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Improving service coordination for children with complex healthcare needs: A scoping review

Abstract

Although recognised by policy incentives shaping children's services, research and service development for children with complex healthcare needs have received limited attention. Both health-care professionals and families of those children affected frequently report fragmented care and unmet needs in the literature. Not only is the wellbeing of the family and health of the child jeopardised, but also the lack of consistent service coordination between diagnosis, impairment, functional need or disability, directly contributes to a lack of data for the subgroup of children with complex healthcare needs. In this scoping review, key themes are identified, proposing priorities for innovation of future services. It is clear from the literature, longitudinal data analysis providing a more accessible platform for service evaluation and improvement, specialist training for key workers, and further research around definitions and classification systems, is lacking.

Introduction

The variation in outcomes and quality of health care for children and young people has been noted as a key area for improvement by the recent initiative to reform children's services, Better Health Outcomes for Children and Young People, and by the Chief Medical Officer's report (Department of Health (DH), 2013a; 2013b). It has been recognised that children and young people with complex health needs have not been well served by the NHS and social services (DH, 2014). Consequently, further attention and research is required into longitudinal pathways through care for children, which may pinpoint stages for critical intervention (Garland et al, 2001). This study aims to highlight themes from the literature to identify features of successful service coordination for children with complex needs; help determine how far policy incentives have shaped current children's services; discover how service features contribute to positive outcomes, and highlight and propose key areas for improvement.

Methodology

This study is a scoping review; Watson et al (2011) support the use of this methodology in health research as it combines a review of both policy documentation and research literature, providing a perspective that is both applicable and transferable to the health service, while seeking to identify 'best practice'. The benefits of a scoping review allow for mapping fields of study that emerge from the literature into key themes, therefore summarising key areas for service improvement (Arksey and O'Malley, 2005). In this study it allows for highlighting gaps in service provision, and synthesizes definitions of children with complex needs used across the literature. A search strategy was developed in line with available guidance from both the Cochrane Collaboration (2009) and Cochrane Qualitative Methods Group (Hannes, 2011). The databases selected for the systematic review were: MEDLINE (In-Process and Other Non-Indexed Citations and Ovid MEDLINE(R), 1948–Present); Embase (Embase 1974–January 31 2012), both accessed via Ovid SP, and CINAHL (from 1960– present), accessed via EBSCO, HMIC (Health Management Information Consortium 1983– present), and Global Health (1983–present).

Papers were only included if they reported: service evaluation, service improvement or classification for children with complex needs; the attitudes of health care professionals working with children with complex needs; and the experiences of families caring for children with complex needs. As 'complex needs in children' is not a universally used phrase, efforts were made to capture health studies, which report on children whose needs are likely to become complex. This included epidemiological studies reporting on prevalence of birth defects or pre/post natal defects and screenings, and studies reporting on geographical, socioeconomic status, and ethnic differences in children born with disabilities. A PRISMA flow diagram is shown in Figure 1.

A total of 222 records were retrieved from database searches, and 36 records were retrieved through other sources. After duplicates were removed, and abstracts were screened, those

deemed relevant were checked for full text eligibility producing a finalised 75 papers for inclusion. Most were qualitative in their methodology, using interviews, surveys and focus groups; one systematic review was found but was an Australian study; and two were cohort studies but also not based in the UK. The rest were a combination of literature reviews, case studies, and commentary pieces; one was a systematic review protocol, and another a cohort study. The following key themes were identified from the literature and will be discussed under the corresponding subheadings:

- Classification
- Coordination of services
- The role of the key worker
- Service use and unmet needs
- Early identification
- Supporting parents and families
- Training.

Classification

Classification, more commonly known as diagnosis or definition, has several complications attached, causing system-wide difficulties in service provision and evaluation. One primary reason for this revolves around the terms 'chronic illness,' 'disability,' and 'chronic condition' being used interchangeably and often categorised by measures of activity limitations. Consequently, no consistent definitions of the term 'complex health-care needs' exist, and it is generally considered to be a function of the child's ongoing health-care. This includes the required number of providers, the diversity of types of providers, and the frequency of provider contacts (Hefner, 2011). Coding systems used to record child diagnosis are an additional source of misclassification. Children with complex needs often do not fall into specific categories of diagnosis from the classifications systems of the ICD-10 and DSM-5 (American Psychiatric Association, 2013; World Health Organization, 2016) Although efforts are being made to revise these systems, classification should focus on description of the individual and their strengths and weaknesses, rather than a specific diagnosis (Baird, 2013). Classification of a child should require the decision of a minimum of two people, or a team of professionals in conjunction with the parents. It should also be treated as a variable which is regularly reviewed, as some children may only have complex needs for a period of time (McConkey et al, 2007).

Coordination

For children with complex needs, service coordination is a complex intervention and several authors have cited the lack of research for evaluating services. Instead there has been a focus on design of new services (Kirk, 2008; Clarke et al, 2011; Watson et al, 2011; Colver et al, 2013).

Some of the barriers to streamlining and coordination in children's services have been attributed to hospital's and community professionals lack of adequate communication; lack of funding for specialist equipment; inexperienced community staff; complicated legal liability issues; and social exclusion for parents who are trying to manage all these aspects of care (Dale and Godsman, 2000; Watson et al, 2002). Services found to be excelling involved the support of health commissioners and primary care trusts, linked with local authority education and social services (Watson et al, 2002; Bachmann et al, 2009; Law et al, 2011; Pratt et al, 2012; Brooks et al, 2013). A combination of a strong pathway, and clearly defined roles, have been suggested as a method of strengthening emotional resilience of staff while adopting holistic models of practice to support coordination (Dale and Godsman, 2000; Elias et al, 2012). Resources have to be on a continuum, across all ages and, planning any transition should be within the context of the family (Tait, 2002; Hewitt-Taylor, 2012).

Key worker

Lead professionals, such as GPs or nurse coordinators, are recommended by the Royal College of Paediatrics and Child Health (2014) and the Chief Medical Officer (DH, 2013b), as a fundamental step towards improving coordination in children's services. Despite frequent mentioning of the benefits of lead professionals, the realities of how this works in practice and how effective implementation occurs remains varied (Beattie, 2000; Garland et al, 2001; Áskelsdóttir et al, 2008; Brombley, 2008; Pratt et al, 2012; Tan et al, 2012; Looman et al, 2013).

Beattie (2000) suggests named professionals are seen as a method of reducing the need for parents to 'tell their tale' many times, as well as ensuring clarity of professional roles and avoiding crossovers for both parents and professionals. A key worker requires a cross disciplinary understanding, with a mix of skills, when trying to facilitate responses to psychosocial, financial and medical needs of a child (Tait, 2002; Farasat and Hewitt-Taylor, 2007; Brombley, 2008; Pratt et al, 2012; Looman et al, 2013). Professionals, who are locked into their particular discipline, limit their ability to function across the range of roles potentially required for children with complex healthcare needs. A lack of definition or consensus around complex needs only further intensifies this difficulty, having a negative effect on care and coordination (Hewitt-Taylor, 2005; DH, 2009; Law et al, 2011).

Service use and unmet needs

Frequency of service use is a regularly mentioned problem. This review discovered a particular focus on the provision and support of technology dependence and respite services. The National Service Framework, DH and Department for Education and Skills (2004), suggest an average of 10 different professionals and over 20 visits per year to hospitals and clinics is to be expected for a child with complex needs. The association between the severity of the condition, and technology dependence of the child is seen to consequently lead to greater strain on the family. Among such families, a larger proportion of unmet needs is apparent, as the complexity of care increases alongside the need to add new equipment across the child's life span (MacDonald and Callery, 2004; Hewitt-Taylor, 2005; Brooks et al, 2013). Respite services appear both difficult to source and access. Despite attention from both government documents and research literature, the meanings and values of this service for parents and providers has not received much attention (MacDonald and Callery, 2004; Thurgate, 2005; Law et al, 2011; DH, 2013a; Whiting, 2013; Whiting, 2014).

Early identification

The Chief Medical Officer (DH, 2013b) recognises early identification is key for all children, and is strengthened through having well-trained health-care practitioners, supported with a clear service model. Some authors found communication between parents, the clinician making the diagnosis and surgical centres, were lacking coordination and a clear pathway for referral. Furthermore, the time between referrals is seen to inflict mood changes, anxiety and negative feelings associated with pregnancy and delivery (Áskelsdóttir et al, 2008; Watson et al, 2011; Aite et al, 2013). There appears to be limited research nonetheless on service coordination between early epidemiological prevention studies, and practical application for shaping service coordination. For example, recognising that low birth weight is associated with higher rates of special educational needs, and with low socioeconomic status, provides another opportunity for preventative services (Bettge et al, 2014).

Supporting parents and families

The multiple roles required of parents for children with complex needs are recognized to create time pressures, and be emotionally stressful for both parents and healthcare staff. There are factors that receive differing attention throughout the literature. What is reflected is the needs of the parents of children with complex needs above those in mainstream services who require specialist attention (Kirk and Glendinning, 2002; Runciman and McIntosh, 2003; Narramore, 2008; Hewitt-Taylor, 2009; McCann et al, 2012; Nicholl and Begley, 2012; Bonanno et al, 2013; Sartore et al, 2013; Fonseca et al, 2014; Whiting, 2014). Time use of health-care staff is an important issue and can affect the establishment of acceptable relationships with families. Community nurses spending prolonged periods of time with one family was inevitable, therefore, an enhanced effort to maintain a balance between professionalism and empathy without being intrusive, is required. Professionals need to be sensitive to the parent's role as an expert. Children with complex needs are likely to miss a lot of school time making equal opportunities difficult. Understanding and ensuring similarities between how parents and professionals view the notion of support, should form the building blocks of enhancing the parent, child, professional support network in the home environment (Kirk and Glendinning, 2002; Hewitt-Taylor, 2008; Hewitt-Taylor, 2009).

Approaches to training

Core team members should be encouraged to share skills and undertake joint training to promote flexibility of roles (Hewitt-Taylor, 2005; DH, 2009; Law et al, 2011). By shaping professionals roles in this way to address the complex needs of children, fragmentation of system-wide care roles may be reduced, thus preventing an imbalance between medical/technical and psychosocial aspects of care.

On the other hand, with these flexibilities comes the risk of over-diluting roles. To retain core skills, arrangements such as shared posts between complex care of the child and mainstream services, or rotation of posts may be useful (Hewitt-Taylor, 2012). Training provided to both parents and carers from health, social work, education or voluntary agencies, based on supporting and educating parents is strongly recommended. Training should include information on specialist equipment and reasoning for particular approaches to care, along with follow-up information (Runciman and McIntosh, 2003; Nicholl and Begley, 2012).

Discussion

Limited consensus has been reached regarding a definition of complex needs in children, or clear and definitive answers to what constitutes successful coordination. This scoping review has underlined areas requiring prioritising in terms of service evaluation. Although coordination is far from simple, services which do excel are seen to involve close liaison with commissioning and management (Watson et al, 2002; Bachmann et al, 2009; Law et al, 2011; Pratt et al, 2012; Brooks et al, 2013) and contain clearly defined pathways supporting accurate referrals, and reduce over-use of services (Dale and Godsman, 2000; Elias et al, 2012).

In terms of service use, quantifying frequency of use remains under-researched, especially UK studies. Specialist training for key professionals, parents and carers is recommended, but is not without its challenges. A logical starting point for researchers therefore, could be a consensus reached on how to accurately define, and measure child disability, with better data to study the effects of child disability on health, economic, and demographic outcomes. Despite the research evidence displaying multiple problems with coordination and unmet need, there are clear and universally accessible national data driving development in children's services. The National Maternal Health Intelligence Network (Public Health England, 2015) makes it possible to select the localities in the UK with the highest child mortality, premature births and poverty (among other variables) to support prioritizing transformations for children's services—as well as placing precedence on areas required for further development. Public Health England (2015) specify the data are for developmental purposes, in terms of preventative investments for commissioners, and provide an evidence base for effective interventions for practitioners. This approach also mirrors findings from the literature proposing improved data collection and collation across agencies (Garland et al, 2001; DH, 2013a; 2013b).

Conclusion

What remains clear is the gap in longitudinal studies evidencing professional achievements made by individual local services to transform services. Also worth considering is the insoluble paradox between the need for evidence-based, clinical governance-monitored, consistent services, and the individual needs and requirements of each unique patient. The lack of quantitative research evaluating current services is not surprising given the complexities of pathways, providing a feasible explanation for the qualitative majority of research in this review. Further research is required relating to a definition of a child with complex needs, gaining consensus of this definition with a range of different professionals, and using longitudinal data to establish trends.

Key Points

- There is a lack of longitudinal data analysis accurately quantifying and justifying service requirements for children with complex needs.
- Specialist training for key workers is required to facilitate coordination through services for children with complex needs.

References

Aite L, Saccara A, Cuttini M, Mirante N, Nahom A, Bagolan P (2013) Lack of institutional pathways

for referral: Results of a survey among pediatric surgeons on prenatal consultation for congenital anomalies. *Prenat Diagn* 33(9): 904–7. doi: 10.1002/pd.4165

American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders*. 5th edn. American Psychiatric Publishing, Arlington, VA: 5–25

Arksey H, O'Malley L (2005) Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 8: 19–32

Askeldottir B, Conroy S, Rempel G (2008) Ethical issues in newborn care. From diagnosis to birth: parents' experience when expecting a child with congenital anomaly. *Adv Neonatal Care* 8(6): 348–54. doi: 10.1097/01.ANC.0000342768.94734.23

Bachmann A, O'Brien M, Husbands C et al (2009) Integrating children's services in England: National evaluation of children's trusts. *Child Care Health Dev* 35(2): 257–65. doi: 10.1111/j.1365-2214.2008.00928

Baird G (2013) Classification of diseases and the neurodevelopmental disorders: the challenge for DSM-5 and ICD-11. *Dev Med Child Neurol* 55(3): 200–1. doi: 10.1111/dmcn.12087

Beattie A (2000) Co-ordinating services for children with complex needs. *J Interprof Care* 14: 296–7

Bettge S, Oberwöhrmann S, Brockstedt M, Bühner C (2014) Birth weight and special educational needs: Results of a population-based study in Berlin.

Dtsch Arztebl Int 111(19): 337–44. doi: 10.3238/ arztebl.2014.0337. Bonanno L, Bennett M, Pitt A (2013) The experience of parents of newborns diagnosed with a congenital anomaly at birth: A systematic review protocol. *JBI Database of Systematic Reviews and Implementation Reports* 11: 100–11

Brombley K (2008) Better at home? Benefits of case management for children with complex needs. *Paediatr Nurs* 20(9): 24–6

Brooks F, Bloomfield L, Offredy M, Shaughnessy P (2013) Evaluation of services for children with complex needs: mapping service provision in one NHS Trust. *Primary Health Care Research & Development* 14: 52–62

Cochrane Collaboration (2009) *The Cochrane Handbook of Systematic Reviews*. Available at: <http://handbook.cochrane.org> (accessed 12 May 2015)

Clarke S, Sloper P, Moran N et al (2011) Multi-agency transition services: greater collaboration needed to meet the priorities of young disabled people with complex needs as they move into adulthood. *Journal of Integrated Care* 19(5): 30–40. <http://dx.doi.org/10.1108/14769011111176734>

Colver AF, Merrick H, Deverill M et al (2013) Study protocol: longitudinal study of the transition of young people with complex health needs from child to adult health services. *BMC Public Health* 13: 675. doi:10.1186/1471-2458-13-675

Dale N, Godsnam J (2000) Factors influencing general practitioner referrals to a tertiary paediatric neurodisability service. *Br J Gen Pract* 50(451): 131–2

Department of Health and Department for Education and Skills (2004) *National Service Framework for Children, Young People and Maternity Services*. Disabled Children and Young

People and Those with Complex Health Needs. Department of Health, London

Department of Health (2009) Health Child Programme: Pregnancy and the First 5 Years of Life. Department of Health, London.

Department of Health (2013a) Better Health Outcomes for Children And Young People: Our Pledge. Department of Health, London

Department of Health (2013b) Chief Medical Officer's Annual Report 2012: Our Children Deserve Better: Prevention Pays. Department of Health, London

Department of Health (2014) Children with Special Educational and Complex Needs. Guidance for Health and Wellbeing Boards. Department of Health, London

Elias ER, Murphy NA; Council on Children with Disabilities (2012) Home care of children and youth with complex health care needs and technology dependencies. *Pediatrics* 129(5): 996–1005. doi: 10.1542/peds.2012-0606

Farasat H, Hewitt-Taylor J (2007) Learning to support children with complex and continuing health needs and their families. *J Spec Pediatr Nurs* 12(2): 72–83

Fonesca A, Nazare B, Canavarro M (2014) Parenting an infant with a congenital anomaly. An exploratory study on patterns of adjustment from diagnosis to six months post birth. *J Child Health Care* 18: 111–22

Garland A, Hough RL, Landsverk JA, Brown SA (2001) Multi-sector complexity of systems of care for youth with mental health needs. *Children Services: Social Policy, Research and Practice* 4(3) 123–40. doi: 10.1207/S15326918CS0403_2

Hannes K (2011) Cochrane Qualitative Research Methods Group. Critical Appraisal of Qualitative Research. Available at: <https://lirias.kuleuven.be/handle/123456789/331203> (accessed 12 May 2015)

Hefner JL (2011) Children with complex special health care needs and the health services system: Unmet needs, barriers to care, and coordination of health services. *Dissertation Abstracts International: Section B: The Sciences and Engineering* 72: 1441

Hewitt-Taylor J (2005) Caring for children with complex needs: Staff education and training. *J Child Health Care* 9(1): 72–86

Hewitt-Taylor J (2008) The nurse's role in supporting young people with complex health needs. *Br J Nurs* 17(15): 970–3

Hewitt-Taylor J (2009) Working with children who have complex health needs. *Journal of Community Nursing* 23: 24–26

Hewitt-Taylor J (2012) Planning the transition of children with complex needs from hospital to home. *Nurs Child Young People* 24(10): 28–36

Kirk S (2008) Transitions in the lives of young people with complex healthcare needs. *Child Care Health Dev* 34(5): 567–75. doi: 10.1111/j.1365-2214.2008.00862.x.

Kirk S, Glendinning C (2002) Supporting 'expert' parents - professional support and families caring for a child with complex health care needs in the community. *Int J Nurs Stud* 39(6): 625–35

Law J, McCann D, O'May F (2011) Managing change in the care of children with complex needs: healthcare providers' perspectives. *J Adv Nurs* 67(12): 2551–60. doi: 10.1111/j.1365-2648.2011.05761.x. Epub 2011 Jul 20

Looman WS, Presler E, Erickson MM (2013) Care coordination for children with complex special health care needs: the value of the advanced practice nurse's enhanced scope of knowledge and practice. *J Pediatr Health Care* 27(4): 293–303. doi: 10.1016/j.pedhc.2012.03.002

Macdonald H, Callery P (2004) Different meanings of respite: A study of parents, nurses and social workers caring for children with complex needs. *Child Care Health Dev* 30(3): 279–88

McCann D, Bull R, Winzenberg T (2012) The daily patterns of time use for parents of children with complex needs: a systematic review. *J Child Health Care* 16(1): 26–52. doi: 10.1177/1367493511420186

McConkey R, Barr O, Baxter R (2007) Complex Needs. The Nursing Response to Children and Young People with Complex Physical Healthcare Needs. Institute of Nursing Research, Ulster University

Public Health England (2015) National Child and Maternal Health Intelligence Network. Child Health Profiles. Available at: www.chimat.org.uk/profiles. (accessed 13 May 2015)

Narramore N (2008) Meeting the emotional needs of parents who have a child with complex needs. *Journal of Children's & Young People's Nursing* 2: 103–107

Nicholl HM, Begley CM (2012) Explicating caregiving by mothers of children with complex needs in Ireland: a phenomenological study. *J Pediatr Nurs* 27(6): 642–51. doi: 10.1016/j.pedn.2011.07.003

Pratt K, Baird G, Gringras P (2012) Ensuring successful admission to hospital for young people with learning difficulties, autism and challenging behaviour: a continuous quality improvement and change management programme. *Child Care Health Dev* 38(6): 789–97. doi: 10.1111/j.1365-2214.2011.01335.x

Royal College of Paediatrics and Child Health and National Children's Bureau (2014) A Policy Response for England to the Report Why Children Die: Deaths in Infants, Children and Young People in the UK: Part A. Royal College of Paediatrics and Child Health, London

Runciman P, Mcintosh J (2013) Evaluation of the PATCH nursing service: partnership and training supporting children with complex needs at home. *Prim Health Care Res Dev* 4(4): 307–18

Sartore G, Lagioia V, Mildon R (2013) Peer support interventions for parents and carers of children with complex needs. *Cochrane Database Syst Rev*. doi: 10.1002/14651858.CD010618

Tait T (2002) Service co-ordination: a successful model for the delivery of multi-professional services to children with complex needs. *Nursing Times Research* 7: 19–32

Tan JS, Docherty S L, Barfield R, Brandon DH (2012) Addressing parental bereavement support needs at the end of life for infants with complex chronic conditions. *J Palliat Med* 15(5): 579–84. doi: 10.1089/jpm.2011.0357

Thurgate C (2005) Respite for children with complex health needs: issues from the literature. *Paediatric Nursing* 17: 14–8

Watson D, Townsley R, Abbott D (2002) Exploring multiagency working in services to disabled children with complex healthcare needs and their families. *J Clin Nurs* 11(3): 367–75

Watson R, Parr JR, Joyce C, May C, Le Couteur AS (2011) Models of transitional care for young people with complex health needs: a scoping review. *Child Care Health Dev* 37(6): 780–91. doi:

10.1111/j.1365- 2214.2011.01293.x

Whiting M (2013) Impact, meaning and need for help and support: The experience of parents caring for children with disabilities, life-limiting/life-threatening illness or technology dependence. *J Child Health Care* 17: 92–108

Whiting M (2014) Support requirements of parents caring for a child with disability and complex health needs. *Nurs Child Young People* 26(4): 24-7. doi: 10.7748/ncyp2014.05.26.4.24.e389

World Health Organization (2016) *International Statistical Classification of Diseases. 10th Revision. 5th edn.* World Health Organization, Geneva