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

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 adolescent* 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). Qualitative data analysis methods (e.g., phenomenology, grounded 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]). |
| 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 characteristics 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 | Siblings |
| [38] dsA3 | 2015 | USA | Feasibility trial | Evaluate intervention | 5.4–12 years | M 52.5% | Obesity and low-income Latino families | Mother | 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, Arthrogryposis, 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% |
| Article     | Year | Geography | Design                           | Aims                          | Ages          | Gender | Ethnicity               | BPS Need                                      | Relation | Age (Years) | Ethnicity   | Family Demographics                      |
|-------------|------|-----------|----------------------------------|-------------------------------|---------------|--------|-------------------------|-----------------------------------------------|----------|-------------|-------------|------------------------------------------|
| dsA14       | 2009 | USA       | Retrospective analysis of RCT     | Effectiveness                 | 2-2.11 years  | M 51% | African American 28%,  | High risk for problem behaviour and from      | Mother   |             | African America 28%, Euro American 50%, | Nuclear and Single parents                   |
|             |      |           |                                  |                               |               |        | European American 50%, | low-income families                          |          |             | biracial 13%, other 9%, Hispanic Amer.   |                                              |
|             |      |           |                                  |                               |               |        | Briracial 13%           |                                               |          |             | 13%          |                                              |
| dsA15       | 2014 | USA       | Feasibility trial—pilot study     | Evaluate intervention         | 11–15 years   | M 60% | African American 50%,  | Referred to mental health services           | Majority Mothers | 32.39–52.01 | African American 50%            | Nuclear and Single parents                    |
|             |      |           |                                  |                               |               |        | White 50%               |                                               |          |             |                           |                                              |
| dsA16       | 2019 | Netherlands | Retrospective analysis of RCT     | Effectiveness                 | <9 months CA  | M 60.5%| African American 50%,  | High risk of CP                              | Majority Mothers | 30–54        |                           | Nuclear                                    |
|             |      |           |                                  |                               |               |        | White 50%               |                                               |          |             |                           |                                              |
| dsA17       | 2016 | Taiwan    | Prospective study                | Effectiveness                 | 18–35 months  | M 75% | White 50%               | Developmental delay                          | Majority Mothers | 30–54        |                           | Nuclear                                    |
|             |      |           |                                  |                               |               |        |                         |                                               |          |             |                           |                                              |
| 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                                    |
|             |      |           |                                  |                               |               |        |                         |                                               |          |             |                           |                                              |
| dsA19       | 2012 | Germany   | Report                           | Evaluate intervention         | From birth    |        |                         | Preterm infants <32 weeks gestation (GA),     |          |             |                           |                                            |
|             |      |           |                                  |                               |               |        |                         | multiple preterms and neonates with congenital|          |             |                           |                                            |
|             |      |           |                                  |                               |               |        |                         | malformations or severe illness.             |          |             |                           |                                            |
| dsA20       | 2014 | Taiwan    | Pilot study                      | Effectiveness                 | 45–69 months  | M 100%| Caucasian & Latino      | Autistic disorder                           | Mother   | 29–44       |                           | Nuclear                                    |
|             |      |           |                                  | Describe intervention         | 2–6.11 years  |       |                         | Autism                                       |          |             |                           |                                              |
| dsA25       | 2013 | USA       | Trial                            | Effectiveness                 | 12.0–18.1 years| M 50% | Non-White 16.7%, Hispanic | Bipolar disease I or II                      |          |             |                           | Nuclear                                    |
|             |      |           |                                  | Describe intervention         |                |       | 9.7%                   |                                              |          |             |                           |                                              |
| dsA26       | 2020 | USA       | RCT                              | Effectiveness                 | 12–17 years   | M 27% | Anglo-Saxon 57.5%,     | Suicidal adolescents.                        | Mother   | 39.67–50.61 | Anglo-Saxon 57.5%, Culturally | Nuclear and Single parents                   |
|             |      |           |                                  |                               |               |        | linguistically diverse/Non-English Speaking 38%, Aboriginal 7.5% |                                              |          |             | linguistically diverse/Non English     |                                              |
|             |      |           |                                  |                               |               |        |                         |                                              |          |             | Speaking 35%, Aboriginal 7.5%        |                                              |
| dsA27       | 2013 | Australia | Preliminary RCT                  | Effectiveness                 | 12–17 years   | M 27% | Anglo-Saxon 57.5%,     | Suicidal adolescents.                        | Mother   | 39.67–50.61 | Anglo-Saxon 57.5%, Culturally | Nuclear and Single parents                   |
|             |      |           |                                  |                               |               |        | linguistically diverse/Non-English Speaking 38%, Aboriginal 7.5% |                                              |          |             | linguistically diverse/Non English Speaking 35%, |                                              |
|             |      |           |                                  |                               |               |        |                         |                                              |          |             | Speaking 35%, Aboriginal 7.5%        |                                              |
| dsA28       | 2016 | Italy     | Retrospective cohort study       | Effectiveness                 | 3–24 months CA | M 56% | Non-White 16.7%, Hispanic | Preterm infant gestational age at birth <32 weeks |          |             |                           |                                            |
|             |      |           |                                  |                               |               |        | 9.7%                   |                                              |          |             |                           |                                            |

Table 3. Cont.
| Article Ref & Code | Year | Geography | Design Description | Aims | Ages | Gender | Ethnicity | BPS Need | Relation | Age (Years) | Ethnicity | Family Demographics | Other Family |
|-------------------|------|-----------|--------------------|------|------|--------|-----------|----------|----------|------------|-----------|---------------------|-------------|
| [64] dsA29        | 2017 | Australia | Mixed methods single-case experimental design. | 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 2%, Asian/Indian 3% | Hearing loss | | |
| [69] dsA34        | 2014 | Germany | Controlled pretest-posttest 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% | Caucasian 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 parents/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 Code | Year | Geography | Design | Aims | Ages | Gender | Ethnicity | BPS Need | Relation | Age (Years) | Ethnicity | Family Structure | Other Family |
|--------------|------|-----------|--------|------|------|--------|-----------|----------|----------|-------------|-----------|------------------|-------------|
| dsA40        | 2015 | USA       | Block comparison design | Effectiveness | 7–11 years | M 68% | Latino 53%, Black/African American 30% | Disruptive behaviour disorders | Single parent | Siblings |
| 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 |
| 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 ($n = 13$, 31.3%), 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.
| Ref and Code | Origin | Recruitment | Preparation | Implemented by | Delivery Method | Primary Location | Secondary Location | Weeks | Days | Sessions | Mins | Min Range | Frequency |
|-------------|--------|-------------|-------------|----------------|----------------|------------------|-------------------|-------|------|----------|------|------------|-----------|
| dsA1        | Existing model | Word of mouth/Flier | Physical therapist | Facilitator to family | Hospital | 6 | 40 | Weekly |
| dsA2        | Existing model | Word of mouth | Occupational therapist | Combo: Facilitator to family and home prog. | Hospital | Home | 20 | 60 | Twice weekly |
| 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 |
| dsA4        | Adapted from existing | Health service | Child and Family Studies Associate Professor | Combo: facilitator to family and independent home programme | Home | | | |
| dsA5        | Original to study | Health service | Train facilitator | Paediatric Physical Therapists | Facilitator to family | Home | 60 | Twice weekly |
| 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 |
| dsA7        | Original to study | Health service | Paediatrician, family counsellor, dietician, physical therapist, exercise specialist | Facilitator to family | Hospital clinic | Home (instruction) | 52 | | Biweekly |
| dsA8        | Original to study | Health service | Occupational Therapist | Comber: Facilitator to family and Written material | Home | 4 | 60 | Weekly |
| dsA9        | Original to study | Health service | Train facilitator | Paediatric physical therapists | Facilitator to family | Home | 60 | | Twice weekly |
| 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 |
| 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.

| Ref and Code | Origin | Recruitment | Preparation | Implemented by | Delivery Method | Primary Location | Secondary Location | Weeks | Days | Sessions | Mins | Min Range | Frequency |
|--------------|--------|-------------|-------------|----------------|----------------|------------------|--------------------|-------|------|----------|------|----------|-----------|
| dsA12        | Existing model | Ad/Flier | Train facilitator | Physical Therapists | Facilitator to family | Home or Clinic | 6 | 40 | Weekly |
| 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 |
| dsA14        | Adapted from original | Health service | Train facilitator | Psychology Research staff, parent consultant | Facilitator to family | Home |
| dsA15        | Theoretical framework | Health service | Train facilitator/make resources | School Mental Health clinicians | Facilitator to family and Written material | School clinic | Home | 6 |
| dsA16        | Original to study | Health service | Train facilitator | Paediatric physiotherapists | Facilitator to family | Home | 52 | Aim weekly (actually 3 × month) |
| dsA17        | Existing model | Health service | Train facilitator | Childcare and educationteacher, speech therapist, occupational therapist | Group | Home visits | 12 | 5 | 60-90 | Every other week, once in last month |
| dsA18        | Theoretical + Model | Health service | Train facilitator | 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 |
| 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 |
| dsA20        | Existing model | Health prof/flier | Train facilitator and parent/s | Occupational therapist | Facilitator to family and DVD Resources | Home | 10 | Variable |
| 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.

| Ref and Code | Origin | Recruitment | Preparation | Implemented by | Delivery Method | Primary Location | Secondary Location | Temporal Features of Family-Centred Care Interventions |
|--------------|--------|-------------|-------------|----------------|----------------|------------------|------------------|---------------------------------------------------------|
| dsA22        | Original to study | Health service | Train facilitator | Psychologist | Combo: Facilitator to family and resources | Home | Community | 52 | Fortnightly |
| dsA23        | Theoretical framework | Not described | Create resources | Speech Language Therapists | Combo: Group and Facilitator to family | Clinic | Home (consolidation) | 9 | 45 | Weekly |
| dsA24        | Adapted from existing | Ad/flier | Paediatric physiotherapist | | Combo: Written material and Independent home programme | Home | | 12 |
| 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 |
| 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 |
| 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 |
| dsA28        | Existing model | Health service | Nursing staff, child neurologist, neonatologist, paediatric physiotherapist | | Combo: Facilitator to family and independent home programme | NICU | Home |
| dsA29        | Existing model | Health service | Train facilitator | Registered Psychologist | Combo: Facilitator to family and written material | Home | | 27 | | weekly, fortnightly |
| 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 |
| dsA31        | Existing model | Health service | Create resources | Child neurologists, paediatric physical therapists | Independent home programme | Home | | 4 | 30–45 | Daily |
| dsA32        | Adapted from existing | Health service | Rehabilitative staff | | Independent home programme | Home | | 4 | 30–45 | Daily |
| 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.

| Ref 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 (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 (assignments) | 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, dietitian, 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 |
| Article Ref and Code | Outcome Measures |
|---------------------|-------------------|
| [62] A27 | Adolescent Suicide Questionnaire—Revised (ASQ-R)  
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 | 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) |
| Article Ref and Code | Outcome Measures |
|---------------------|------------------|
| [76] A41            | Pubertal Development Scale |
| [77] A42            | 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 measurements 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](image-url)
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.](image)

### 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%) [36,39,47,49,51,53,60,72] 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%) [38,40,45,46,57,68,70,71], 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
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 ($n = 17, 40.5\%$) \cite{42,44,46,48,53,54,55,57,58,60,63,64,66–68,71,72}. Processes of feedback, evaluation and/or reflections were used ($n = 10, 23.8\%$) \cite{36,39,46,48,53,56,58,63,69,73,75,77} 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.](Image)
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...
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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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