

DOCUMENT SUMMARY This meta-narrative review analyzes seven distinct research traditions concerning the collaborative relationship between professionals and parents of children with neurodisability. It highlights the historical and systemic tensions between paternalistic, medical-model approaches and empowering, family-centered philosophies rooted in social justice and critical disability studies. The paper provides substantial evidence of the gap between policy ideals and lived experience, critiquing systems that devalue parental knowledge and enforce neurotypical norms, which directly supports Enliten's mission to challenge traditional paradigms.

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Why This Matters to Enliten

This paper is a foundational text for our work. It systematically breaks down the history of thought around neurodisability services, providing a rich, citable evidence base for our core arguments. It validates our stance against paternalistic, deficit-focused models by showing how they create conflict and fail families. The review's focus on "paradigm shifts," the "professional dilemma," and the critique of "normative" goals provides the academic and historical context for why the Enliten revolution is both necessary and timely. It directly contrasts the medical/functionalist paradigm with the social/structural paradigm, giving us powerful language and concepts to use in our whitepaper and marketing.

Critical Insights & Arguments for Our Work

- **The "Identity Crisis" in Services:** Disability services are in an "identity crisis" navigating debates about inherent ableism in their practices, which is the perfect opening for Enliten to present a new model.
- **Critique of Normative Bias:** Relationship-focused therapies are questioned for selecting child outcomes that follow a "normative, neurotypical bias (e.g., focusing on social engagement, sitting still)", and for using assessment tools that reinforce "unconscious ethnocentrism." This is a direct attack on standardized, normative approaches.
- **Systemic Failure:** There is a persistent gap between the "work as imagined" (family-centered policy) and "work as done" (professional-led, deficit-focused practice). Research shows "highly significant differences between parents' actual roles in therapy and the ideal roles."
- **The Parent Paradox:** Parents must simultaneously "complying with" and "adapting to" disability services, whilst also "negotiating" and "resisting" to get care while maintaining a positive disability identity for their child. This perfectly describes the struggle our clients face.

- **Professionals as Gatekeepers:** Social policy forces professionals into a "gatekeeper" role for allocating finite resources, creating a conflict between what's best for the individual and the needs of the population they serve. This explains why even well-meaning professionals can't provide the care families need within the current system.
- **Devalued Knowledge:** Institutions create "'buried and disqualified' knowledge, an undervaluing of the knowledge which parents bring", a core problem Enliten's solves by centering lived experience.

Quotes We Might Use

- **On Unsatisfactory Encounters:** "Many parents view these encounters as unsatisfactory, citing a failure of professionals to listen to their perspectives."
- **On the System's "Identity Crisis":** "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."
- **On Resisting Professional Dominance:** Parent activism can be seen as "resistance to the 'professional appropriation of parenthood' a social phenomenon occurring throughout the 20th Century."
- **On the Professional Dilemma:** Professionals may experience "a moral anxiety due to conflicting responsibilities and roles between 'benefits for all' versus 'best outcomes for the individual'."
- **On Neurotypical Bias:** "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)."
- **On the Unattainable Ideal:** "Following 40 years of family-centred practice, questions remain as to whether family-centred services are deliverable or remain an unattainable ideal."
- **On the Cause of Conflict:** "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."

Alternative Approaches Mentioned

- **Meta-Narrative Review:** The methodology itself is useful, as it traces the history and conflicts between different scientific paradigms rather than just aggregating data. This allows for a deeper critique of the system.
 - **Critical Disability Studies:** This tradition is explicitly named and used to critique policy and the construction of "normal" development.
 - **Systems Theory (Social-Ecological Model):** Challenges the validity of treating a child in isolation, acknowledging family and wider environmental influences. It moves from a pathology-focused view to a humanistic view of interdependent families.
 - **Community Psychology (Empowerment Model):** Focuses on empowerment as both a process and outcome that "enables marginalised people to gain control and autonomy over their lives." The professional's role is to *promote* the parent's agency.
 - **Parent Coaching:** Contrasted with "parent training," coaching is a "collaborative reciprocal process involving cycles of action or practice, self-reflection, and self-correction" where goals are "primarily articulated by the parent."
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Developing Collaborative Relationships between Professionals and Parents of Children with Neurodisability: A Meta-Narrative Review

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.

Introduction

In this meta-narrative review, 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" Our review focuses on children with neurodisability described as having complex medical needs or chronic care needs; numbers of whom are rising due to medical advances in the survival of vulnerable infants as well as improved diagnosis. 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. 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. Definitions typically encompass two distinct aspects: relational practices such as active listening and the development of rapport, and participatory practices such as agreeing goals, planning therapy, and obtaining resources and supports. 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.

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. 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. 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.

In this review, we adopted meta-narrative review methodology drawing on Kuhn's writings. 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. 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. 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.

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?

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).

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; which have traditionally been part of the professional role.

Turnbull's 1980s collection of essays, authored by parent-professionals and entitled "Parents speak out: Then and now", is a seminal work having influenced a subsequent body of research examining family quality of life including parental roles, and advocacy. 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.

Parents have been described as either assuming or being compelled into multiple roles towards their disabled child and when responding to disability services, 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, 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 1970s and continuing to the 2000's, 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. 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 20th Century.

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. 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. 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 proposed in recent literature to offer a way forward for both disabled people and their families.

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 1970s, and in response to the development of General Systems Theory 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.

A seminal work within this research tradition is Seligman and Darling's book, *Ordinary Families Special Children*. 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. A subsequent research tradition developed with a focus on understanding and intervening in family systems.

In contrast, the social ecological model located the family in the wider social, economic, and political systems which influence its functioning. Within the social-ecological paradigm, the parent-professional encounter is viewed from a sociological perspective as an interaction situation. 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 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. In Rappaport's work, 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. The focus is on the agency of the parent, and the professional role in promoting this agency.

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 Foucaudian and Bourdesian 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. In this way, parents navigate the paradoxical situation of both complying with' and 'adapting to' disability services, whilst also 'negotiating' and 'resisting', as they develop positive models of disability whilst striving to maintain their partnerships with professionals.

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. As this body of literature developed, increasing ambiguity of related terms such as empowerment, engagement, enablement, participation, and involvement was described.

Relationship-Focused Interventions

This research tradition arises from a conceptual paper by Baird and Peterson discussing tensions between family-centred philosophy and interventions aimed at modifying aspects of parent-child interaction. 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. Parent-child interaction therapy involves an evaluation and assessment process aimed at helping parents to modify their behaviours when interacting with their children.

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. This may negatively impact the collaborative relationship. Parent-child interaction therapies can be viewed as problematic and running counter to the tenets of family-centred philosophy. There are valid concerns about professionals making value-based judgements about parents in relation to their parenting. 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.

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.

Emerging within this research tradition examining relationship-based interventions is research discussing the application of coaching strategies. 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. Coaching is a collaborative reciprocal process involving cycles of action or practice, self-reflection, and self-correction. 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.

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'. Family-centred philosophy has its early roots in nursing practice with hospitalised children. Drawing on earlier theories, seminal work by Rosenbaum and colleagues along with Dunst and collaborators and King and collaborators 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. Such services should be delivered in a collaborative, trusting relationship with respect for families' cultural identities, beliefs, values, and styles of coping.

Four paradigm shifts, as recommended by Dunst et al., 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. 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 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.

Goodley and Runswick-Cole's 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. 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.

Hellawell 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, 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. 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. 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. 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'.

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. 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.

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. Also, collaborative processes are often described as including mutually agreed goals, shared planning, shared implementation, shared responsibility, and shared evaluation. 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 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. 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.

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.