

## **Improving service coordination for children with complex needs**

BISHOP, Christine, SMALL, Neil, PARSLOW, Roger and BOWLES, David

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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.

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