveness of EI to child and family needs.</p>

<p>Regan, K. M., Curtin, C., & Vorderer, L. (2006). Paradigm Shifts in Inpatient Psychiatric Care of Children: Approaching Child- and Family-Centered Care. <i>Journal of Child and Adolescent Psychiatric Nursing</i>, 19(1), 29-40.</p>	<p>Literature review</p>	<p>Psychiatric care of children</p>	<p>U.S.</p>	<p>Child and family centred care (CFCC) – a valued model of care to which most nurses aspire. CFCC is collaborative and respectful, is consistent with emerging values in health care, and is increasingly perceived to be essential to the provision of care for children.</p> <p>CFCC practices increase patient and family satisfaction, decrease child and parent anxiety, facilitate more rapid recovery from medical procedures, have a positive impact on the mental health of mothers who have children with chronic illness, decrease health care costs, and increase staff satisfaction. In order to provide care that is truly child and family centred, however, practitioners must radically alter the way in which institutional structures, clinical practices, and policies are devised and carried out.</p> <p>This article provides an overview of the components of CFCC and will describe practice and policy shifts</p> <p>The institute for family-centred care (IFFCC) defines CFCC as “an approach to the planning, delivery and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients and families. It redefines the relationships between and among consumers and healthcare providers.</p> <p>CFCC is a philosophy of care based on the following principles</p> <ol style="list-style-type: none"> 1. People must be treated with dignity and respect 2. Healthcare providers must be communicate with and share complete and unbiased information with patients and families in ways that are affirming and useful 3. Individuals should be supported to build their strengths and participate in experiences that enhance their control and independence in the process of receiving care 4. Collaboration among patients, families, and providers should occurring policy and program development and professional education as well as in the delivery of care. <p>Barriers to providing family –centred care</p> <ol style="list-style-type: none"> 1. Lack of knowledge regarding principles of CFCC 2. Lack of strong organizational support of CFCC 3. Healthcare providers perceptions that adhering to principles of CFCC will threaten their professional identities, 4. Individual professional’s personal belief system and/or values that hinder interactions with certain families in ways that are consistent with CFCC <p>Staff may feel that their efficacy is compromised if they are asked to involve families in procedures.</p> <p>Parents Perspectives on Family Centred Care Parents need to establish rapport and share actively in their child’s care during hospitalization in order to partner effectively with nurses. Care that does not include can lead to mistrust and increased parental stress. Parents perception of care as being family centred is tied to their satisfaction with the care their</p>
---	--------------------------	-------------------------------------	-------------	--

			<p>child receives and to feeling emotionally supported.</p> <p>Parents identify communication, responsiveness, honesty and emotional support as being important to the delivery of CFCC.</p> <p>Parents identify the need for emotional support in addition to care of their child. This can be done by encouraging parents to express their needs, identifying existing support systems within and outside the family, assisting parents to accept the child’s condition and to develop realistic expectations, facilitating the family’s ability to “normalize the experience, and assisting the family to adapt and reorganize to meet the child and family’s needs.</p> <p>Parents reported that significant people in their lives assist them in making important decisions and that these peoples participation in the child’s hospitalization was important. Thus in delivering CFCC the structure of the inpatient unit must allow for a variety of family and support systems to be involved in sharing the care.</p> <p>Establishing trust with a child requires providing honest explanations, getting ot know the child as a person, conveying a sense of genuine like and respect for the child, sharing of one’s self (sharing personal stories), resisting emotional detachment as a protective mechanism, and recognizing the essential importance of physically touching as evidence of a reciprocal process in forming a trusting bond.</p> <p>In the provision of care to children, the rationale for procedures that cause children pain are often considered in light of the “best interests” of the child but may not always take into account the “rights of the child”</p>
--	--	--	--