Update to the NMCN CEN Literature Report focused on Early Years  
(April 2012)

Literature search with a focus on early years support for children with exceptional and complex healthcare needs.

Sources: Medline, Embase, Cinahl, PsycInfo, Cochrane Library, general Internet search

Limits: last 5 years, English language

Provided by Seona Hamilton, Knowledge Manager, Children & Young People's Services Managed Knowledge Network.

Suggested search terms (Dawn Moss): complex health care needs, early years support, parent support, parental expectations, diagnosis

Search strategy (Medline – other databases searched using similar terms)

1 ((complex or exceptional or multiple or several or profound) adj3 (health care need* or care need* or disab* or impair*)).mp.
2 Child, Preschool/
3 early years.ti,ab.
4 Infant/
5 (infant*1 or toddler* or child*).ti,ab,jw.
6 2 or 3 or 4 or 5
7 1 and 6
8 exp Parent/
9 ((parent* or mother* or father* or carer*) adj3 (support or help or advice or service* or expect* or hope*)).mp.
10 8 or 9
11 diagnosis.ti,ab.
12 7 and 10 and 11
22 (early adj3 (interven* or treat* or diagnos*)).mp.
23 7 and 22

The articles with a focus on autism were removed from this search.

This literature search will contain a selection of material gathered from a search of the evidence base, and is not intended to be comprehensive. Professional judgment should be exercised when appraising the material. The Library takes no responsibility for the wording, content and accuracy of the information supplied, which has been extracted in good faith from reputable sources. NHSGGC is not responsible for the content of external internet sites.
RESULTS


OBJECTIVES: To profile the national prevalence of more medically complex children with special health care needs (CSHCN) and the diversity of caregiver challenges that their families confront. DESIGN: Secondary analysis of the 2005-2006 National Survey of Children With Special Health Care Needs (unweighted n = 40 723). SETTING: United States-based population. PARTICIPANTS: National sample of CSHCN. MAIN EXPOSURE: More complex CSHCN were defined by incorporating components of child health and family need, including medical technology dependence and care by 2 or more subspecialists. MAIN OUTCOME MEASURES: Caregiver challenges were defined by family-reported care burden (including hours providing care coordination and home care), medical care use (on the basis of health care encounters in the last 12 months), and unmet needs (defined by 15 individual medical care needs and a single nonmedical service need). RESULTS: Among CSHCN, 3.2% (weighted n = 324 323) met criteria for more complex children, representing 0.4% of all children in the United States. Caregivers of more complex CSHCN reported a median of 2 (interquartile range, 1-6) hours per week on care coordination and 11 to 20 (interquartile range, 3->21) hours per week on direct home care. More than half (56.8%) reported financial problems, 54.1% reported that a family member stopped working because of the child's health, 48.8% reported at least 1 unmet medical service need, and 33.1% reported difficulty in accessing nonmedical services. CONCLUSIONS: Extraordinary and diverse needs are common among family caregivers of more complex CSHCN. Enhanced care coordination support, respite care, and direct home care may begin to address the substantial economic burden and the multiple unmet needs that many of these families face.


BACKGROUND: Fathers are increasingly providing substantial amounts of technical and nursing care to growing numbers of children with complex healthcare needs. This exploratory study reports some of the first in-depth evidence of fathers' experiences and presents a research agenda in this critically under-researched area. METHODS: We conducted in-depth qualitative interviews with 8 fathers who provided a substantial amount of complex technical and nursing care for their child at home. The aim was to describe their experiences of fathering, parenting and caring. Interviews were recorded, transcribed and analysed using Burnard's approach, which has commonalities with phenomenological and content analysis. RESULTS AND DISCUSSION: Fathers enjoyed their caring role and found it rewarding and at times stressful. They instituted structured regimes, which focused on the father/child/family. Performing intimate care posed specific challenges for which there is no guidance. Children's community nursing
was highly valued. Fathers generally rejected the need for specific father-focussed services, as such provision would induce guilt feelings. Fathers reported positive relationships with their children and partners. CONCLUSIONS: Key areas for future exploration include gaining a better understanding of fathers' motivations and styles of caring, developing interventions to support fathers' caring role, developing guidance on intimate care, and delivering tailored services to fathers in a family context. There is little understanding of fathering and caring by non-resident, teenage and step-fathers. Finally, knowing more about resilience and coping of fathers in strong relationships with partners and children may help inform interventions to support fathers who do not feel able to stay with their family.


BACKGROUND: Families of children who have disabilities experience multiple stressors. "Sense of coherence" (SOC) reflects a person's view of life and his or her capacity to respond to stressful situations. PURPOSE: The purposes of this paper are to (1) introduce the concept of SOC; (2) review the literature on the stresses experienced by parents of children with disabilities; and (3) discuss how SOC can be used to evaluate systematically and to address effectively parents' resiliency against stressors. KEY ISSUES: The literature shows a strong correlation between parental stress, avoidant coping, depression, and low SOC. Preliminary evidence suggests that an early intervention program can help increase parents' SOC. IMPLICATIONS: Occupational therapists can use the SOC as a framework from which to identify the strength of a parents' SOC, and, when deemed to be low, help create a process for enhancing resilience.


BACKGROUND: Recent government initiatives in the UK encourage collaborative working among professionals and highlight the importance of a co-ordinated and collaborative approach in early years for families and children. There are many models of collaborative working but the evidence base for its effectiveness in early years (0-2.5 years) in a community setting in the UK is patchy. The aim of this study is to objectively evaluate the transdisciplinary model of collaborative working in this setting. METHODS: This paper describes the development of a transdisciplinary early intervention team providing services to a 0- to 2.5-year-old age group in a community setting in the UK, between 2004 and 2007. The effects on waiting times, therapy session attendance and caseload were evaluated. RESULTS: Statistically significant reduction in waiting times from an average 114-35.6 days for the highest priority children was demonstrated. Attendance at therapy sessions increased significantly from 49% in 2005 to 56% in 2006 and 75% 2007, despite an increasing case load from 29 in 2004 to 64 in 2008 through more efficient utilization of time and resources. CONCLUSION: It is felt that this paper demonstrates, for the first time, the objective benefits to clients and fundholders/Primary
Care Trust (PCT) of practical application of the theory of transdisciplinary working in a community paediatric service setting in the UK.


BACKGROUND: Continuity of care has been explored largely from academic and service provider perspectives, and in relation to adult patient/client groups. We interviewed parents of children with complex chronic health conditions to examine how their experiences and perceptions of continuity of care fit with these perspectives; and to identify the salient factors in the experience of, and factors contributing to, continuity in this population. METHODS: Parents of 47 elementary school-aged children with spina bifida, Down syndrome, attention-deficit/hyperactivity disorder, Duchenne muscular dystrophy or cystic fibrosis participated in semi-structured interviews. Parents described and mapped the pattern of their interactions with service providers over time in all domains relevant to their child's health, well-being, and development (medical, rehabilitational, educational, and social supportive services), with particular attention paid to their perceptions of connectedness or coherency in these interactions. Verbatim transcripts were analyzed thematically using a framework approach to impose structure regarding parents' perspectives on continuity of care. RESULTS: Existing academic concepts of relational, informational and management continuity were all discernable in parents' narratives. A thorough knowledge of the child on the part of service providers emerged as extremely important to parents; such knowledge was underpinned by continuity of personal relationships, principally, and also by written information. For this population, notions of continuity extend to the full range of service providers these children and families need to achieve optimal health status, and are not limited to physicians and nurses. Communication among providers was seen as integral to perceived continuity. Compartmentalization of services and information led to parents assuming a necessary, though at times, uncomfortable, coordinating role. Geographic factors, institutional structures and practices, provider attitudes, and, on occasion, parent preferences and judgments, were all found to create barriers to "seamless" management and provision of care continuity across providers, settings, and sectors. CONCLUSIONS: These findings add new perspectives to the understanding of continuity within chronically ill children's health care. They are relevant to contemporary initiatives to improve continuity of services to children with special health care needs, demonstrate the need for parental support of their important role in maintaining continuity, and suggest avenues for further research.


Early Support is the England-wide government programme to achieve child-centred and family-focused services for children aged nought to five years with a disability or complex need and their families. Integral to the ethos of Early Support is the understanding that every decision should be influenced and led by children and families. Families are expected to play a strategic role in the development and monitoring of
policy and practice, and the service is expected to be proactive in seeking their views. Section 242(1B) of the NHS Act 2006 now places a duty to involve service users in planning the provision of services, changes to services and the operation of services. Yet for many frontline staff, user involvement and partnership working in this way presents real challenges. Using a framework based on principles of interpretive phenomenology, this paper documents efforts to ensure that the stories of families are heard and used to inform the development of proposals for Early Support in Bedfordshire and explores ways to overcoming barriers to meaningful user-involvement.


This article reviews the literature on the transdisciplinary approach to early intervention services and identifies the essential elements of this approach. A practice model describing the implementation of the approach is then presented, based on the experiences of staff members in a home visiting program for infants that has been in existence for over 30 years. The benefits and challenges experienced by therapists and managers of the program are considered, along with the unique aspects of the program and implications for program management. The managerial and team resources required to successfully implement a transdisciplinary model are high, but the potential payoffs for children, families, and therapists’ development of expertise are considerable.

http://journals.lww.com/iycjournal/Fulltext/2009/07000/The_Application_of_a_Transdisci plinary_Model_for.6.aspx?WT.mc_id=HPxADx20100319xMP


PURPOSE: To measure enrollment of children with mechanical respiratory support needs within the Massachusetts early intervention programmes (EIP) and describe challenges in execution of individual family service plans (IFSPs). METHODS: Mixed methods provided a complementary assessment. Quantitative data were collected in 2005 from the Commonwealth of Massachusetts EIP administrative database as part of a cross-sectional state census. Qualitative data were retrieved from EIP regional coordinators in a key informant focus group. Descriptive statistics were used for quantitative survey data. Audio-recordings were transcribed verbatim and a qualitative, thematic analysis was undertaken. RESULTS: Four hundred and eighty children requiring mechanical respiratory support at the time of EIP enrollment were identified between 1 July 1997 and 1 January 2005. Focus group analysis revealed themes including: (1) barriers to community transition; (2) community expertise and training; (3) interface with medical providers; and (4) the role of web-based resources. Isolation of families emerged as a recurrent and resounding concept, relating to all of the themes. CONCLUSIONS: Findings support the assumption that implementation of IFSPs for the cohort of children with chronic mechanical respiratory support needs in EIPs is challenging. Barriers reflect inconsistent care coordination and practical encumbrances, contributing to the physical and social isolation of these children and their families.

BACKGROUND: Parents of children requiring complex care provide intense and demanding care in their homes. Unlike professionals who provide similar care in institutions, parents may not receive regular breaks from care giving. As a result, parents, over time, experience health and social consequences related to care giving. Respite care, one form of a break from care giving, is frequently cited as an unmet need by such parents. 

METHOD: Given the paucity of literature on the impact of care giving over time, an ethnographic approach that involved in-depth interviews, participant observation, eco-maps, and document review was used. Parents of children requiring complex care, nurses and social workers participated in the study. 

RESULTS: A developmental map of care giving over time was constructed from the parents' retrospective accounts of parenting a child requiring complex care. The developmental map describes the trajectory of care for the children from infancy through young adulthood and the parents' evolving needs for respite care. 

CONCLUSION: Existing literature focuses on the day-to-day experiences of parents, who are carers, rather than their experiences over time. As parents of children requiring complex care are providing care from infancy through the death of either child or parent, respite needs will change. This developmental map identifies how a group of parents reported these changes in care giving and their perceived needs for respite care. [References: 21]


AIM: Parents are ultimately responsible for organising and accessing health services for their children. How parents experience those services are likely to influence subsequent use. Understanding parental preference for service provision can inform compliance strategies with recommended child health recommendations. The aim of this study was to explore parental experiences and preferences which influence subsequent use of post-discharge health services for children born preterm with a birthweight < or =1250 g. 

METHODS: Focus groups consisted of randomly selected families recruited from a population-based cross-sectional cohort study of 2-, 4- and 7-year-old children corrected age for prematurity. Parents were asked to consider which aspects of childhood health service delivery influenced subsequent use. Transcripts were analysed and themes constructed. SWOT analysis evaluated health service practices by systematically mapping parents' accounts of the perceived strengths (S), weaknesses (W), opportunities (O) and threats (T) of services in relation to subsequent use. RESULTS: Fifteen parents participated in three groups (by children's age). Three dominant themes emerged and included (i) assistance with accessing appropriate services; (ii) provision of consistent information and comprehensive child health records; and (iii) support of parental self-efficacy in the health care of their child. 

CONCLUSION: Primary health carers are ideally suited to co-ordinate and provide continuity to improve parental involvement and compliance with health promoting recommendations for their preterm
children. This approach may improve interagency co-operation and access to services enabling early identification and intervention. Adopting these strategies may be effective in optimising child health follow-up strategies and improve uptake of recommended intervention and prevention programmes.


Families with disabled children represent a sizeable share of all American households. Living with a disabled child can have profound effects on the entire family, which in turn can affect the health and well-being of the child who is disabled. Much needs to be learned about how children’s health affects their parents, siblings, and other family members and about how family characteristics and resources modify those associations. Numerous programs and organizations provide resources for disabled children and their families, but the system is extremely fragmented and difficult to navigate. This commentary reviews what is known about the effects of child disability on the family, provides an overview of the complex needs of and multitude of resources available to families of disabled children, and concludes with suggested directions for practice, research, and public policy. [References: 22]


The first contact parents may have with a professional in relation to their child with a disability is often at the point of diagnosis. From that moment onwards, parents embark on a journey that generally involves the formation of many relationships with professionals working in the field. These relationships have the potential to facilitate individual and family outcomes but may also jeopardise these outcomes. It is not surprising that researchers have been interested in examining the components of productive relationships and the impact these may have on the quality of life for individuals with disabilities and their families. This article draws on the work of contributing authors to this special issue to examine some of the research that has led to our current understandings of how parents who have a child with a disability and professionals can form meaningful and productive partnerships. It considers how the nature of these partnerships is changing, and some of the issues that have been raised as a result of these changes.