



Developing Collaborative Relationships between Professionals and Parents of Children with Neurodisability: A Meta-Narrative Review

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Abstract

Purpose of Review Parents of children with complex neurodisabilities have multiple encounters with healthcare and disability professionals. Many parents view these encounters as unsatisfactory, citing a failure of professionals to listen to their perspectives. This meta-narrative review provides a novel synthesis of the research traditions examining parent-professional collaboration. This re-evaluation of collaborative relationships is timely given current dialogues within children's services in response to evolving understandings of disability and neurodiversity.

Recent Findings Seven research traditions are described with roots in: social justice, social ecology and sociology, community psychology, adolescent psychiatry, special education, cultural anthropology, and critical disability studies.

Summary This review highlights several 'mixed messages' arising between policies and experiences which can create discord between parents and professionals; along with institutional contexts which prohibit relationship building. Flexible and responsive services are challenging to deliver yet co-developed interventions which value parents' knowledge and skills are an important driver for institutional and policy change.

Keywords Collaboration · Parent-professional relationships · Neurodisability · Family-centred · Child-rehabilitation

Introduction

In this meta-narrative review [1, 2], we explore collaboration between healthcare and disability professionals and parents of children with neurodisability. The term 'parent' is used throughout this review to refer to a child's primary family

caregivers or paid carers fulfilling the parent role. The term neurodisability "describes a group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations....The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion, and behaviour" [3, p.1103]. Our review focuses on children with neurodisability described as having complex medical needs or chronic care needs [4, 5]; numbers of whom are rising due to medical advances in the survival of vulnerable infants as well as improved diagnosis [5]. These children are typically under the care of multiple healthcare professionals. In addition, children with neurodisabilities are reliant on a range of supports provided by family members [6]. Parents are responsible for embedding therapeutic interventions in their child's 'real world' through structured practice or generalisation to natural activities.

In defining and delivering such interventions, the relationship between parents and professionals relies on *collaboration*; a concept which remains poorly defined [7]. Definitions typically encompass two distinct aspects: *relational practices* such as active listening and the development of rapport, and *participatory practices* such as

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agreeing goals, planning therapy, and obtaining resources and supports [8–10]. In this paper, our working definition of collaboration is the process whereby parents and professionals work together with a common aim; and which requires the development of a therapeutic relationship and partnership where power, responsibility, and decision making are shared based on knowledge and expertise [11].

Current dialogues within and about children's services are driven by greater understandings of disability/difference and neurodiversity, initiated by disability advocacy movements and critical disability scholarship [12, 13]. Many disability services are currently experiencing what could be described as an 'identity crisis' as they navigate these growing debates about ableism viewed to be inherent in practice [14, 15]. Such evolving attitudes and beliefs have an impact on parent-professional relationships which has yet to be explored in the literature. Recent reviews are limited in scope when examining the complexity of parent-professional relationships in healthcare and disability services [6, 16, 17].

In this review, we adopted meta-narrative review methodology drawing on Kuhn's writings [18, 19]. Kuhn proposed that science advances not in a cumulative fashion, but via shifts in scientific paradigms. When a paradigm shifts, received wisdom is abandoned in favour of a new scientific explanation [19]. Paradigm shifts give rise to new research traditions. In the field of disability services and research, such a shift focused on the **neurodiversity paradigm** (credited to Walker, 2011) is currently being debated [20]. This review is, therefore, timely in addressing how collaboration with parents may be viewed in the light of changing attitudes

and roles. Our research questions are derived from meta-narrative review methodology (see Fig. 1) [1, 21].

In this review we aim to identify paradigms and research traditions and to examine how researchers working within each tradition, have approached the topic of collaboration in childhood neurodisability. Specifically, our research questions are:

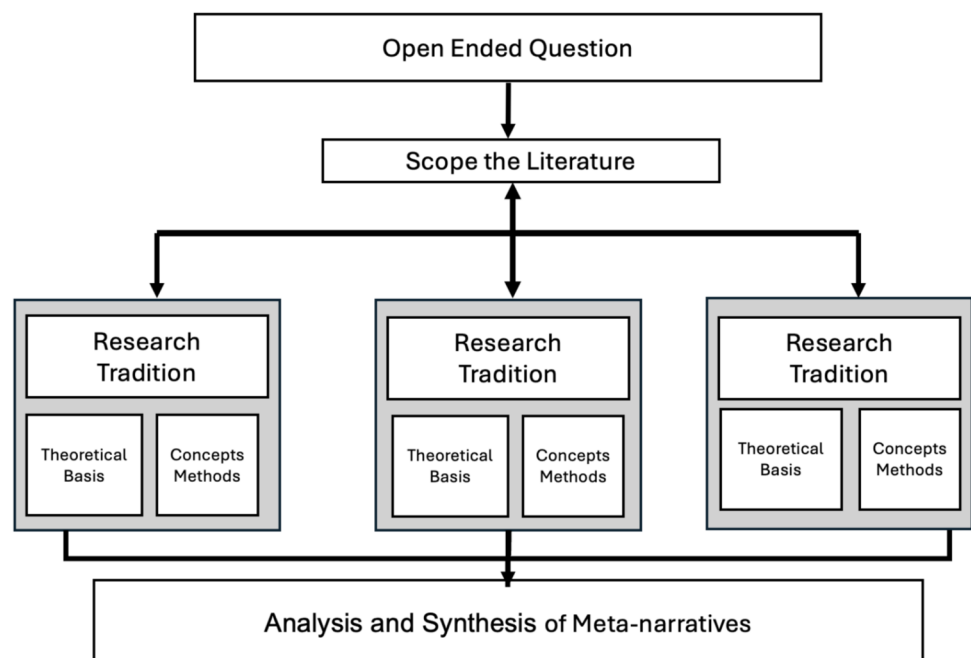
1. Which research traditions address the collaborative relationship between healthcare and disability professionals, and parents of children and adolescents with neurodisabilities?
2. How have researchers conceptualised collaborative relationships between professionals and parents in terms of their philosophical assumptions and the methodological traditions used to investigate them?
3. How have researchers within each tradition sought to identify or capture what constitutes a successful or unsuccessful relationship between healthcare and disability professionals and parents?

Methods

Guiding Principles of Meta-Narrative Review

Meta-narrative reviews are guided by six principles: pragmatism, pluralism, historicity, contestation, reflexivity, and peer review [2]. In accordance with the principle of pragmatism, the review has been shaped by considering how the included information will benefit the prospective audience

Fig. 1 Meta-narrative Methodology (Adapted with permission from Henry W. W. Potts and Trish Greenhalgh (unpublished))



of clinicians, families, researchers, and policy-makers. The authors have approached all traditions openly with the intention of learning from different insights, following the principle of pluralism.

To address historicity, narrative accounts have been written in chronological sequence detailing how the research evolved over time and how earlier work influenced subsequent enquiry or resulted in a change of research direction. We consider how evolving attitudes to disability/difference have impacted policy, attitudes, and experiences of parent-professional relationships [22]. Evolving attitudes at times lead to contestation between researchers in different traditions who hold diverse views about the nature of reality. In the case of our review, contestation is most clearly illustrated by differences between theory and the ‘real-life’ experiences of parents.

The first author’s positionality embraces insider–outsider perspectives as both the parent of an adult with complex support needs and practicing speech and language therapist. The first author therefore engaged constantly in the process of reflexivity to examine how personal beliefs and attitudes may have influenced responses to the material. The review team, comprising experts from various traditions, engaged in dialogic peer review of the first author’s interpretive decisions as the review progressed.

Review Stages

The protocol for this review was pre-registered on the PROSPERO database (CRD42022326880) on 5 th May 2022. This review protocol was based on training materials for meta-narrative review [2] and the RAMESES publication standards [1] which set out the information which should be reported when writing up a meta-narrative review. Meta-narrative reviews involve a process of sense-making from the literature and proceed in the following iterative phases:

i) Exploratory Scoping

Scoping searches identified articles eligible for inclusion, being those that include a focus on parents of children/adolescents (birth- 25 years) with neurodisability accessing health and disability services and professionals delivering these services. Included papers focused on aspects of the collaborative relationship. A key search term was ‘parent-professional relationship’. Exclusions occurred at two stages: title and abstract and full paper according to the following criteria: (i) not published in English; (ii) not including parents of a child/adolescent aged birth- 25 years with neurodisability and professionals working with these parents/children; (iii) not focused on how to improve relationships or how to work collaboratively; (iv) less than 50% of included children are reported as having neurodisability; (v) children are not in receipt of interventions focused on health and wellbeing; (vi) focused on adult health (mean age of

participants is > 25); (vii) focused on interprofessional collaborations not mainly on parents; (viii) focused on children as carers or child as decision maker; (ix) focused on adult peer supporters not professionals; (x) refers to ‘decision-making’, ‘ethical practice’ or ‘informed consent’ which does not involve mutual information sharing and arriving at a joint decision.

Reviews, commentaries, theory papers, and grey literature were considered for inclusion to ensure that parent-authored contributions were represented beyond the peer reviewed literature and to avoid publication bias. Hand bibliography searching identified further relevant articles. Stakeholder Involvement took place via a series of one-to-one discussions between the first author and disabled activists, families of disabled children, and professionals working in disability services. Stakeholders were asked to recommend relevant authors, for example, insights from disabled stakeholders led to inclusions from the disability studies literature.

ii) Identification of seminal sources

As each research tradition was defined, seminal sources were identified. These were defined as conceptual papers making a core contribution to the understanding of collaboration between parents and healthcare or disability professionals [2], and influencing future research traditions. Seminal sources were identified via scoping searches, citation tracking, and discussion with stakeholders familiar with the research area.

iii) Systematic snowball sampling

Key theories which underpin the seminal sources were identified via citation searching. A prospective snowballing approach, using the Web of Science Core Collection Citation Indexes and Google Scholar, was used to identify documents meeting the inclusion criteria which cited the seminal sources. Within each emerging tradition the historical roots, scope, theoretical basis, questions and research methods, key concepts, assumptions, and evolution over time were explored. Main contributors to the field were identified from citations [1].

iv) Data extraction

Data extraction included author, date, title, context: country and setting, type of article, population: (professionals, parents and child), research question/aims, methods, theoretical background, themes/concepts, main findings, and application. Papers were imported into MAXQDA, qualitative and mixed methods data analysis software [23], for storage, retrieval and analysis across the studies.

Retrieved Articles.

A total of 4,647 records were retrieved in the initial searches. Following exclusions, 688 papers were considered as part of the developing narratives as shown in the adapted PRISMA in Fig. 2.

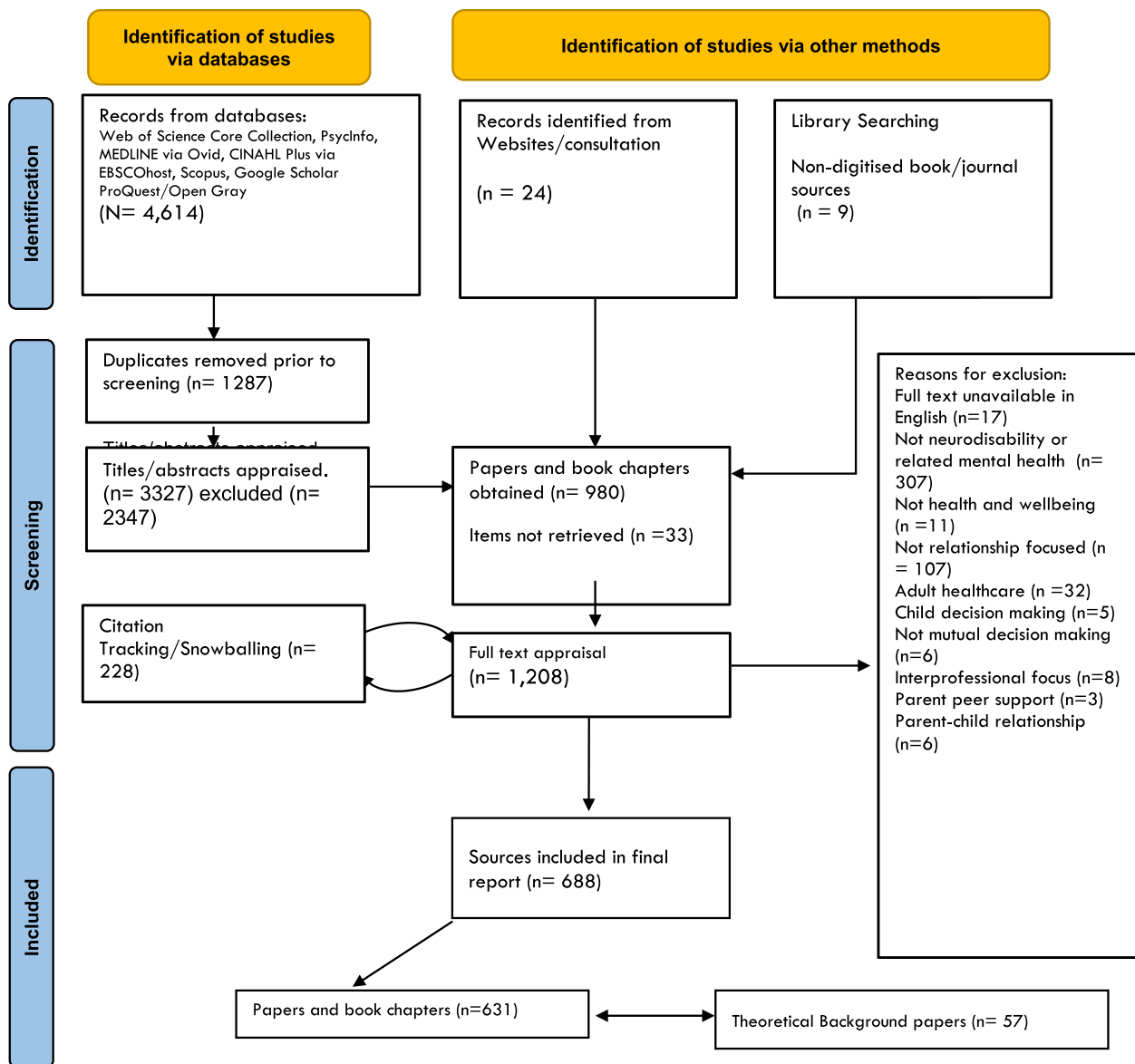


Fig. 2 PRISMA diagram adapted from Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting system-

atic reviews. *BMJ* 2021;372:n71. 10.1136/bmj.n71. For more information, visit: <http://www.prisma-statement.org/>

xxii) Analysis and Synthesis

A meta narrative review involves an interpretative decision-making process. Included articles were read, coded, and categorised into research traditions by the first author. A sense-making check was completed between the first author and TG. The paradigms and research tradition groupings were reviewed for coherence, then 10% of included papers (selected at random) were blind categorised into research traditions with an initial agreement rate of 60%. Following discussion to clarify theoretical domains, the rate of agreement rose to 89%. The first author made the final decision in cases of disagreement based on the ‘fit’ of the paper

within the relevant research tradition narrative. A decision was made not to apply strength of evidence criteria to the included articles due to the number of theoretical studies and parent narratives included.

Results

The 688 included papers reviewed were coded according to field or discipline these being: child rehabilitation (occupational therapy, physiotherapy and speech and language therapy) (n = 169), special education and early intervention

($n = 103$), child-health services (mixed or unspecified professions) ($n = 97$), mental health ($n = 75$), neonatal intensive care ($n = 41$), paediatric physicians ($n = 33$), nursing ($n = 30$), palliative care ($n = 20$), disability social policy ($n = 20$), parent authored ($n = 18$), social work ($n = 13$), hospital-based care ($n = 12$), and theoretical papers ($n = 57$).

Addressing the Research Questions

The results relating to the first two research questions are summarised in Table 1. Researchers within these traditions and the authors of the seminal papers were identified as having generated new thought about aspects of parent-professional relationships. The table lists the concepts identified from each seminal paper and within each research tradition. We acknowledge the majority of this research is derived from Western contexts and countries associated with an Anglo-centric worldview. The majority of authors were affiliated with institutions in the United States and only 48 articles originated from majority world countries.

Each research tradition is presented as a narrative account to answer the second and third research questions. Within each account, the seminal paper is described, and a brief chronology outlines the historical development and most recent research.

Parent narratives: Tales of Resistance and Resolution

This research tradition foregrounds the narrative discourses of parents with disabled children. Many of these parents were also professionals working in the sphere of childhood disability and embodied the challenges inherent in developing the collaborative relationships addressed by this review. These parent authors described the challenges to forming relationships in terms of parent-professional conflict and resolution, contextualised against the backdrop of individual, institutional, and societal power relationships. Power relationships in this context refer to decision-making authority, control of resources, and influence over people and supports [24]; which have traditionally been part of the professional role.

Turnbull's 1980 s collection of essays, authored by parent-professionals and entitled "Parents speak out: Then and now" [25], is a seminal work having influenced a subsequent body of research examining family quality of life including parental roles, and advocacy [26, 27]. The parent-professional discourses of disability reflected societal views and the attitudes reflected by the terminologies do not always sit comfortably with a modern audience, attuned to disability rights and empowerment. Even so, there are useful insights to be gained from these discourses; including Shultz's "the Parent-Professional Conflict". Shultz, both a teacher and parent, describes herself

as the "object of my own dissatisfaction" which captures the often-impossible positioning of the parent-professional in this *inoperable* relationship [25, p.3].

Parents' relationships with children's services begin before and at the start of their child's diagnostic journey. The impact of this experience will likely develop the context for subsequent relationships with professionals [28, 29]. Parents have been described as either assuming or being compelled into multiple roles towards their disabled child and when responding to disability services [26, 30], being: (a) the source of their child's problems, (b) recipients of professionals' decisions, (c) family members, (d) consumers, (e) learners and teachers, (f) organisation members, (g) political advocates, (h) educational decision-makers, and (i) service developers.

Political advocacy, service development, and membership of parent organisations can be forms of parent activism [26], a term which reflects the motivation of parents to bring about change in the policies and systems which control access to community participation for their children. The parent movement, arising in the early 1970 s and continuing to the 2000's [31], specifically in the United States and other Western nations, acting through a network of organisations, has promoted the rights of people with disabilities, ascribed value to disabled people, and promoted inclusion in community life [26]. These activities preceded the rise in disability rights groups organised and run by disabled activists and can be seen as resistance to the 'professional appropriation of parenthood' a social phenomenon occurring throughout the 20 th Century [26]. Parent organisations empower parents with the skills and knowledge to advocate both for their individual child and to challenge broader systems and professional practices.

The prevailing medical model at the time equated disability with impairments of the physical body. The functionalist paradigm in which the medical model of disability is situated views disability as inherently pathological with a focus on assessment, diagnosis, and treatment [32]. By contrast, the structural paradigm, in which the social model of disability is often situated, focuses on the oppositional structures producing inequalities and social injustice, and leading to disablement [33, 34]. The spaces between subjectivity and objectivity—often associated with the post-modernist paradigm—represents a deconstructing of the subjective/objective and disability/impairment binaries to simultaneously examine both the physical body and symbolic meanings of disability [35]. Gabel asserted that there is a growing conceptual acknowledgement of resistance theory across these medical/social paradigms. As disability advocates, many parents have navigated this tension. Resistance and self-advocacy allow for more complex interpretations of disability/impairment than either the medical or social models provide and are

Table 1 Research Traditions developed from seminal papers

Seminal papers	Historical Roots Discipline	Concepts from seminal paper	Concepts added through citation mapping	Final paradigm selection (total number of papers)	Justification
Turnbull & Turnbull, (1985) <i>Parents Speak Out: Then and Now-series of essays from parent-professionals</i>	Resistance & resolution narratives Special education Drawing on medical ethics Parent authored discourses	Targeting specific services Monitoring values of programs and staff Minimizing system-induced crisis Identifying the 'enemy' Misunderstanding/maltreatment	Identities, lobbying, advocacy Pathologizing and validating, mediation, negotiating	Parents' narratives: tales of resistance (32)	The study of disability through the narratives of parent-professionals. Social model of disability toward resistance theories of disability Interpersonal, organisational and community factors
Seligman & Darling., (1989) <i>Ordinary Families. Special Children</i>	Bronfenbrenner Bowen General Systems Theories	Systems-based therapeutic modalities Social-ecology models Family structure/interaction/functions Family life cycle	Mutual interdependence Psychosocial factors Embodiment	Systems of influence on parent-professional collaboration (19)	The study of the social ecology of family relationships and the impact on supports for disabled children Interpersonal, organisational and community factors
Dunst, & Paget., (1991) <i>Parent-professional partnerships and family empowerment</i>	Rappaport (1981, 84, 87) definitions of empowerment Community psychology Sociology	Empowering Help giving Collaboration Equal partnerships Enablement Informed decisions Proactive stance Strengths based Family-centred	Quality of life Power Knowledge Normalisation Mutuality Agency Social support Family paradigms Relational autonomy Social capital	Empowerment through partnership-the parent paradox (94)	The study of addressing and restructuring hierarchies within the parent-professional relationship focusing on empowerment and partnerships Interpersonal relationships Reference to organisational and societal levels
Colson., (1991). Perceived Treatment Difficulty and Therapeutic Alliance on an Adolescent Psychiatric Hospital	Freud Rogers Psychotherapy Psychology	Therapeutic Alliance Guardedness Conflict Disengagement	Guilt Shame Trust Personality Learned Helplessness Self-concept Stress and coping Hope and realism Sense of coherence	Parent-therapist alliance (96)	The study of therapeutic alliance as applied to the parent-therapist relationship and the influence on child therapy outcomes Parent and therapist factors-individual and interpersonal
Baird, S. & Peterson, J. (1997) <i>Seeking a comfortable fit between family centred philosophy and infant-parent interaction in early intervention: Time for a paradigm shift?</i>	Rosenberg Mahoney Nugent Klein Turnbull Special Education Relationship-based Cross-cultural studies	Relationship -based Family vision Interaction Value basis Respect for beliefs and culture	Parent coaching Health behaviour change Self-efficacy	Relationship-focused interventions (31)	The study of approaches and interventions which target modifications in parent-child interaction in the context of the therapist -parent relationship Individual and interpersonal

Table 1 (continued)

Seminal papers	Historical Roots Discipline	Concepts from seminal paper	Concepts added through citation mapping	Final paradigm selection (total number of papers)	Justification
Rosenbaum, King, Law, King, Evans., (1998) <i>Family-Centred Service: A Conceptual Framework and Research Review</i>	Burlingham Freud Bowlby Robertson Rogers Special education Rehabilitation	Parent decision making Collaborative relationships Accessible Services Consideration of psychosocial needs Strengths based Individualised services Accepting diversity	Care coordination Goal setting Shared decision making Cultural competence	Family-centred or service-centred (336)	The study of collaborative models of service delivery Interpersonal, institutional and organisational factors
Goodley & Runswick-Cole., (2011). <i>Problematising policy: conceptions of “child”, “disabled” and “parents” in social policy in England</i>	EDCM (Every Disabled Child Matters), 2007 HM Treasury and DfES, 2007. Aiming high for disabled children: Better support for families Social policy Critical disability studies	Policy Transformation Disadvantage Government responsibility Legislation Normative narratives of child development Conceptualisation of disability The mother as the key agent of social and developmental change	Procedural infrastructures Organisational theory Resource sharing Paternalism Collaboration with families/obstacles/bridge building Grass Roots Integration	Social Policy- the professional dilemma (23)	The study of the influence of social policy on conceptions of parents and therapists/ impact on relationships Socio-political structures Public policy community and organisational factors

proposed in recent literature to offer a way forward for both disabled people and their families [29, 32].

Systems of Influence on Parent-Professional Collaboration

This narrative describes the influence of ‘systems-thinking’ on parent-professional collaboration within healthcare and disability services. Starting from the 1970 s, and in response to the development of General Systems Theory [36] there was an evolution in scientific thinking from traditional linear paradigms of cause and effect, towards the conceptualisation of circular, interdependent models of complex systems. When applied to health and disability services, systems theory challenges the validity of ‘treating’ the disabled child in isolation, instead acknowledging the role of the family and wider environmental influences. In psychology, this was illustrated by a move from the psychoanalytic view of the individual as patient, suffering from a pathology, towards the humanistic view of families as interdependent [37, 38]. System’s theories are the paradigm underlying family therapy [39].

A seminal work within this research tradition is Seligman and Darling’s book, *Ordinary Families Special Children* [40]. Their influential ideas, drawing on the philosophy of systems theories, presented the family as a complex and interactive system, in which each member interacts with every other in an interdependent way [40]. A subsequent research tradition developed with a focus on understanding and intervening in family systems. To understand any aspect of families, the relationship between the members needs to be explored, including the impact on the family of having a disabled child. Within each family, a series of subsystems—named as “spouse” (or partner), “parents” and “siblings”, and extended family relations—interact. Families vary in the way in which boundaries between subsystems interact and degrees of cohesion, adaptability, stress, and resilience. Coping styles may include internal strategies (e.g., passive appraisal and reframing) and external strategies (e.g., the use of social or spiritual support and formal professional delivered supports and resources) [40]. According to Tomlinson et al. [41], stress in the family system decreases the functioning of the whole family.

Orientation to systems theories as a model for intervention with families of disabled children has continued over subsequent decades. Bronfenbrenner’s Ecological Systems Theory represents an integration of the biological, psychological, and social sciences in a holistic explanation of human development [42, 43]. Bowen’s Family Systems Theory [44], and the body of work by Turnbull and Rutherford explore systems approaches to communication within families and parent-professional partnerships [30, 45, 46].

Prior to an understanding of family systems, the disabled child had been the sole or main focus of research and

intervention, followed by a later focus on mother–child relationships, especially the concept of bonding [47]. In contrast, the social ecological model located the family in the wider social, economic, and political systems which influence its functioning [43]. Within the social-ecological paradigm, the parent-professional encounter is viewed from a sociological perspective as an interaction situation [40].

Recent work in communication science includes the integration of several theoretical models: family systems theory, ecological systems theory, family paradigms, and the self-created genogram [48, 49] as frameworks to guide family-centred practice and promote family resilience [50]. For children with medical complexity, the interplay of multiple healthcare needs and providers, coupled with socio-demographic factors, can lead to a poorer experience for families [5]. When the child and family are the sole focus of intervention social-system influences can be overlooked. Thus, complex interventions which strengthen all levels of family functioning are required to strengthen resilience [50] and improve collaboration.

Empowered through Partnership: The Parent Paradox

Research categorised within this tradition addresses and restructures hierarchies within the parent-professional relationship. The partnership paradigm developed from the underlying philosophy of proactive empowerment through partnerships, drawing upon Rappaport’s work in community psychology [51, 52].

In Rappaport’s work [51, 52], empowerment is conceptualised as both the process and outcome that enables marginalised people to gain control and autonomy over their lives. Application of this work to the parent-professional relationship sees an empowered parent being able to fully participate in partnership with professionals involved in their child’s care [53]. The focus is on the agency of the parent, and the professional role in promoting this agency. Subsequently, Dunst and Paget’s [54] seminal conceptual work provided a definition and operationalised the characteristics of partnerships between professionals and parents of disabled children. These ideas were influential in the development of later research exploring partnerships as an aspect of parent-professional collaboration [53, 55]. Fundamental elements of partnership include presuming competence in parents’ existing strengths and capabilities, whilst providing enabling ‘help-giving’ experiences for family ‘help-receivers’ to develop new competences. Help-giving by professionals, and ‘help-seeking’ or ‘receiving’ by parents, should result in increasing parents’ control over their lives and reducing dependency [56]. These enabling experiences are said to foster parental empowerment or a sense of control and self-efficacy. The professional role is conceptualised as providing experiences that will lead to parental empowerment.

Research exploring the experiences of parents identifies a situational paradox, which some scholars argue arises from parenting a disabled child in a largely ableist society. This work draws on Foucaultian [29] and Bourdiesian [57] theories to explore how parents navigate power and knowledge relations in the context of their child's perceived 'deviance or normality'. The discourses of parents, mainly documented by and with mothers, indicate that they navigate between a position of adaptation and resistance or appeasement in the face of professionals' descriptions of their child's dis/ability. Parents will actively negotiate adhering to medical definitions of 'normativeness' at the same time as advocating for their children's positive social worth as a disabled child [57]. In this way, parents navigate the paradoxical situation of both 'complying with' and 'adapting to' disability services, whilst also 'negotiating' and 'resisting' [29], as they develop positive models of disability whilst striving to maintain their partnerships with professionals.

Empowerment can be viewed across individual, group, organisational, and community levels of analysis. The body of work from Dunst et al. [54] and works since [53, 55] promoted a shift away from paternalistic practices with parents of disabled children through enacting major policy changes at societal level, as well as individual strategies to enable practitioners to work in a help-giving-partnership way. However, the existence of 'artificial' bureaucracies in institutions gives rise to what Foucault described as 'buried and disqualified' knowledge, an undervaluing of the knowledge which parents bring [58]. As this body of literature developed, increasing ambiguity of related terms such as empowerment, engagement, enablement, participation, and involvement was described [59]. For example, empowerment can be conceptualised as resulting from both enablement (acquisition of abilities), and engagement (increasing motivation) [59]. This linguistic dispersal could serve to fragment and confuse the literature, potentially inhibiting its use.

Parent-Therapist Alliance

In this research tradition the therapeutic alliance between parents and therapists is foundational to collaborative engagement in children's therapy. The concept of therapeutic alliance incorporates the affective aspects of relationships, feelings, and emotions. Its' origins can be related to the early 20th Century in Freud's psychoanalytical concepts of transference and countertransference [60], reflecting the emotional reactions of the client and therapist towards each other. Affective micro-level interpersonal interactions (e.g., empathic resonance and mutual affirmation) are regarded as key determinants of positive outcomes in therapy [61]. Emotional reactions may relate to other significant relationships and can have either a positive or negative effect on the outcomes of therapy. In the case of parents, relationships

developed with previous health professionals may influence the alliance with later ones. Rogers [37], in working with 'personality' described the essence of the optimal therapeutic environment being when the therapist demonstrates acceptance, warmth, and unconditional positive regard. This empathy allows the client to feel validated leading to improved outcomes of the therapy.

Colson and collaborators [62] examined family issues as contributors to treatment difficulties in adolescent mental health care. This seminal work, informed a research tradition exploring how therapist-parent alliance influences child-therapy outcomes [63, 64]. Family involvement factors such as guardedness, conflict, and disengagement were examined for their contribution to the adolescent's behaviour in treatment [62]. In this tradition, family dynamics are framed as contributing to the adolescent's treatment difficulty, although potential mediating factors are not explored; it is possible that a climate of judgement by professionals may have accounted for families' disengagement with their young person's treatment.

Subsequently, the alliance between parents and their child's therapist became a topic of study, acknowledging that parent participation is crucial to the outcomes of child therapy. Karver proposed a theoretical model of common process factors (relationship variables) in parent-therapist alliance [64]. Karver's model of process factors included parental characteristics such as stress, mental health issues, and expectations of therapy as impacting parental engagement. Despite increased research effort parent-therapist alliance, in relation to both therapist personal factors [65] and parent engagement in therapy is still under-researched and not well understood. Parent-therapist alliance measures vary in the dimensions being assessed and methodological flaws in research, such as reliance on self-report questionnaires, lead to difficulties in measuring the effects of parent and therapist factors on children's outcomes [66].

In addition to work examining the effect of parents on the outcomes of their child's therapy, a separate but aligned body of work has examined the psychological impact of the child's medical or emotional needs on their parents. In contrast to the practice discussed above, in which family dynamics were related to the child's emotional disorder with the risk of apportioning blame, it is acknowledged that creating an empathetic environment, in which to foster positive working relationships, requires professionals not to view parents as the cause of their child's disability or associated difficulties [67].

Relationship-Focused Interventions

This research tradition arises from a conceptual paper by Baird and Peterson [68] discussing tensions between family-centred philosophy and interventions aimed at

modifying aspects of parent–child interaction. Baird and Peterson’s paper [68] informed a subsequent body of research examining relationship-focused approaches. This concerned both parent–professional collaboration and parent–child interaction in early intervention for disabled children or vulnerable infants [69]. Proponents of family-centred philosophy regard the family as the expert and ultimate decision maker for their child, whilst respecting differences in parents’ beliefs, values, and coping styles [70]. Parent–child interaction therapy involves an evaluation and assessment process aimed at helping parents to modify their behaviours when interacting with their children [68]. Both family-centred philosophy and parent–child interaction approaches have their roots in attachment theory [71, 72] and the latter also draws on social learning theory [73, 74]; which proposes that young children’s learning takes place in the social context of secure, attached relationships with caregivers. Both of these approaches require effective collaborative relationships between parents and professionals.

Baird and Peterson’s paper was written when early intervention practice was shifting away from directive, child-focused teaching towards both family-centred and parent–child interaction therapy practices. Their paper summarises the evidence for the impact of various infant-caregiver interaction variables and encompasses a mix of causal and correlational studies. A more recent summary can be found in Topping et al. [75]. Interventions which focus on improving the interaction between parents and young children have the potential to change children’s outcomes in terms of social, emotional, cognitive, and communicative development [75, 76].

Parent–child interaction therapies may require professionals to make subjective judgements about the interaction behaviour of parents and children which can be at odds with respect for the families’ values, beliefs, and practices [68]. This may negatively impact the collaborative relationship [68, 76]. Parent–child interaction therapies can be viewed as problematic and running counter to the tenets of family-centred philosophy [58]. There are valid concerns about professionals making value-based judgements about parents in relation to their parenting [63]. A second concern, in the light of evolving understandings about neurodiversity, is the selection of desired child outcomes which follow a normative, neurotypical bias (e.g., focusing on social engagement, sitting still). Making any assessment of parent–child interaction necessitates a judgement of that interaction against a set of values derived by professionals. Should those values not align with the family’s own, such judgements and associated goal selection could conflict with the tenet of family empowerment and decision making [68]. Ethical issues may also arise from the professional’s primary responsibility to the child, should some culturally variable interaction patterns

(e.g., authoritarian parenting) be considered detrimental to child development [76].

According to Mahoney et al. [77], some practitioners believe that parent–child interaction therapy constitutes an ethical dilemma at odds with respect for differences in family interaction practices. It is thought that the challenge to the integration of family-centred and parent–child interaction approaches arises in part from work in cross-cultural studies [78]. Cross-cultural work challenges the validity of assumptions about child development such as ‘normality’ and ‘risk’, described as ‘cultural constructs’. This research suggests that assumptions arise from unconscious ethnocentrism, which may be reinforced by the assessment tools used to evaluate parent–child interaction and in the goals promoted by professionals [78]. In subsequent research, Baird and Peterson were labelled as both critics of family-centred practice, on the grounds that it ‘leaves out the child’ and ‘fails to target child learning and development’ [79], and as advocates of family-centred practice ‘in early intervention and paediatric rehabilitation’ [80, 81]. In fact, Baird and Peterson were calling for a paradigm shift to achieve a culturally responsive integration of these two approaches [68].

Emerging within this research tradition examining relationship-based interventions is research discussing the application of coaching strategies within child rehabilitation, such as those borrowed from business and sports traditions [82]. Parent coaching is seen as a method to achieve family centred services and facilitate parent-mediated interventions. Whilst parent–child interaction therapies and parent coaching have similarities, there is an important distinction in the identification of the goals for therapy. In parent–child interaction therapy, the goals are derived from research evidence relating to infant–parent interaction variables [75]. In a coaching model, coaches work together with parents to go beyond the identification of common goals to identify goals primarily articulated by the parent [82].

Methods and definitions of coaching differ, according to Schwellnus et al. and Kemp et al. along a continuum from ‘parent training’ to ‘parent coaching’ [82, 83]. Coaching is a collaborative reciprocal process involving cycles of action or practice, self-reflection, and self-correction [84]. Coaching includes the idea of an equal parent–professional partnership and shared decision making [84]. For healthcare professionals to move away from professional-led practice towards the use of coaching requires changes in professional behaviour and a need for role negotiation with parents as a pre-cursor to coaching [70]. Coaching strategies have gained popularity in, for example, paediatric physiotherapy practice, but interventions may lack a clear theoretical basis and therapists require additional training to apply the strategies [85]. Likewise, it may be challenging for parents to take an equal role in decision making, planning, action, and reflection; but meeting that challenge and striving for parity in

decisions can lead to positive outcomes for parents including increased confidence, self-efficacy, and parenting capacity [81, 86]. Services centering the relationships between parent-professional and parent-child, and operating on a solution-focused and strengths-based approach, require professionals to engage in reflective examination of their own cultural biases and to act in ways which are congruent with the families' culture, beliefs and values [87].

Family-Centred or Service-Centred

The focus of this research tradition is collaborative models of service delivery as summed up by the philosophy of 'Family Centred Care'. Whilst derivative of the parent empowerment and systems paradigms above, there is an extensive research tradition regarding family-centred care incorporating the concepts of partnership, engagement, dignity and respect, shared decision making, and collaborative goal setting [88]. Family-centred philosophy has its early roots in nursing practice with hospitalised children. In post second world war London, evidence from Burlingham and Freud indicated that children maintained their psychological stability if they remained with their mothers [89].

Two major voices in this debate were Bowlby, a child psychiatrist, and Robertson, a social worker [90]. Bowlby was the theorist who propounded the negative impacts of breaking the emotional ties between mother and child at an early age [91]. Coupled with the work of Rogers [37], these theories led to a paradigm shift in paediatric healthcare. Drawing on these earlier theories, seminal work by Rosenbaum and colleagues [92] along with Dunst and collaborators [93] and King and collaborators [80] developed the theory and practice around family-centred care in early intervention and paediatric rehabilitation.

Family centred philosophy positions the family unit as the recipient of services and parents as expert and ultimate decision maker for their child. Family-centred care recognises the family as constant in the child's life with autonomy to decide their level of participation, priorities, and goals [93]. Such services should be delivered in a collaborative, trusting relationship with respect for families' cultural identities, beliefs, values, and styles of coping. Family-centred care is the mandated method of service delivery in the USA and has influenced health and social policy in the UK and Australia.

Four paradigm shifts, as recommended by Dunst et al. [94], are needed for services to become family-centred, being shifts away from (a) intervention practices based solely on professional identified needs towards responsive practice, (b) intervention practices focusing primarily on correcting child and family deficits towards strength-based practice, (c) defining solutions to child and family needs solely in terms of professional services, and (d) paternalistic, dependency forming help giving practices towards

empowering practices. Following 40 years of family-centred practice, questions remain as to whether family-centred services are deliverable or remain an unattainable ideal [72]. Specifically, the four paradigm shifts described above are a constant challenge for service delivery. Therapists working in child-focused services may still receive training which is largely focused on child development rather than client change processes or family outcomes [6]. Research has indicated highly significant differences between parents' actual roles in therapy and the ideal roles involving participation in decisions, assessment of their family's needs, and family centred services [95, 96] representing a gap between 'work as imagined' and 'work as done' in relation to service delivery for children and families.

Social Policy: The Professional Dilemma

This narrative explores the influence of social policy and legislation on parent-professional relationships. Social policy dictates the roles that parents and professionals are expected to fulfil in the provision of services to children with special educational and health needs. To illustrate this narrative, examples will be drawn from the United Kingdom context, which is familiar to the first author, although there are parallels with social policies in other Western democracies.

Goodley and Runswick-Cole's [97] work on 'developmentalism', conceptualised the 'child', 'disabled', and 'parents' in social policy in England and influenced scholarship within the growing field of Critical Disability Studies. Developmentalism arose from developmental psychology, drawing on the work of Piaget and Vygotsky, and has led to terminology and practice in both education and healthcare which is focused on 'normal' versus 'abnormal' child development [97]. Mothers are positioned as the means by which children's development is accelerated towards 'normal' developmental milestones. New Labour government policy between 1997–2007 outlined both parents' rights and responsibilities leading to a mixture of support and surveillance for parents of disabled children, by these parents having the most frequent and sustained contact with professionals [97].

Explorations of child developmental outcomes point to parental mental health, relationships, financial resources, and housing as key determinants suggesting that parents bear primary responsibility for children's physical, social/emotional, and cognitive development [98]. A critical discourse analysis of the UK's 2022 Special Educational Needs and Disability Governmental Review [99] gives a current view of the positioning of disabled children and families in UK policy. This discourse is framed by Hyatt's Critical Higher Education Policy Discourse Analysis (CHEPDA) framework [99]. The Review was conducted in the context of recognised system failures for disabled children, diminishing parental

and provider confidence, and escalating costs. The authors point to a concealment of pupil need and removal of ideas of inclusion achieved through nominalisation, potentially leading to the justification of reduced state funding for special educational needs and disability [99].

Hellawell [100] describes the paradoxical situation in which parents are led to believe they will have choice in the decision-making processes regarding their child's placements and service provision, whilst authorities have the right to overturn these decisions. Professionals are gatekeepers to the allocation of resources [101], and are therefore given finite resource and service availability; parents' wishes are often disregarded. Conversely, when things go wrong in children's lives, the implication from policy is that parents are wholly accountable [102]. This is a situation which threatens parent-professional partnerships and poses a dilemma for professionals who are empathetic to parents' challenges and wish to avoid conflicts arising from parental expectations [103]. Many parents will advocate for their own child's needs, expressing their individual preferences; whilst professionals often have a sense of distributive justice based on the needs of the population they serve in the light of available resources [100, 103]. This can lead to professionals experiencing a moral anxiety due to conflicting responsibilities and roles between 'benefits for all' versus 'best outcomes for the individual' [100]. Faced with these dilemmas, professionals may limit or divide their ethical and moral responsibility based on the role they are occupying at the time [98, 100].

Discussion

The need for parents and professionals to work collaboratively in the interests of the child with disability can be traced back to roots in the disability rights movements of the 1970 s and the social model of disability (credited to Oliver, 1983) which states that physical, societal, and attitudinal barriers disable people with impairments [33, 104]. In the five decades since, research traditions have evolved, raising awareness of the imperative for collaboration. However, divergent or potentially conflicting research traditions and policy frameworks have fragmented the concept of collaboration into multiple terms and approaches, all of which lack clear definition [59]. There is some agreement across research traditions that contributors to collaborative partnerships include honest communication, mutual commitment, parent empowerment, professional competency, equality, trust, and respect [55, 105]. Also, collaborative processes are often described as including mutually agreed goals, shared planning, shared implementation, shared responsibility, and shared evaluation [106]. However, the tensions and potential conflicts between divergent traditions and approaches, outlined in this review, show how parents and professionals

can be inhibited in behaving in these ways by societal and institutional contexts, even when they are motivated to do so.

The review has explored how aspects of both the internal and external environments, within which these relationships are centred, can lead to conflict and inhibit the development of productive collaborative partnerships. Important differences exist between individualism of choice and equality of provision [93] and these need to be resolved. In particular, there should be clarification of roles and expectations, in recognition that parent and professional role ambiguity is driven by cultural understandings of power in parent-professional relationships [98]. Dialogue and discussion about conceptualisations of children's disability should explore why consideration of both strengths and impairments can lead to conflict between parents and professionals [48].

The seven research traditions presented here represent the authors' decision-making process when categorising a diverse and disparate literature with the aim to produce informative insights regarding collaborative practice. Challenges with the review process included lack of clarity in the literature about the many concepts involved in parent-professional relationships, many papers lacking a theoretical background, limited operationalisation of constructs, and different understandings regarding similar concepts across disciplines. Nonetheless, this review highlights the need for further research examining the complexity of parent-professional relationships and how these interact with health and well-being interventions in local contexts and cultural values. It is important to identify how varying attitudes to disability and neurodivergence impact parent-professional attitudes towards the goals of intervention and how professional interactions can demonstrate cultural responsiveness in multicultural settings.

In conclusion, collaboration between parents and professionals is vital for both the process and outcomes of interventions for children with neurodisabilities. Such interventions need to be considered in the context of the complex systems within which parents, children, and professionals interact and, as such, need to be flexible and responsive. Models of service delivery for disabled children have attempted to move away from former paternalistic attitudes. However, these persist due to the nature of professional training, policy and organisational barriers and resource pressures.

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- o Investigates the relationships between two types of family-centred practices (relational and participatory) and parent involvement in early childhood intervention
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 - o A realist review which identifies key themes related to parental engagement strategies.
- Klatte IS, Ketelaar M, de Groot A, Bloemen M, Gerrits E. Collaboration: How does it work according to therapists and parents of young children? A systematic review. *Child: care, health & development*. 2023. <https://doi.org/10.1111/cch.13167>.
 - o Provides an overview of concrete strategies for therapists to use in their collaboration with parents of children with developmental disabilities.
- Coburn KL, Jung S, Ousley CL, Sowers DJ, Wendelken M, Wilkinson KM. Centering the family in their system: a framework to promote family-centered AAC services. *Augmentative and alternative communication*. 2021;37(4):229–40. <https://doi.org/10.1080/07434618.2021.1991471>.
 - o Proposes a framework for practitioners to effectively obtain and understand information about unique dynamics within families as part of service delivery
- Reeder J, Morris J. Becoming an empowered parent. How do parents successfully take up their role as a collaborative partner in their child's specialist care? *Journal of child health care: for professionals working with children in the hospital and community*. 2021;25(1):110–25. <https://dx.doi.org/https://doi.org/10.1177/1367493520910832>.
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 - o Critical discourse using the Critical Higher Education Policy Discourse Analysis (chepda) framework

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Declarations

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