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Review

Family-Centred Care for Children with Biopsychosocial Support Needs: A Scoping Review

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Abstract: Children's health and wellness are influenced by a wide range of biological, psychological or social factors with a rising number of children requiring supportive healthcare. Family-centred care is considered best practice paediatric healthcare; however, processes and actions are not well explored in the literature. This research aimed to synthesise the evidence on the processes of implementation of family-centred care for children with biopsychosocial support needs and identify outcome measures used in the studies. A scoping search across Cinahl, Medline, Web of Science, Scopus, Psyc INFO, Embase and Education Research Complete for English language publications published between 2005 and 14 October 2020 was conducted. A total of 42 studies met the inclusion criteria: a focus on the processes of implementation of family-centred care for children aged 0–21 years with biopsychosocial needs. Diversity in the implementation of interventions of family-centred care was evident due to heterogeneity in study populations, methodology and reporting. Health condition or impairment focused outcome measures were found to be standard with a paucity of outcomes measuring participation or activity. Theoretical and practical elements of implementing interventions were identified as novel and key attributes of family-centred care and contributed to a new standardised framework for the processes of implementation of family-centred care. Future research should address whether mapping family-centred care to the International Classification of Function model helps families and health professionals identify meaningful participation and activity outcomes, which in turn may guide the processes of implementation of family-centred care interventions.

Keywords: family-centred care; paediatric; biopsychosocial needs; healthcare; outcome measures

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1. Introduction

Children's physical, psychological and social health and wellbeing are influenced by a complex interaction of biology and social determinants (biopsychosocial factors). A significant proportion of children globally have lived experience of impairment and/or long-term health conditions with an estimated 15% of the world's population living with a disability [1]. This includes a speculative 93 million children between the ages of 0–14 years worldwide, although this number must be interpreted cautiously due to variable definitions of disability and data collection methodologies internationally [2]. Children with disabilities may be defined as those "who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" [3] (p. 3). The World Health Organisation's International Classification of Functioning, Disability and Health (ICF) [4] emphasises that disability is a "dynamic interaction between health conditions and environmental and personal factors". In addition to physical needs, children's health and wellness are subject to social and environmental inequities with poorer children having poorer health and developmental outcomes [5]. Children with additional biopsychosocial needs may require support to maintain an optimal state of health or wellness to ensure

their full participation in society. Family-centred care is considered best practice in providing health care services to children and families [6] as families have an integral role in a child's life experiences and participation opportunities [7] and are a contextually integral component of the environmental factors of the ICF model.

Family-centred care is a model of healthcare characterised by; a respectful family-professional partnership [8] that fosters collaboration between all involved parties [9,10], that includes family members in the delivery of the child's treatment [9] and involves parents as co-decision makers in their child's care whenever possible [11]. King and Chiarello [12] described three core concepts of family-centred care as, (1) respect for children and families, (2) appreciation of the family's influence on the child's well-being, and (3) family-professional collaboration as core beliefs for family-centred care. Family-centred care is a biopsychosocial model that recognises that the health and wellness of everyone are influenced by a complex interconnection between biology, psychology and social factors. In family-centred care, the unit of care includes not only the individual (child) but also their family [13]. Family-centred care is associated with improved health and well-being of the child, improved parental reports of satisfaction of care, greater efficiency of health care resources, increased access to care, better family-provider communication and better transition services [14]. Qualitative studies suggest that family-centred care provides versatile support that can be used within our healthcare, education and social systems [15].

Descriptions and principles of family-centred care are well established [6] but there are very few specific definitions [13] and a systematic review by Kuhlthau et al. [14] noted the need to more clearly define and operationalise family-centred care. A 2019 scoping review by Kokorelias et al. [16] reporting original models of family-centred care highlighted the lack of concrete strategies in the literature to help implement key concepts and noted the paucity of research on family-centred care model implementation [16]. Kuo [9] also reported a lack of consensus on the specific processes and actions that constitute family-centred care and fundamental misunderstandings regarding implementation. Similarly, Uniacke [17] purported the need for a better understanding of family-centred care requirements. Since family-centred care is therefore somewhat open to interpretation, ambiguity may arise, and interventions will often include some but not all the characteristic principles [9]. Adding to the complexity is the heterogeneous nature of the populations of both children and health professionals involved in family-centred care, as well as the diverse nature of families, all of which influence the ideals of care. Best practice indicates that an inter-professional approach is necessary to provide support to the child with complex biopsychosocial needs [18]. However, without consistent guidelines or processes, there is the potential for varying applications of family-centred care when used inter-professionally. This may lead to siloed management and less than ideal service provision and outcomes for children with biopsychosocial needs, which could be considered another disabling element of society for these children.

The ICF is a biopsychosocial model that is an international standard for describing health and disability [19,20]. The ICF provides a framework and classification system to understand and describe outcomes and changes in health and functioning and may be used to map outcome measures for an individual's functioning [19].

This scoping review on family-centred care for children with biopsychosocial needs aims to (1) synthesise the evidence on the processes for implementing family-centred care and (2) determine which outcome measures have been used to measure the effects of family-centred care and map them to core concepts of the International Classification of Functioning (ICF).

2. Materials and Methods

Scoping review protocols and methodologies outlined by Arksey and O'Malley [21], Levac et al. [22] and the Johanna Briggs Institute [23] were used to guide and summarise the existing literature describing how family-centred care has been used in health care for children with biopsychosocial needs. Review articles by Thomas et al. [24], Colquhoun [25]

and Peters et al. [26] were consulted to gain a comprehensive understanding of scoping review methodology as well as the PRISMA extension for scoping reviews [27]. Scoping reviews are iterative in nature [24] and as such the search and subsequent data collection processes were flexible and evolved over time to map the main concepts.

Electronic database searches were conducted in Cinahl, Medline, Web of Science and Scopus, PsycINFO, Embase and Education Research Complete during October 2020. Search keywords included variations of family-centred care, implementation, children and disabilities or impairments including but not limited to physical, social, psychological or educational needs. All searches were limited to English language publications published between 2005 and 14 October 2020 inclusive (Table 1). The search period was chosen after preliminary scoping searches to trial search terms revealed a lack of relevant family-centred care literature prior to 2005.

Table 1. Search strategy used in electronic databases.

Search No.	Keywords (Not Mapped to Search Headings)
1.	"family centered" OR "family centred" OR "family focused" OR "family focussed" OR "family-centered" OR "family-centred" OR "family-focused" OR "family-focussed"
2.	Care
3.	#1 AND #2
4.	Child* OR infant* OR adolescen* OR youth* OR young OR "young person" OR "young people" OR teen* OR juvenil* OR kid* OR baby OR babies OR preschool* OR toddler* OR pediatric OR paediatric* OR "school age*" OR kindergarten*
5.	social OR mental OR "mental health" OR physical OR education* OR psycholog* OR intellectual
6.	"special need*" OR "need*" OR disab* OR impair*
7.	#5 AND #6
8.	disab* OR impair*
9.	"developmental delay" OR "long term condition*" OR "health care need*" OR "healthcare need*"
10.	#7 OR #8 OR #9
11.	#3 AND #4 AND #10
Filters	Language: English dsDates: 2005–2020

Endnote reference management software was used to store and organise the literature and a systematic de-duplication process was conducted [28]. Hand searches of relevant article reference lists and discussions with colleagues occurred. The resulting EndNote library of three articles was imported into the Veritas Health Innovation Covidence systematic review software for screening and data extraction. Consultation regarding terminology and the inclusion and exclusion criteria occurred between the primary researcher (LC) and the second reviewer (AQ) prior to the independent screening of eligible abstracts and titles and again following full-text review (Table 2). Initially, 10 titles were screened by both reviewers and decisions compared to ensure agreement and consistency. As the purpose of the scoping review is to provide a preliminary examination of emergent research and to map the available knowledge [24], a quality appraisal was not deemed appropriate or congruent with the aims of this study.

Table 2. Inclusion and exclusion criteria, and terminology used within the scoping review.

Inclusion Criteria	**Definitions**
Primary research	Studies directly collected data
Qualitative studies	Qualitative data collection methods (e.g., focus groups, individual interviews). dsQualitative data analysis methods (e.g., phenomenology, grounded theory, general inductive approach).
Mixed-method studies	Qualitative and quantitative methods and/or analysis methods.
Quantitative studies	Quantitative methodology including cross sectional, prospective and randomised controlled trials.
Search parameters	Only peer-reviewed research published in the English language from 2005 to 14 October 2020.
Implementation processes of family-centred care	The focus of the study includes the processes of implementation of a family-centred model of care and/or service delivery.
Children	Aged from birth up to 21 years of age, to include children that require additional learning support and are eligible under the Special Education Act 2020 in New Zealand [29] and the Individuals with Disabilities Education Act in the United States to attend special education and related services until the end the age of 21. [30]
Biopsychosocial needs	Persons effected by physical, social, environmental, psychological and/or emotional factors that hinder participation in society.
Exclusion Criteria	**Definition**
Peer-reviewed and non-peer-reviewed literature	Abstracts, proceedings, books, book chapters, commentaries, opinion pieces, reviews, protocols and thesis dissertations.
Indirect family-centred care interactions	Articles focusing on only interactions between or discussion regarding family members.
Family-centred care intervention not implemented	Articles that reviewed or discussed only the history, implications, rationale, ethics or theoretical understanding of family-centred care. For example, the study conclusions suggested the need for a model of family-centred care (adapted from [16]). dsArticles that focused on the assessment or the evaluation of a tool that measured the degree of family-centred-ness of a programme, intervention or setting. The focus of the study was not the implementation of a family-centred care model (adapted from [16]).
Insufficient family-centred care processes	Articles which do not describe who is involved in the decision making and/or goal-setting processes in the family-centred care model.
Terminology used in this study	**Definition**
Biopsychosocial needs	All biopsychosocial factors that hinder participation for children in society, including physical, social environmental, psychological and emotional factors. A broad definition of 'disability' to align with the biopsychosocial model of health, with the recognition that biopsychosocial needs which hinder participation are additional to the everyday needs of the child.
Family-centred care	Care for children and their families within services (such as health or education) that are planned around the whole family, not just for the individual child and in which all the family members were recognised as care recipients [31].
Key attributes of family-centred care	(1) Family members are included in the delivery of the child's treatment [9] or care, (2) Parents are co-decision makers in their child's care [11], (3) There is family-professional collaboration [12].
Implementation of family-centred care interventions	Implementation in this context refers to the different practical and theoretical elements comprised within each individual primary study that strive to make it family centred and how these processes were delivered and put into action. It is acknowledged that this differs from the common definition of 'implementation' science relating to the promotion of systematic uptake of research findings into routine practice to improve health services quality and effectiveness [32].
Family-centred model of care original to the study	Model of care with family-centred characteristics created specifically for the intervention, not previously described in other literature.
Existing family-centred model of care	Model of family-centred care that had been previously defined and described in other literature.
Family-centred care model derived from theoretical backgrounds	Model of care that used a theoretical background to define the family-centred characteristics of the intervention.
Family-centred care adapted model	Model of family-centred care that used the framework of an existing family-centred model but was adapted to suit the population or environment of the new intervention.

The following data were extracted from the included studies; year of publication, country, study design, aims, study populations, identified biopsychosocial needs, family demographics. Features of family-centred care models were recorded including recruitment, preparation, implementation, delivery methods, location and temporal measures of interventions. Microsoft Excel table was used for data entry and database management by the primary researcher (LC) and added to in an iterative manner throughout the search as recommended by Thomas et al. [24]. Raw data were initially summarised numerically and then synthesised to convey key themes and processes in Microsoft Word as indicated by Thomas [33]. Following data analysis, the outcome measures identified within reviewed studies were categorised to align with the World Health Organisation's International Classification of Functioning (ICF) [34], a framework for describing functioning and disability in relation to a health condition. The ICF is based on the biopsychosocial model of health and is used clinically and to structure clinical guidelines [35]. The ICF was developed and endorsed by the World Health Organisation in 2001 as a multi-purpose classification system and framework to recognise the complex interactions between the multitude of factors that influence a person's wellbeing [34]. The ICF consists of functioning and disability components; body structures, body functions, activities and areas of participation of importance to the person, as well as contextual components; personal and environmental factors [34]. The ICF considers individual's needs, however, it is also an appropriate framework to apply to family-centred care due to its holistic and biopsychosocial approach. Children live within the context of their family, their environment and society and therefore it is important to consider all elements of the ICF. Whilst there is the possibility for an outcome measure to fall into more than one classification, each measure was categorised according to its primary purpose in its corresponding journal article.

3. Results

The initial search yielded 3064 articles after duplicate removal. Following abstract and title screening 101 articles remained with a further five articles identified from the hand search of these references. Following full-text review of 106 included articles, both reviewers (LC, AQ) met to reach a consensus on 11 articles, with two articles requiring arbitration by a third reviewer (MP). Following full-text screening, 42 articles were included for data extraction (Figure 1). Included articles were published between 2006 and 2020 and conducted over five continents in 16 different countries (Table 3). The United States of America (USA) published most studies (n = 16, 38%) whilst all other countries yielded between 1–4 studies.

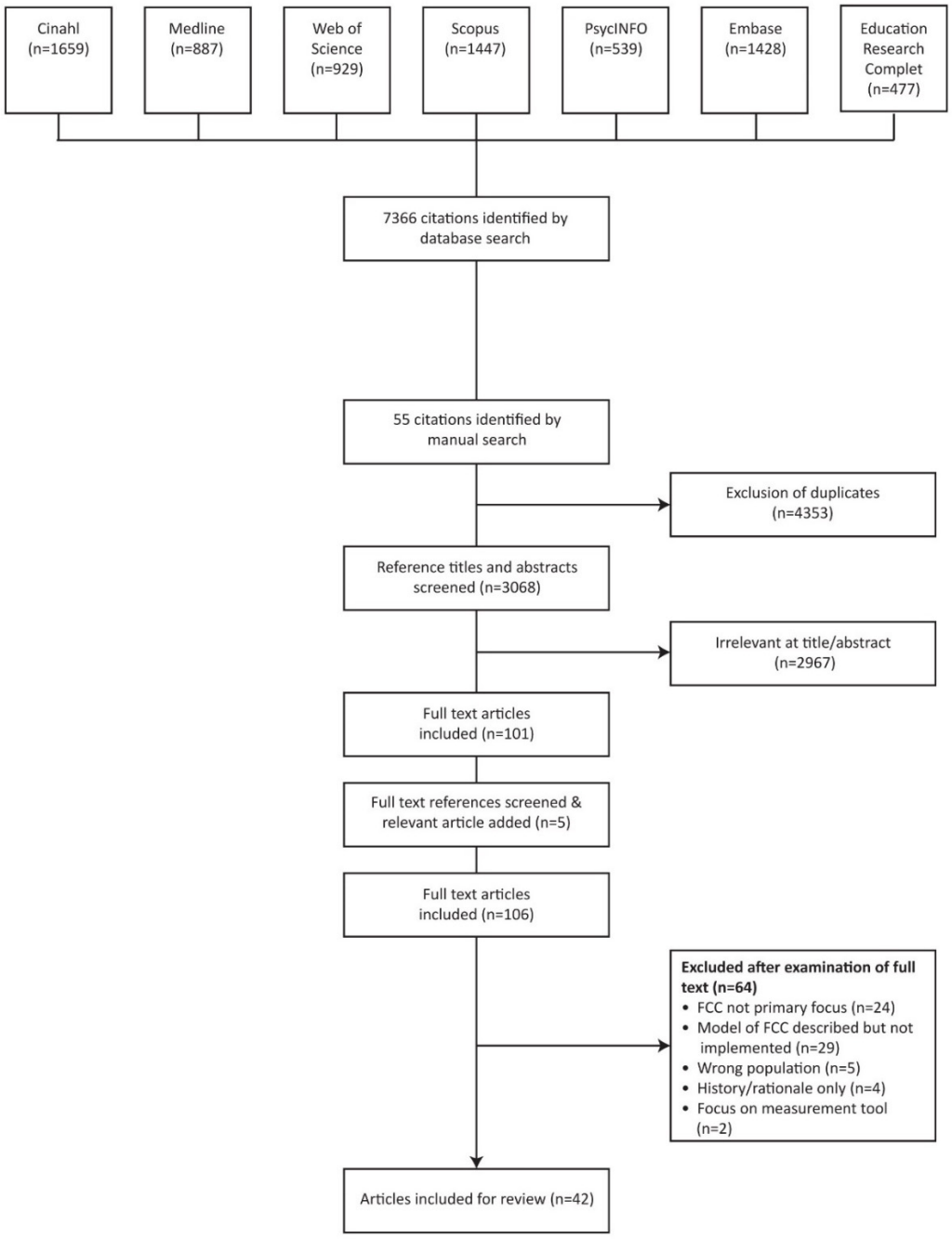


Figure 1. PRISMA flow chart of study selection process.

Table 3. Population ch'racteristics as reported within included family-centred care studies.

Article		Study			Children			Primary Caregiver			Family Demographics	
Ref & Code	Year	Geography	Design	Aims	Ages	Gender	Ethnicity	BPS Need	Relation	Age (Years)	Ethnicity	Family Structure	Other Family
[36] dsA1	2016	South Korea	Case report	Describe implementation	10 & 8 years	M 50%		Physical disability, Leigh disease, CP	Mother	33–44		Nuclear	Siblings
[37] dsA2	2014	South Korea	Case study	Effectiveness	16 months	M 100%		Global dev delay. Proteus syndrome, infantile spasm	Mother	31		Nuclear	
[38] dsA3	2015	USA	Feasibility trial	Evaluate intervention	5.4–12 years	M 52.5%		Obesity and low-income Latino families		28.6–47		Nuclear	Siblings
[39] dsA4	2015	USA	multiple-baseline intervention	Describe implementation	5–7 years	M 100%	Caucasian	ASD or language delay with sensory processing problems	Mother			Nuclear and Single parents	Siblings
[40] dsA5	2011	Netherlands	Two-arm randomised trial	Describe implementation	3–6 months CA	M 43.5%		Infants at high risk for dev disorders					
[41] dsA6	2019	Brazil	Pilot study	Effectiveness	3–9 months	M 53%		Congenital Zika virus syndrome (CZS)	Mother				
[42] dsA7	2015	USA	Retrospective analysis	Effectiveness	8.4–15.2 years	M 42%	White 45%, Black 32%, Hispanic/Latino 18%, Other 5%	BMI 95th percentile for age and gender. Obesity related medical comorbidities.					
[43] dsA8	2016	Australia	Single case experimental design	Effectiveness	48–57 months	M 67%		Atypical sensory processing, behaviour and sensory challenges, ASD, global dev delay	Mother	33–38	Vietnamese, Indian, Australian-Asian		
[44] dsA9	2011	Netherlands	Two-arm randomised trial	Evaluate intervention	3–6 months CA	M 43.5%		High risk for developmental delay. Motor disorder	Majority Mother	24.3–36.7 years			
[45] dsA10	2015	USA	RCT	Effectiveness	5–12 years	M 49%	Latino	Obesity and low-income Latino families	Majority Mothers	30.2–43	Latino		
[46] dsA11	2019	USA	RCT	Effectiveness	8–12, 13–16 years	M 51%	Non-Hispanic/ White 84%	Type 1 diabetes	Majority Mothers	32.4–51	Mostly White, non-Hispanic		
[47] dsA12	2019	Korea	RCT	Effectiveness	4.6–11.7 years	M 67%		Cerebral palsy, Aarthrogryposis, Down syndrome, Prader-Willi syndrome, Moyamoya disease, Dev delay	Mother	39.3–40.1			
[48] dsA13	2017	USA	Randomised parallel-group clinical trial	Effectiveness	8–16 years	M 50.9%	White (Non-Hispanic) 83.6%	T1D diagnosis	Majority Mothers	mean 41.8	Non-Hispanic 87.9%		

Table 3. *Cont.*

Article			Study		Children				Primary Caregiver			Family Demographics	
Ref & Code	**Year**	**Geography**	**Design**	**Aims**	**Ages**	**Gender**	**Ethnicity**	**BPS Need**	**Relation**	**Age (Years)**	**Ethnicity**	**Family Structure**	**Other Family**
[49] dsA14	2009	USA	Retrospective analysis of RCT	Effectiveness	2–2.11 years	M 51%	African American 28%, European American 50%, Biracial 13%	High risk for problem behaviour and from low-income families	Mother		African America 28%, Euro American 50%, biracial 13%, other 9%, Hispanic Amer. 13%	Nuclear and Single parents	
[50] dsA15	2014	USA	Feasibility trial—pilot study	Evaluate intervention	11–15 years	M 60%	African American 50%, White 50%	Referred to mental health services	Majority Mothers	32.39–52.01	African American 50%	Nuclear and Single parents/caregivers	Grandmother
[51] dsA16	2019	Netherlands	Retrospective analysis of RCT	Effectiveness	<9 months CA	M 60.5%		High risk of CP					
[52] dsA17	2016	Taiwan	Prospective study	Effectiveness	18–35 months	M 75%		Developmental delay.	Majority Mothers	30–54		Nuclear	
[53] dsA18	2020	Taiwan	Pilot randomised control trial	Effectiveness	6 to 33 months	M 79.2%	Chinese	Motor delays	Grandparents and Parents	mean 39.5		Nuclear	
[54] dsA19	2012	Germany	Report	Evaluate intervention	From birth			Preterm infants < 32 weeks gestation (GA), multiple preterms and neonates with congenital malformations or severe illness.					
[55] dsA20	2014	Taiwan	Pilot study	Effectiveness	45–69 months	M 100%		Autistic disorder	Mother	29–44		Nuclear	
[60] dsA25	2013	USA	Trial	Describe intervention	2–6.11 years		Caucasian & Latino	Autism				Nuclear and Single parents	
[61] dsA26	2020	USA	RCT	Effectiveness	12.0–18.1 years	M 50%	Non-White 16.7%, Hispanic 9.7%	Bipolar disease I or II				Nuclear	
[62] dsA27	2013	Australia	Preliminary RCT	Effectiveness	12–17 years	M 27%	Anglo-Saxon 57.5%, Culturally linguistically diverse/Non-English Speaking 35%, Aboriginal 7.5%	Suicidal adolescents.	Mother	39.67–50.61 years	Anglo-Saxon 57.5%, Culturally linguistically diverse/Non English Speaking Background 35%, Aboriginal 7.5%	Nuclear and Single parents	Siblings
[63] dsA28	2016	Italy	retrospective cohort study	Effectiveness	3–24 months CA	M 56%		Preterm infant gestational age at birth of <32 weeks					

Table 3. *Cont.*

Article			Study		Children				Primary Caregiver			Family Demographics	
Ref & Code	**Year**	**Geography**	**Design**	**Aims**	**Ages**	**Gender**	**Ethnicity**	**BPS Need**	**Relation**	**Age (Years)**	**Ethnicity**	**Family Structure**	**Other Family**
[64] dsA29	2017	Australia	mixed methods single-case experimental des.	Evaluate intervention	9–12 years	M 0%		Foetal alcohol spectrum disorder (FASD)	Parents	43–57			Siblings
[65] dsA30	2013	Iran	Pre-post, cross-over design	Evaluate intervention	3–17 years	M 70.3%		ASD		<30–50+ years		Single parent	Siblings
[66] dsA31	2016	Denmark and Italy	Pilot study	Evaluate intervention	3–9 months CA	M 61.9%		Pre-term infants, born between 28 + 0 and 32 + 6 (weeks + days) of gestational age.					
[67] dsA32	2017	Italy and Denmark	Multicentre RCT	Effectiveness	3–8.9 months CA	M 46.3%		Pre-term infants born between 28 + 0 and 32 + 6 (weeks + days) of gestational age					
[68] dsA33	2008	South Africa	Descriptive research design	Evaluate intervention	3–43 months	M 53%	Black 66%, white 22%, mixed race %, Asian/Indian 3%	Hearing loss					
[69] dsA34	2014	Germany	Controlled pretest-post-test design	Evaluate intervention	5–10 years	M 54.8%		Down syndrome, physical or mental retardation, diverse disabilities					
[70] dsA35	2017	USA	Two-site RCT	Effectiveness	7–14 years	M 44%	Caucasion 51%, Latino/hispanic: 15%, African American 26%, other 8%	MDD, DD, or depressive disorder-not otherwise specified				Nuclear	
[71] dsA36	2006	USA	Trial	Describe intervention	5–16 years	M 65.6%	African American 18.8%, European American 81.3%	Traumatic Brain Injury	Mother				
[72] dsA37	2018	Norway	Mixed methods pre-test post-test cohort design	Evaluate intervention	6–17 years	M 53.3%		Range of disabilities leading to activity limitations and participation restrictions				Nuclear and Single par-ents/caregiver	
[73] dsA38	2006	China	Pre-test/post-test control group	Effectiveness	<2–11 years	M 75%	Chinese	Developmental disability	Majority Mothers	<20–45			Siblings
[74] dsA39	2011	USA	Comparison two models	Evaluate intervention	11–14 years			Parents and their children who live in family shelters.					

Table 3. *Cont.*

Article			Study		Children				Primary Caregiver			Family Demographics	
Ref & Code	**Year**	**Geography**	**Design**	**Aims**	**Ages**	**Gender**	**Ethnicity**	**BPS Need**	**Relation**	**Age (Years)**	**Ethnicity**	**Family Structure**	**Other Family**
[75] dsA40	2015	USA	Block comparison design	Effectiveness	7–11 years	M 68%	Latino 53 %, Black/African American 30 %	Disruptive behaviour disorders				Single parent	Siblings
[76] dsA41	2015	USA	Two-group RCT	Effectiveness	8–12-years.	M 52%	White 71%, Black 16%, Other 13%	BMI percentile above the 50th percentile		mean ~41 years	80% White, 13% black, 7% other		
[77] dsA42	2010	UK	Pilot study	Evaluate intervention	8–13 years			BMI > 91st percentile		33 and 44			

3.1. Study Characteristics

Characteristics of all included articles are reported in Table 3. Study designs were, case studies (n = 4, 9.5%), feasibility and pilot trials (n = 10, 23.8%), randomised controlled trials (n = 15, 35.7%) and other design types (n = 13, 31%). Study aims were to: develop, evaluate acceptability or test the implementation of an intervention (n = 5, 11.9%), investigate the effectiveness of an intervention (n = 34, 81%), describe the components and processes of a family-centred care intervention (n = 1, 2.4%), compare a family-centred intervention with a traditional, non-family-centred intervention (n = 3, 7.1%) and evaluate the effect of moderating factors on a family-centred intervention (n = 1, 2.4%).

3.2. Population Characteristics

Population characteristics are reported in Table 3. There were 4133 children reported in the included studies. Gender was recorded for 91% of children, with more males (n = 2030, 55%) reported than females (n = 1643, 45%). Children's ethnicity was described in 60% of articles (n = 25) and most commonly recorded as Caucasian or non-Hispanic (n = 14, 33.3%) as cited directly from the included study's terminology. All articles reported the ages of children, which ranged from birth to 21 years. Studies reported an array of age cohorts broadly categorised as children aged < 5 years (n = 16, 38.1%), aged > 5 years (n = 20, 47.6%) or < 21 years (n = 6, 14.3%). The following cohorts were repeated in studies; birth to 2 years (n = 9, 21.4%), 6–12 years (n = 6, 14.3%), 6–16 years (n = 6, 14.3%). The age ranges of participants within any given study varied between 3 months to 15 years difference, with a mean age range of 54.75 months over all the studies combined.

Studies had a strong focus on health condition, body, structure or functional limitations (n = 33, 78.6%); within this group Autism Spectrum Disorder (n = 8, 19%) and unidentified syndromes or physical conditions (n = 9, 21.4%) were the most commonly stated. Other conditions included risk of developmental disorder or pre-term infants (n = 7, 16.7%) and obesity (n = 5, 11.9%). Behavioural or psychological needs were reported in five studies (11.9%) and social risk in one study (2.4%).

The primary caregiver was described in 22 studies (52.3%), most of which described the caregiver/s as 'the mother' (n = 10, 23.8%) or as 'majority of mothers' (n = 8, 19%). The remaining primary caregivers included parents or a combination of mothers and fathers or grandparents and parents (n = 4, 9.5%). The age of the primary caregiver was reported in 18 studies (42.9%), ranging from 24.3–57 years (with one outlier reported as <20 years). The ethnicity of caregivers was reported in only eight studies (19%). Varying descriptions of family members other than the primary caregiver were provided in 26 studies (61.9%). Family demographics were described in 19 studies (45.2%) in a variety of ways, including marital status (n = 17, 40.5%), description of siblings (n = 8, 19%) and extended family (n = 2, 4.8%), whilst 54% of included articles provided no additional family information.

3.3. Family-Centred Care Model Characteristics

Models were categorised as; models of care original to the study (n = 13, 30.9%) [38,40,42–44,46,48,51,57,61,70,73,75], existing models of care (n = 12, 28.6%) [36,37,41,47,52,55,60,63–66,68], models derived from theoretical backgrounds (n = 6, 14.3%) [50,58,69,71,76,77], adapted models (n = 9, 21.4%) [39,45,49,54,59,62,67,72,74], or a combination of theoretical frameworks and existing models (n = 2, 4.8%) [53,56] (see Table 2 for definitions).

Full characteristics of family-centred care models are reported in Table 4. Recruitment was described in most studies (n = 38, 90.5%) with a majority of studies recruiting from health practices, health professionals or services involved with the child (n = 28, 67%%). Preparation for the family-centred care interventions emerged as an important feature in 27 studies (64.3%) and methods included training the facilitator (n = 20, 47.6%), creating resources (n = 5, 64.3%), or a combination of methods (n = 2, 4.8%). Most studies described who was responsible for implementing and facilitating the family-centred model of care (n = 37, 88.1%). Therapists working independently were most often physical ther-

apists (n = 6, 14.2%) and examples of multi-disciplinary teams or facilitators (n = 22, 52.4%) included care coordinators (n = 4, 9.5%) and experienced parents used as facilitators (n = 3, 7.1%). Family-centred care had one method of delivery in 20 studies (47.6%) with the remaining 22 studies (52.4%) reporting a combination of either two (n = 16, 38.1%), three (n = 6, 14.3%) or four (n = 1, 9.5%) delivery methods, which included, facilitator to family delivery, written materials, group sessions or independent home programmes.

The primary location of the intervention was described in 39 studies (92.9%) and covered 3 main settings, a clinic or healthcare centre (n = 14, 33.3%), the child's home (n = 13, 31%), and the community or school environment (n = 6, 14.3%). In five studies (9.5%) the family was given the choice of location (either home or clinic) [36,47,62,64,71]. In addition, there was a secondary location described in 18 studies (42.9%); which was predominantly the child's home (n = 15, 35.7%). Only one study (2.4%) noted proximity of location to participants home [38] and the use of outdoor spaces was indirectly noted in 11 studies (26.2%) [36,38,43,45,57,59,65,69,72,73,75]. The temporal measures for family-centred interventions differed significantly across studies and were most frequently reported as; number of weeks of care (n = 29, 69%), minutes per session (n = 30, 71.4%) and frequency of sessions (n = 33, 78.6%). Other studies reported only partial information with 27 studies (64.3%) providing enough detail regarding frequency, duration and length of intervention to enable replication.

3.4. Outcome Measures Used in Family-Centred Care Studies

Studies described 119 outcome measures, consisting of 87 quantitative measures (73%) and 32 qualitative measures (27%) (Table 5). There were 152 occurrences of outcome measures over all studies, 100 measures were reported once and 19 measures were reported in more than one study as follows: Bayley Scale of Infant Development [41,63], Measure of the Processes of Care [41,58], Goal Attainment Scale [58,72], Conflict Behaviour Questionnaire [61,71], Infant Motor Profile [66,67], Teller Acuity Cards [66,67], Child Depression Inventory [70,74], Child Behaviour Checklist [70,71], Brief Symptom Inventory [71,74] and Paediatric Quality of Life Inventory Family Impact Module [48,52], all recurred in two studies; Albert Infant Motor Scale [40,66,67], Paediatric Evaluation of Disability Index [40,51,53], Haemoglobin A1c [45,46,48], Family Environment Scale [47,51,56], Vineland Adaptive Behaviour Scales [51,55,60] and Parenting Stress Index [53,55,65], were repeated in three studies; Canadian Occupational Performance Measure [36,41,47,72] was repeated in four studies; and Body Mass Index/ Standardised Body Mass Index [38,42,45,50,76,77] were repeated in six studies.

Table 4. Characteristics of family-centred care models from included studies.

	Family-Centred Care Model Characteristics					Location		Temporal Features of Family-Centred Care Interventions					
Ref and Code	**Origin**	**Recruitment**	**Preparation**	**Implemented by**	**Delivery Method**	**Primary Location**	**Secondary Location**	**Weeks**	**Days**	**Sessions**	**Mins**	**Min Range**	**Frequency**
[36] dsA1	Existing model	Word of mouth/Flier		Physical therapist	Facilitator to family	Hospital		6			40		Weekly
[37] dsA2	Existing model	Word of mouth		Occupational therapist	Combo: Facilitator to family and home prog.	Hospital	Home			20	60		Twice weekly
[38] dsA3	Original to study	Health service		Bilingual program coordinator, dietitians, paediatricians, chef, nutrition and exercise experts, bilingual culturally aware volunteers	Group	Community Centre		16			120		Weekly
[39] dsA4	Adapted from existing	Health service		Child and Family Studies Associate Professor	Combo: facilitator to family and independent home programme	Home							
[40] dsA5	Original to study	Health service	Train facilitator	Paediatric Physical Therapists	Facilitator to family	Home					60		Twice weekly
[41] dsA6	Existing model	Health service	Train facilitator	physical therapist, occupational therapist, speech therapist, psychologist	Combo: Group and Facilitator to family		Home	16				60–90	Weekly
[42] dsA7	Original to study	Health service		Paediatrician, family counsellor, dietician, physical therapist, exercise specialist	Facilitator to family	Hospital clinic	Home (instruction)	52					Biweekly
[43] dsA8	Original to study	Health service		Occupational Therapist	Combo: Facilitator to family and Written material	Home				4	60		Weekly
[44] dsA9	Original to study	Health service	Train facilitator	Paediatric physical therapists	Facilitator to family	Home					60		Twice weekly
[45] dsA10	Adapted from existing	Health service		Registered dietitian, Physician, Promotora, Medical assistant	Combo: Facilitator to family and Group	Health centres		10		5	120		Every other week
[46] dsA11	Original to study	Health service	Train facilitator	Registered nurses, Certified diabetes educators, Motivational Interviewing Network of Trainees, Paediatric health psychologists	Group	Diabetes clinic		36		4	75		

Table 4. *Cont.*

	Family-Centred Care Model Characteristics					Location		Temporal Features of Family-Centred Care Interventions					
Ref and Code	**Origin**	**Recruitment**	**Preparation**	**Implemented by**	**Delivery Method**	**Primary Location**	**Secondary Location**	**Weeks**	**Days**	**Sessions**	**Mins**	**Min Range**	**Frequency**
[47] dsA12	Existing model	Ad/Flier	Train facilitator	Physical Therapists	Facilitator to family	Home or Clinic		6			40		Weekly
[48] dsA13	Original to study	Ad/flier	Train facilitator	Registered nurses, Certified diabetes educators, Motivational Interviewing Network of Trainees, Pediatric health psychologists	Group	Healthcare facilities	Home (assignments)	36		4	75		Every 3 months
[49] dsA14	Adapted from original	Health service	Train facilitator	Psychology Research staff, parent consultant	Facilitator to family	Home							
[50] dsA15	Theoretical framework	Health service	Train facilitator/make resources	School Mental Health clinicians	Combo: Facilitator to family and Written material	School clinic	Home			6			
[51] dsA16	Original to study	Health service	Train facilitator	Paediatric physiotherapists	Facilitator to family	Home		52					Aim weekly (actually 3× month)
[52] dsA17	Existing model	Health service		Childcare and educationteacher, speech therapist, occupational therapist	Group			6		6	120		Weekly
[53] dsA18	Theoretical + Model	Health service		Paediatric physical therapist, social workers, local paraprofessional, physical therapist	Facilitator to family	Home visits		12		5		60–90	Every other week, once in last month
[54] dsA19	Adapted from existing	Not described	Train facilitator	Specialised nurses, social education workers, case managers, psychologists, Neonatologists	Facilitator to family	Hospital/NICU	Home	12					Variable
[55] dsA20	Existing model	Health prof/flier	Train facilitator and parent/s	Occupational therapist	Combo: Facilitator to family and DVD Resources	Home		10					Variable
[56] dsA21	Theoretical + Model	Health service	Train facilitator	Clinicians (neurodevelopmental disabilities), Care coordinator (registered nurse, clinical social worker)	Facilitator to family	Neurodevelopmental outpatient clinical setting	Care coordination from respective workplaces	36			90		Variable

Table 4. *Cont.*

	Family-Centred Care Model Characteristics					Location		Temporal Features of Family-Centred Care Interventions					
Ref and Code	**Origin**	**Recruitment**	**Preparation**	**Implemented by**	**Delivery Method**	**Primary Location**	**Secondary Location**	**Weeks**	**Days**	**Sessions**	**Mins**	**Min Range**	**Frequency**
[57] dsA22	Original to study	Health service	Train facilitator	Psychologist	Combo: Facilitator to family and resources	Home	Community	52					Fortnightly
[58] dsA23	Theoretical framework	Not described	Create resources	Speech Language Therapists	Combo: Group and Facilitator to family	Clinic	Home (consolidation)	9			45		Weekly
[59] dsA24	Adapted from existing	Ad/flier		Paediatric physiotherapist	Combo: Written material and Independent home programme		Home	12					
[60] dsA25	Existing model	Health service	Train facilitator	Professional therapist (medical centre)	Combo: Facilitator to family and independent home programme	Medical centre	Home	12			60		Every 3 weeks
[61] dsA26	Original to study	Health prof/flier	Train facilitator	unspecified clinicians	Facilitator to family	Outpatient clinics of University hospitals		39		21	60		Weekly, every other week, 3 monthly
[62] dsA27	Adapted from existing	Health service	Train facilitator	Accredited RAP facilitators, psychologists, social workers, registered nurses	Combo: Facilitator to family and written material	Outpatient mental health setting or at the family's discretion in the home				4	120		Weekly, every other week
[63] dsA28	Existing model	Health service		Nursing staff, child neurologist, neonatologist, paediatric physiotherapist	Combo: Facilitator to family and independent home programme	NICU	Home						
[64] dsA29	Existing model	Health service	Train facilitator	Registered Psychologist	Combo: Facilitator to family and written material	Home		27				60–120	weekly, fortnightly
[65] dsA30	Existing model	Health service		Psychologist	Combo: Group and DVD resources and written material and home programme	Private school/clinic for students with special needs	Home (training materials)			7		60–90	
[66] dsA31	Existing model	Health service	Create resources	Child neurologists, paediatric physical therapists	Independent home programme	Home		4				30–45	Daily
[67] dsA32	Adapted from existing	Health service		Rehabilitative staff	Independent home programme	Home		4				30–45	Daily
[68] dsA33	Existing model	Health service	Train facilitator	Parent advisors and deaf mentors, professionals from infant's individualised team	Combo: Facilitator to family and written material	Home		52				60–90	Weekly

Table 4. *Cont.*

	Family-Centred Care Model Characteristics					Location		Temporal Features of Family-Centred Care Interventions					
Ref and Code	**Origin**	**Recruitment**	**Preparation**	**Implemented by**	**Delivery Method**	**Primary Location**	**Secondary Location**	**Weeks**	**Days**	**Sessions**	**Mins**	**Min Range**	**Frequency**
[69] dsA34	Theoretical framework	Not described		Speech therapists, occupational therapists, Physiotherapists, Dolphin trainer	Facilitator to family	Dolphinarium			10		30		Daily
[70] dsA35	Original to study	Health prof/flier	Train facilitator	Psychology prof, social worker	Combo: Written material and independent home programme		Home (assignments)	16		15		50–60	weekly
[71] dsA36	Theoretical framework	Health service	Train facilitator	Clinical psychology graduate student	Combo: Facilitator to family and written material	Clinic or Home	Home (assignments)	24		7		75–100	Every other week
[72] dsA37	Adapted from existing	Health service	Create resources	Occupational therapist, Physiotherapists, adapted physical activity specialist	Group	Health/sports Centre	Local community		19			120–300	6 days per week
[73] dsA38	Original to study	Not described	Create resources	Unspecified researchers	Combo: Group and facilitator to family and written material	In house rehab centre.		10		10	120		Weekly
[74] dsA39	Adapted from existing	Health prof/flier	Train facilitator	Community coordinators, social work university researchers, peer community educators, childcare providers	Combo: Group and written material	Six shelters in New York City				8			
[75] dsA40	Original to study	Health service	Train facilitator	Clinician, Family partners advocates (previous parents)	Combo: Group and Home programme	Outpatient mental health agencies.	Home (assignments)	16		16		90–120	Weekly
[76] A41	Theoretical framework	Health prof/flier		Registered dietitians, public health nurse	Combo: Group and written material	Recreation community centres	Home (tasks)	40		10			Monthly
[77] dsA42	Theoretical framework	Health service	Create resources	Steering group: programme developer, obesity service manager, paediatric, dietician, school nurse, health intelligence manager, GP, schoolteacher, child psychologist, and representatives from the child/adolescent mental health service and local council leisure services	Combo: Written material and group	Local further education college		12			120		Weekly

Characteristics/terminology described as in original papers.

Table 5. Outcome measures used within included studies.

Article Ref and Code	Outcome Measures							
[36] A1	Interviews	Canadian Occupational Performance Measure (COPM)	Response Class Matrix					
[37] A2	Interviews							
[38] A3	Survey	Child weight	Child BMI					
[39] A4	Individualised Behaviour Rating Scale Tool (IBRST)							
[40] A5	Neurological examination	Alberta Infant Motor Scale	The Paediatric Evaluation of Disability					
[41] A6	Canadian Occupational Performance Measure (COPM)	Bayley Scales of Infant and Toddler Development	Affordances in the Home Environment for Motor Development-Infant Scale	Measure of Processes of Care (MPOC)				
[42] A7	Child BMI	Child BMI z-score						
[43] A8	Mothers' perceptions of the children's behaviour = visual analogue scale (VAS)							
[44] A9	Time spent in different positions	Measures of family involvement.						
[45] A10	Child BMI changes	Child BMI z-score	Child blood pressure	Child fasting lipids	Child blood glucose—haemoglobin A1c	Child insulin	Child homeostasis model assessment-estimated insulin resistance	Parent weight
[46] A11	QOL for children and their parents	Glycaemic control A1c data						
[47] A12	Family Empowerment Scale (FES)	Canadian Occupational Performance Measure (COPM)						
[48] A13	Diabetes-specific PedsQL	PedsQL Family Impact Module	PRISM barrier scores	Surveys	Percentage of patients meeting A1c target			
[49] A14	Eyberg Child Behaviour Inventor (ECBI)	Maternal depression: Centre for Epidemiological Studies on Depression Scale (CES-D)	Marital Adjustment Test	Cumulative risk index				

Table 5. *Cont.*

Article Ref and Code	Outcome Measures							
[50] A15	Measurement of psychosocial variables	BMI	Standardised BMI					
[51] A16	Family Empowerment Scale (FES)	Nijmeegse Ouderlijke Stress Index questionnaire, short version (NOSI-K)	Utrechtse Coping List	Vineland Adaptive Behaviour Scales (VABS), Dutch version	Infant and Toddler Quality of Life Questionnaire (ITQOL)	CBS-list Quality of Life	Paediatric Evaluation of Disability Index (PEDI)	Gross Motor Function Classification System (GMFCS). Factor analysis
[52] A17	Pediatric Quality of Life Inventory (PaedsQL) Family Impact Module	the PedsQL Healthcare Satisfaction Module	Hospital Anxiety and Depression Scale	World Health Organisation Quality of Life brief assessment				
[53] A18	Paediatric Evaluation of Disability Inventory Chinese Version (PEDI)	Peabody Developmental Motor Scale, 2nd edition	Disability-Adapted Infant–Toddler version of Home Observation for Measurement	Knowledge of Infant Development Inventory	Parental Stress Index-Short Form			
[54] A19	Economic impact length of stay	Re-hospitalisation rate for patients in—and outborn	Number of stays longer than average	Gestational age at discharge				
[55] A20	Parenting Stress Index-Short Form	Vineland Adaptive Behaviour Scales	Functional Emotional Assessment Scale					
[56] A21	Family goals outlined in the SPoC, and progress against those documented goals	The National Survey of Children with Special Health Care Needs (CAHMI)	Shared Plan of Care, (Family Experience of Care Coordination measurement set)	Family Empowerment (Family Empowerment Scales—about my child and about my family)	Family worry (Centre for Medical Home Improvement			
[57] A22	Qualitative interviews	Questionnaires on perceived outcomes and project quality	Rating scales specific to study					
[58] A23	"Getting to know your child" questionnaire with contextual Factors of the ICF-CY	The Measures of Processes of Care (MPOC)	Satisfaction survey (developed for the study)	Goal Attainment Scaling GAS	Diagnostic Evaluation of Articulation and Phonology (DEAP)	The Risk Assessment and Prediction Tool (RAPT)		
[59] A24	Movement Assessment Battery for Children	Developmental Coordination Disorder Questionnaire						
[60] A25	Psychoeducational Profile Revised (PEP-R)	Vineland Adaptive Behaviour Scale (VABS)	Parental sense of competence scale (PSCS)					
[61] A26	The Family Adaptability and Cohesion Evaluation Scale (FACES-II)	The Conflict Behaviour Questionnaire (CBQ)	The Mania Rating Scale (MRS; Chambers, 1985)	Depression Rating Scale of the K-SADS-PL				

Table 5. *Cont.*

Article Ref and Code	Outcome Measures							
[62] A27	Adolescent Suicide Questionnaire—Revised (ASQ-R)	Adolescent and parental reports on the Strengths and Difficulties Questionnaire (SDQ)	Health of the Nation Outcomes Scale for Children and Adolescents (HoNOSCA)	Family Assessment Device (FAD) (McMaster Model of Family Functioning)				
[63] A28	Bayley Scales of Infant Development 2nd Edition							
[64] A29	Survey	Semi-structured interviews	The 86-item Behaviour Rating Inventory of Executive Function (BRIEF)	The NEPSY, Second Edition (NEPSY-II)	The 64-item Youth Outcome Questionnaire—Self Report (Y-OQ SR)			
[65] A30	Post-course interviews	General Health Questionnaire	Coping Styles Questionnaire (CSQ)	Family functioning	The Short Form of the Parenting Stress Index (PSI-SF)			
[66] A31	The Infant Motor Profile (IMP)	Alberta Infant Motor Scale	Teller Acuity Cards					
[67] A32	Infant Motor Profile (IMP)	Alberta Infant Motor Scale (AIMS)	Teller Acuity Cards					
[68] A33	Surveys	HI HOPES data sheets	SKI-HI language development scale					
[69] A34	Questionnaires							
[70] A35	Children's Depression Rating Scale-Revised (CDRS-R)	Parent- and child-rated 5-point scales of overall satisfaction	Child Depression Inventory (CDI)	Social Adjustment Scale for Children -Self-Report (SAS-SR)	Multidimensional Anxiety Scale for Children	Child Behaviour Checklist		
[71] A36	Two-part satisfaction survey	Child Behaviour Checklist	Brief Symptom Inventory	Conflict Behaviour Questionnaire				
[72] A37	Short structured interview with parents	Canadian Occupational Performance Measure (COPM)	Goal Attainment Scaling (GAS)					
[73] A38	Knowledge Questionnaire	Maternal Self-Rating Scale	Short Form of the Questionnaire of Resources and Stress (QRS–F)	Community Activity Questionnaire (CAQ)	Parent Experience Survey (PES)	Parent–Child Interaction Assessment System		
[74] A39	The Within Family support subscale	Family Assessment Measure	Parenting Skills Questionnaire	Family Stress Scale	Monitoring the Future survey	Child Depression Inventory (CDI)	Brief Symptom Inventory	Sexual behaviour structured interview pre- and early adolescents
[75] A40	Parent-report measures IOWA Connors Rating Scale (IOWA CRS)	Impairment Rating Scale (IRS)	Social Skills Rating System: Social Skills Subscale (SSRSSSS)					

Table 5. *Cont.*

Article Ref and Code	Outcome Measures			
[76] A41	Child BMI z-score	Pubertal Development Scale		
[77] A42	Amended version of the Self-Perception Profile for Children (SPPC)	BMI	Physical activity survey	Family behaviours questionnaire developed by the programme

The focus of the outcome measures varied between the child (n = 93, 61.2%), the parent/caregiver (n = 28, 18.4%), the family (n = 19, 12.5%) or had an unclear focus (e.g., unspecified survey) (n = 12, 7.9%). Measurements relating to body, structure or functional limitations or health conditions (n = 49, 32.2%) [38,40–42,44–46,50,51,53,54,56,58–63,65–68,75–77] were most frequent. Personal contextual measurements included; psychological measures of mental health (n = 18, 11.8%) [49,51–53,55,56,61,64,65,70,71,73,74] including stress, depression, anxiety of the caregiver (n = 9, 5.9%), child (n = 7, 4.6%) or family (n = 2, 1.3%), measures of behaviour (n = 16, 10.5%) [39,41,49,51,55,60,64,65,70,71,74,75] of the child (n = 15, 9.9%) or family (n = 1, 0.7%), and measured perceptions including parents perceptions of model efficacy (n = 10, 6.6%) [43,56–58,60,70,71,73,74]. Environmental contextual measures included those of family interactions (n = 9, 5.9%) [36,44,49,61,62,65,73,74]. Measures of participation (n = 6, 3.9%) [36,41,47,48,72,73] that also included measures of quality of life (n = 8, 5.3%) [46,48,51,52] for the child (n = 5, 3.3%) and family (n = 3, 2%), and family empowerment (n = 3, 2%) [47,51,56], were not as common. Similarly, there were a limited number of goal setting measures (n = 4, 2.6%) [41,56,58,72], which were defined as ICF 'activity' measures. Bespoke instruments (e.g., surveys, interviews and questionnaires) created for individual studies were recorded as Miscellaneous (n = 15, 9.9%) [36–38,48,57,58,64,65,68,69,72,73]. The spread of outcome measures across the ICF model is illustrated as percentages in Figure 2. Evidence of intervention effectiveness was measured in 15 RCT's [40,44–49,51,58,61,62,67,70,71,76] with nine studies reporting some results as significant [45–47,49,58,61,62,67,70]. The biopsychosocial focus of these studies were obesity (n = 2, 1.3%) [45,46], physical disability (n = 1, 0.7%) [47], problem behaviour and depression (n = 3, 2%) [49,62,76], speech language pathology (n = 1, 0.7%) [58], pre term infants (n = 1, 0.7%) [67].



Figure 2. Outcome measures classified into ICF categories; Health Condition, body structure or body function measures (dark blue), activity measures (orange), participation measures (grey), contextual environment measures, (green), contextual person measures (yellow), Miscellaneous measures (light blue).

3.5. Thematic Analysis: Key Features of Family-Centred Care Implementation Processes

Synthesis of the processes for implementing family-centred care interventions resulted in the identification of four common themes that described the key features deemed important within the reviewed studies for putting family-centred care into practice, namely (1) collaborative decision making/goal setting, (2) parental supports, (3) specific elements of intervention content and (4) individualised programming. Collaborative decision making and goal setting is a well-recognised characteristic of family-centred care whilst the other three themes are novel to this review. Thirteen recurring processes were identified within the four themes and Figure 3 illustrates the distribution between the themes.

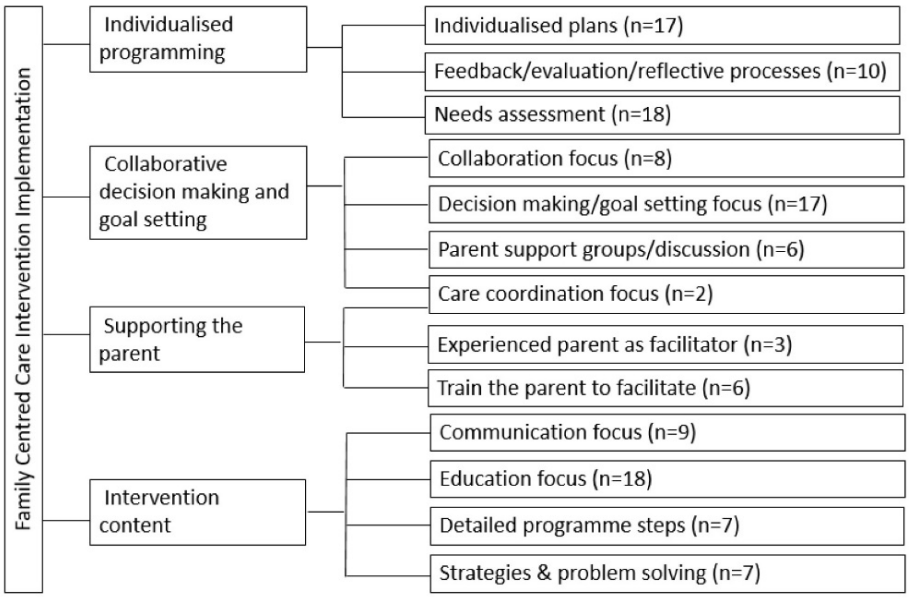


Figure 3. Key features of family-centred care model implementation processes.

3.5.1. Theme 1: Collaborative Decision Making and Goal Setting

The goal setting or decision-making process was reported in 32 studies (76.2%) in varying degrees of detail and formed the first theme of collaboration. Examples included family-professional collaboration (n = 8, 19%) [36,43,47,49,51,53,60,72] and shared decision making and goal setting processes (n = 17, 40.5%) [36,37,39–42,47,50,53,56,58,59,68,71,72,76,77]. Group sessions involving other parents and/or a facilitator (n = 6, 14.3%) [38,46,48,52,72,75] and professional care coordinators within multidisciplinary teams (n = 4, 9.5%) [38,56,62,74] were also suggested. Decision making and goal setting processes were described as; collaborative goal setting (n = 15, 35.7%) [37,39,47,50,53–56,58,60,61,63,64,72,76], goal setting by the 'family' (n = 9, 21.4%) [38,40,45,46,48,57,68,70,71], and goal setting by parents (n = 7, 16.7%) [42–44,49,59,67,77]. Importantly, the child was specifically identified as being involved in this process in only five studies (11.9%) [46–48,56,70].

3.5.2. Theme 2: Parental Supports

Parental support was implemented through the processes of providing care coordination services (n = 2, 4.8%) [54,56], using an experienced parent as a facilitator (n = 3, 7.1%) [49,60,75] and training the parent of the child to facilitate the intervention (n = 6, 14.3%) [51,54,55,60,63,66].

3.5.3. Theme 3: Intervention Content

Specific elements of family-centred care content recurred between studies, namely; content focused on communication (n = 9, 21.4%) [52,54,55,61,65,70,71,74,75], and/or education (n = 18, 42.3%) [50–52,54,58–62,64,65,70–74,76,77] and content made of detailed

steps (n = 7, 16.7%) [36,39,46–48,53,56], specific strategies and problem solving tactics (n = 7, 16.7%) [36,43,50,61,64,71,77].

3.5.4. Theme 4: Individualised Programming

The aim to individualise programmes to each child was identified as a common theme. Processes to achieve this were assessment of the child's biopsychosocial needs prior to the family-centred care intervention (n = 18, 42.9%) and subsequent tailoring of the intervention to the child (n = 17, 40.5%) [42,44,46,48,49,53,54,57,58,60,63,64,66–68,71,72]. Processes of feedback, evaluation and/or reflections were used (n = 10, 23.8%) [36,39,56,58,59,63,69,73,75,77] to ensure the programme continued to meet the individual needs of the child.

3.6. Framework for the Processes of Implementing Family-Centred Care

Using the synthesised themes and accompanying processes a framework to guide the implementation processes for family-centred care was created (Figure 4). The framework starts with clear definitions of who is involved in the model of care and assessment of their respective biopsychosocial needs. Next, collaboration, shared and supported decision making and goal setting strategies are exercised with clear identification of child involvement. The needs of the family guide the choice of model of family-centred care and the particular content of the intervention which includes but is not limited to, communication strategies, delivery of education and use of detailed steps or problem-solving strategies. Delivery of the family-centred care and temporal features of the programme should be provided in detail so that the intervention may be replicated. Family-professional collaboration is essential to determine primary and secondary intervention locations (where appropriate), to choose appropriate facilitators for the programme, and determine meaningful measurements for intervention outcomes. Feedback, reflections and evaluation from both the family and the facilitators will highlight potential changes to be made to the processes of implementation of the intervention. Details of each key element and process of the programme should be clearly recorded to allow for comparison with future studies.

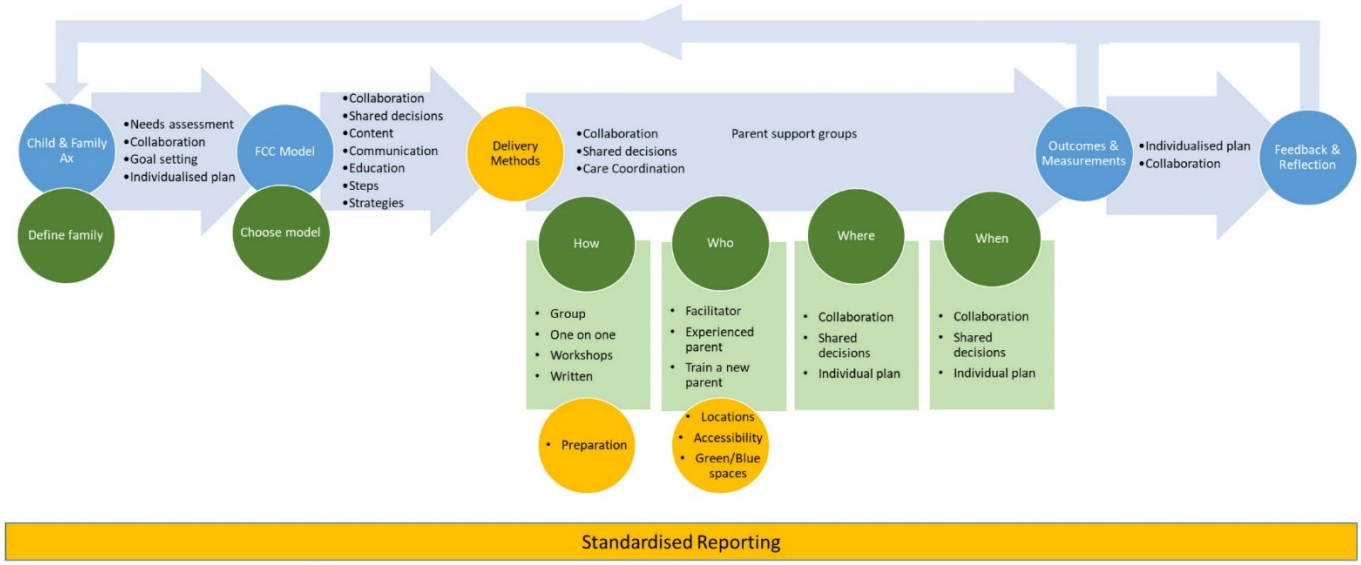


Figure 4. Framework for the processes of implementing family-centred care. Blue circles represent elements of family-centred care that are well reported in the literature, green rectangles to describe ways in which these key elements could be expanded to provide greater detail to increase homogeneity between studies, and yellow circles highlight new elements that are key to family-centred care which have not been well reported in past literature. Processes of implementation are described within the pale blue figure arrows and each process is influenced by the biopsychosocial needs of the child and family unit.

4. Discussion

The purpose of this scoping review was to synthesise the processes for implementing family-centred care interventions for children with biopsychosocial support needs and to illustrate the outcome measures used in the studies. The search returned 42 articles from 16 countries, illustrating that the implementation of family-centred care has been widely applied. However, a lack of consistency was evident in how the family-centred care interventions were put into practice and reported demographics of the child's family were found to be sparse or altogether lacking from the literature. A health condition or body structure or functional limitation focused outcome measures were found to be the norm, illustrating a focus on impairment and the paucity of outcomes directed towards participation. Through the synthesis of the literature, a strategy for family-centred care implementation was developed and is presented alongside further implications for practice.

4.1. Paucity of Demographic Reporting and Definitions of the Family Unit

Family demographics were poorly defined and lacked detail with regards to both the primary caregiver and the family. For example, demographic information on the Mother's employment status was mostly reported as part-time or described as homemaking, however, studies failed to explore the Mother's choice to work in this capacity and made no speculations on whether this was a reflection of the time required to care for their child. Caregiving responsibilities may create a financial burden as illustrated by the AARP Public Policy Institute description of 69% of working caregivers caring for a family member having reported as changing, decreasing or leaving their work to meet their caregiving responsibilities [78]. Similarly, the National Alliance for Caregiving and AARP Public Policy Institute reported that 39% of caregivers leave their job to have more time to care for a loved one [79], and 45% of family caregivers have had at least one financial impact [80]. Therefore, understanding the impact on the primary caregiver's employment from factors such as time required for their child's appointments and therapies and general caregiving tasks may provide a greater understanding of the psychosocial stress the caregivers are under. Formal definitions of 'family' were also lacking in the literature, making it unclear whether there was a lack of family inclusion within the interventions or rather paucity of reporting. Without clear identification of immediate and (where appropriate) extended family members it is difficult to understand how they are integrated into the family-centred care model. Sibling demographics may be considered particularly important as they provide a unique opportunity for peer modelling. A systematic review and meta-analysis by Kracht and Sisson [81] noted the importance of siblings as motivators for participation in activity and sports and in modelling health habits. Ascertaining sibling's ages and activity preferences may inform the implementation of an intervention in a home setting and facilitate sibling collaboration. Variations in family relationships should also be explored as they may lead to different psychosocial challenges, for example, a systematic review by Arakelyan et al. [7] illustrated that living in a single-parent family was consistently associated with decreased participation in leisure activities. It is undoubtedly important to consider the child at the centre of the family-centred care model care, but also essential to understand their family and consider the influences they will bring to the home environment and their capacity to enable the intervention. Analysis of the family may also highlight supports for family members that are necessary for successful implementation of the intervention.

4.2. Processes of Implementing Family-Centred Care Interventions

Significant variation existed between the processes of family-centred care models due to the extremely diverse population of children included in the studies and health professionals or support persons acting as facilitators. Interventions were primarily delivered in the health care setting related to the facilitating health professional. However, the location for family-centred care interventions should be guided not only by the facilitator but should include environments in which children and families feel at ease and in which they

may experience a wide range of benefits, including increased participation and enjoyment. A systematic review by Thompson Coon et al. [82] reported that the benefits of exercise in outdoor natural areas are holistic and include associations with increased energy, enhanced mental well-being and greater intent to repeat the activity. As interventions mostly focused on implementing theoretical key attributes of family-centred care, meaningful environments for the families were not explored and there was a failure to address potential barriers such as accessibility or facilitators such as ease of use or familiarity. Factors such as proximity to the home, benefits of nature, use of outdoor spaces, holistic health, accessibility and community engagement may also be important considerations but were not evident in this review.

4.3. Outcome Measures Used in Family-Centred Care Studies

Holistic qualitative outcomes relating to participation, family empowerment and child/family goal achievement, which are arguably closer to the core of family-centred care, were under-reported in this review. Synthesis of the literature illustrated a strong focus on the measurement of impairment (body structure and function limitations), followed by person-centred outcomes and a correspondingly limited focus on participation and activity outcomes. Several influences on outcome measures emerged including, the biopsychosocial need of the primary caregiver and the philosophy and purpose of the intervention.

Studies in which psychological measures were used mostly focused on the biopsychosocial need of the primary caregiver rather than the child. In addition, parental anxiety emerged as an influencing factor that reflects the psychological caretaking burden reported by O'Neil et al. [83] for parents of children with physical disabilities. A literature review by Wang and Barnard [84] focusing on children dependent on long-term medical and technical support reported parent's mental and physical "overburden" for a multitude of reasons including, stress and insomnia from worry, financial concerns and physical exhaustion due to direct care of their child. These findings highlight that outcome measures of stress/anxiety or depression may relate to the biopsychosocial needs of the family not just those of the primary caregiver. Another influence on outcome measure choice is the philosophy of the intervention which guides the purpose of the study and associated research question. Studies that seek to determine the effectiveness of interventions relating strictly to health condition, body, structure or function will require the use of validated quantitative outcome measures. Conversely, if the philosophy of the study seeks to identify what is most meaningful and important to the family, the ICF model may be used to guide the purpose of the study and research question which may result in measures of participation and activity. This can naturally lead to the use of more qualitative outcomes and provide an important additional lens on the value of the treatment for the participants.

4.4. Implications for Practice

The lack of concrete strategies to implement the key attributes of family-centred care in the real world [16] indicates the need for a guiding framework for family-centred care implementation as presented in the results. The framework for the processes of implementing family-centred care has important implications for practice as it incorporates both existing and new key attributes of family-centred care as identified by the thematic analysis of this review and illustrates a variety of possible processes to put these into action.

The framework highlights the need to clearly define who is involved in the model of family-centred care and emphasises that all parties should be adequately described. This will allow for the needs of the whole family (including siblings and extended family where relevant) to be identified and enable family-centred care interventions to be tailored to the child and their family. Furthermore, this process paves the way for the family's meaningful goals to be mapped to the ICF model to inform the purpose of the intervention and guide the choice of outcome measures. Quantitative outcome data can be used to justify funding/policy change, however, application of the ICF model may also highlight areas of activity or participation that are important to the family, in which case qualitative outcomes

may be best suited to demonstrate improvements. The environment of the intervention should be guided by the family who may wish to use familiar locations, thus interventions may move away from primary care settings into broader spaces, for example enjoying nature as a family and enabling incidental exercise. The framework leads the user to clearly define whether the child is included in 'family goal setting' and it is imperative that goal-setting collaboration extends to include the child where at all possible. At times the child's age or competency may exclude them from an independent goal-setting process or when both parties are included, children and parents may sometimes express different goal-setting priorities, which will necessitate strategies to reach a compromise. As identified in the framework, it is important to prepare the facilitator of family-centred care and processes may include formal training, written materials, supervision or equipment instructions. Family–family collaboration and support should also be facilitated via support/discussion groups and is a newly identified key attribute of family-centred care. However, the concept of mothers supporting mothers is not unique to this review with a meta-analysis by Dunst et al. [85] also noting the value of such mutual support. Workshops or group sessions with families in similar circumstances may help with information sharing and provide families with a sense of solidarity and a feeling of being understood. Thought should be given to the accessibility of the intervention location, funding for the intervention and/or additional support networks. Future studies can use this framework to provide a systematic approach to choosing key attributes and processes to include in family-centred care interventions to decrease heterogeneity between studies.

4.5. Strengths and Limitations

This study included articles from the past 15 years and was restricted to those published in English with an available full text, thus excluding examples of family-centred care outside of these limits. Also, the broad scope of this review and emergent nature of family-centred care intervention implementation and heterogeneous nature of the population of children with biopsychosocial needs made it difficult to draw comparisons between the included studies. Synthesis of the results led to the creation of a new framework for family-centred care model implementation based on thematic analysis; however, the search was limited to a paediatric population, therefore application to other populations such as older adults with dementia or young adult populations may not be automatically inferred.

A strength of this scoping review was the comprehensive synthesis of an extremely complex and diverse population. The inclusion of a wide range of databases and methodical framework allowed for a comprehensive search across many disciplines. This review adds to the knowledge base of family-centred care and builds on that of previous authors. Furthermore, it presents a working framework for implementing the processes of family-centred models of care which has the potential to enhance future practice and research.

4.6. Recommendations

Use of the Framework for Implementing the Processes of Family-Centred Care Interventions to apply practical recommendations for additional aspects of service delivery of family-centred care interventions as follows:

- Standardised questions to identify 'family unit',
- Standardised demographic questionnaires,
- Purpose of study and individual's assessment mapped to the ICF model to ensure outcomes are meaningful to the family,
- Prepare the facilitator for the family-centred care intervention,
- Family to family support systems.

5. Conclusions

This scoping review focuses on family-centred care for children with additional biopsychosocial needs which require support to maintain an optimal state of health or wellness to ensure their full participation in society. This review synthesises the evidence on processes

for implementing family-centred care for this population of children and identifies key features. The processes of family-centred care are inconsistent between studies, which may be largely due to the heterogeneous nature of the study populations and there is the paucity of family demographic information. Outcome measures used in family-centred care studies are strongly focused on health condition, body structure or functional limitations. The findings from this scoping review provide a framework to guide the processes of implementation for future interventions for this population of children and their families to improve consistency between studies.

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