Caring for Children with Complex Needs in the Community
For my dad, who would have been proud

Jean Teare
Caring for Children with Complex Needs in the Community

Edited by

Jean Teare
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David Wray has worked within the middle, secondary, adult and further education sectors, performing a variety of roles in the areas of teaching, management, professional and curriculum development and also teacher training. He left full-time, paid employment in 1997 to help his wife with the care of their son. However, he found that a significant amount of his time needed to be spent being an advocate for the family, trying to obtain the support services that were needed, but were not readily available. Although many people were eventually involved in their son’s care, passing on their skills and knowledge, it was still necessary for the parents to do a considerable amount of independent research to find solutions to the many problems the family faced. As a consequence, much of what has been written in Chapter 10 is the result of practical, as well as professional, experience.
I would like to thank the child branch teaching team at the University of Bradford for their support professionally and personally, Helen Monks, Sarah Hamilton and Janice High. I would like to thank Jane Welby in particular for her critical feedback on draft sections of the work. I would also like to thank the practitioners in the Children’s Community Nursing team in Bradford for their expertise, Ercky Radic and Sarah Boron especially. I would also like to extend my thanks to all the contributors of the book for their hard work and quick responses to my comments.

JT
Introduction

There is no agreed definition of what constitutes ‘complex care needs’, yet this group of children are discussed in general health and social policy guidance (National Service Framework for Children; Department of Health, 2004). Professionals that work with children who have complex needs therefore have to decide who falls into this category to meet the criteria for service provision.

Recognition of children with complex needs as a particular group requiring nursing and health care support has developed from research studies exploring and evaluating community children’s nursing services, children’s palliative services and children’s specialist social services (While et al. 1996; Kirk & Glendinning 1999; Heaton et al. 2003). Particular conditions have also emerged in the research literature related to complex needs – technology-dependent children, and children with long term, life-limiting illness or disability. Most of the literature appears as articles in journals or reports of studies that have been carried out. There are also anecdotal papers detailing function and delivery of services to children with complex needs. Several papers refer to service development and multi-agency collaboration (Watson et al. 2002; Sloper 2004) but there are no child focused textbooks related to caring for children with complex needs.

This book will attempt to provide a comprehensive overview of all the main factors that relate to caring for children with complex needs and their families. It will bring together some of the information that has developed from research studies into one practical text, and develop further discussion of key issues that practitioners need to consider when working with this group of children. It is aimed at professionals working predominantly in the community who deal with children who have complex needs. This may include workers in respite care settings, social services, education and nursing teams. It will be useful to children’s nursing students on both pre- and post-registration courses who would like to gain an insight into family nursing of children who have complex and continuing health care needs. Case studies will be used to
illustrate practical issues, when professionals from varying service backgrounds are working with children and families.

Chapter 1 provides an overview of the terminology of complex care needs, and discusses health and social policy that has contributed to the emergence of children with complex needs being cared for in the community. The two main groups of children, those that are dependent on technology, and those with disabilities, are used as a focus for discussion, with Department of Health exemplars used as case studies to identify key points. Issues of multi-agency service provision, respite care, equipment and funding requirements, are considered as influencing factors in the identification of children with complex needs.

Chapter 2 considers the funding of services to care for children with complex needs in the community. Commissioning services at a strategic level are discussed with links to individual care packages and business cases. The development of children’s trusts and collaborative organisation of health and social services to children are relatively new developments following governmental guidance to improve children’s well-being (Department for Education & Skills, 2004). This provides the context for discussion of how services may be funded and delivered to children with complex care needs. Children’s community nurses in particular are linked to planning and commissioning services to meet the needs of children with complex needs.

Chapter 3 discusses the care needs of technology-dependent children, focusing on technology required to assist respiration. Children who receive long term ventilation, tracheostomy care or are dependent upon oxygen therapy are examples of technology dependency that categorise children as having complex needs. They are discussed using three case studies to illustrate aspects of specialised care, and resources that are necessary to care for this group. Negotiation of care with families and use of guidelines and protocols for professional carers in the home is discussed, to provide a comprehensive view of the particular care needs of children using technology in the community.

Chapter 4 focuses on long term enteral tube feeding as a particular aspect of caring for many children with complex needs. Parental support is discussed from a practical, psychological and social point of view, considering how professionals may provide effective support to families. The difficulties of long term enteral tube feeding are highlighted from a parental viewpoint, with links to policy and guidance that could improve professional support in this area. Evidence-based recommendations for practice emerge from the discussion, placed in
the context of many of the generic issues related to caring for children in the community.

Chapter 5 discusses the care of children with complex disabilities, as improvements in health technology have led to long-term survival of children with continuing and life-long care needs. The financial, social and physical demands of caring upon the family are considered in the context of multiple services and professionals that are available to help support the child and family. Key working and transitional care from child to adult services are discussed, as aspects of continuing support to children and young people with complex disabilities.

Chapter 6 provides an overview of some of the communication issues that need to be considered when multiple agencies and professionals are involved in caring for children with complex needs. Portage services and Child Development Centres are used as examples of specialist services that may be involved with universal services to families, demonstrating the range of professionals that have to communicate with families as well as each other. Varying models of service provision such as Team Around the Child, Lead Professional and Key Workers are used to highlight good practice, while processes such as the Common Assessment Framework are considered to improve communication and collaboration between professionals.

Chapter 7 is written by a parent of a child with complex care needs, and is therefore a realistic portrayal of the experience of caring for a child who may be described as having complex needs by services. The reality of being both a carer and a parent is presented, along with examples of how services can be supportive in the ongoing management of a child with complex needs. The complex relationship between professionals, the child and parents is highlighted with an interesting perspective on who can really be the advocate for a child, when the child disagrees with particular aspects of care.

Chapter 8 considers family-focused respite care or short breaks for children with complex needs. The range of respite options is discussed with a particular focus upon hospice care and support of siblings. The impact of caring upon the family gives context to the discussion, allowing a broader consideration of parental expertise and negotiation of care as important factors in the provision of respite. Responsibilities of services to provide responsive and effective respite care is discussed through the use of a case study, demonstrating the benefit not only to the family, but to the young person receiving care. Respite is therefore viewed as a positive and pro-active experience for the recipient, rather than just relief from the pressure of caring for carers.
Chapter 9 discusses the care of children with complex needs from the perspective of social services. Policy and legislation that guides the provision of social services is presented, focusing on children with disabilities. Practical application of social service support is demonstrated through the use of a case study. Particular strengths of social worker interaction with families are highlighted, demonstrating the range of services that can be provided to ensure children receive appropriate care, and that their families are assisted in making choices of how care will be delivered and maintained. The changing nature of care over time is considered, raising the issue that circumstances may alter necessitating re-assessment and re-negotiation of care to meet the complex needs of the child and family.

Chapter 10 considers the educational support of children with complex needs. The author has a professional education background, but also has the expertise associated with being a parent of a child with complex needs. This experience has enabled him to raise issues concerned with the relationship between parents and educational professionals, and question the system when a child is losing skills and abilities, rather than developing them. Useful recommendations for practice are discussed providing links between a real-life case study example and services involved in the education of children with complex needs.

Common threads that run through all the chapters are issues related to providing services to families that are caring for children in the community with needs that are often described as complex. The common issues relate to multi-agency collaboration and services working across professional boundaries to negotiate care with parents who are often the real experts in caring for children who have complex needs. Services aim therefore to support carers in continuing their care and ultimately ensuring that the needs of the child and family are met in a timely and effective manner, whether this is from a health, social service or education perspective.

References


Defining Children with Complex Needs

Jean Teare

Key Points

- Parental participation in the care of their sick children has contributed to expectations from both parents and professionals that ultimately children with ongoing health care needs will be cared for at home by parents. This is a factor in the identification of children with complex care needs who have emerged as a group of children requiring care in community settings.
- Factors associated with complex care needs relate to multi-agency involvement in care, the need for respite, technology dependence and disability.
- Variations exist in identification and interpretation of complex care needs with care predominantly delivered by health and social services.

Introduction

This chapter will discuss the categorisation and identification of children who have complex care needs. In order to achieve this, a consideration of particular health and social policies that refer to children with complex care needs is necessary, followed by an overview of caring for children in the community. For the purpose of this chapter the policies discussed apply to England; there are variations in structure and delivery of child policy in Northern Ireland, Scotland and...
Wales. However, the philosophy of improving child health through development of specific childcare strategies is common to all four countries, resulting in some commonalities such as Ministers for children’s health, and strategic plans or frameworks for child services. Health and social service views of children with complex care needs will be discussed through consideration of technology-dependent children and children with disabilities. Finally, specific issues of multi-agency collaboration, respite care, funding, equipment and risk assessment will be discussed as major contributory factors in the description and identification of children with complex care needs.

Health and social policy related to children with complex care needs

**Case example 1  Maria**

Maria was born prematurely at 28 weeks; she was ventilated and received intensive care in the neonatal unit. During this time she developed a pneumothorax and was diagnosed with cerebral palsy. When she was discharged home she remained under the care of the consultant neonatologist and the neonatal outreach nurse. Problems developed with movement and feeding, resulting in her referral to the local child development centre. Professionals involved in her care were the consultant paediatrician, speech and language therapist and physiotherapist for specialist support and advice. Routine child health promotion interventions were continued by the health visitor and general practitioner, and a social worker from the children’s centre became involved to give advice about benefits and support groups to Maria’s parents. The health visitor became the key worker for the family to co-ordinate services. At the age of 20 months Maria developed epilepsy. She also had delayed development affecting her ability to walk or achieve continence. Scoliosis was later diagnosed, which was severe enough to require surgery. (Adapted from Complex Disability Exemplar; Department of Health, 2005a.)

**Case example 2  Rachel**

Rachel stopped breathing shortly after a normal birth; she was ventilated and transferred to neonatal intensive care. She was diagnosed
Case example 2 (Continued)

with congenital central hypoventilation syndrome. The result was that Rachel required mechanical ventilation for periods of the day as well as overnight, which will continue for the rest of her life. A tracheostomy was performed to make ventilation easier and care was transferred to a children’s intensive care unit. Once stabilised, Rachel was referred to the community nursing team to prepare for discharge. A key worker was identified from the team to communicate and negotiate with Rachel’s parents and services, to provide care for long term ventilation of Rachel at home. Funding was sought for a multi-professional care package as Rachel’s future care would be outside the normal core provision for child health care in the community. (Adapted from Long Term Ventilation exemplar; Department of Health, 2005b.)

The two examples above are used by the Department of Health (DH) to illustrate some of the aspects of complex care needs in children; they highlight both the diversity and commonalities that exist when children are described as having complex care needs. They also illustrate the two most common areas requiring intervention for children’s services: the child with a disability and the child who is technology dependent and requires ongoing medical and nursing care.

The picture of children’s health in western societies has changed over the years, due to the development of health care knowledge, technology and drugs, which have contributed to the recovery of children who would not have survived previously. The resultant advances in health care have contributed to the fact that there is an increasing number of children who are dependent upon technology (Glendinning et al., 2001), in the form of equipment or specialist nursing support. In addition, there are children who have disabilities or life limiting illnesses that have also been supported by improved health care.

As the number of children with continuing health and specialist care needs has increased it is not possible or feasible to continue caring for them in secondary care settings. Governmental policy (House of Commons Health Committee, 1997), and recognition of the best psychological outcomes for children, demands that health and nursing care needs are delivered at home, rather than long term care in hospital. Parental participation in the care of their sick children has also contributed to expectations from both parents and professionals, that ultimately children with ongoing health care needs will be cared for at home by parents.
Parental participation in the care of their sick children has increased over the last 50 years following publication of reports that highlighted the benefits to children (Ministry of Health, 1959; Department of Health & Social Security, 1976). In 1991, the Department of Health recommended that parents should be involved in the care of sick children in hospital, based on the premise that it improves the well-being of children physically and psychologically. The underlying ethos of parental participation has led to an expectation from professionals that parents will participate and eventually take over the care of sick children, particularly when an illness is long term. While (1992) in her study of parent’s views of hospital and home care found that several parents felt they were expected to care for their child. This has implications for exploitation of parents due to the lack of alternatives when children are viewed as medically stable and ready for discharge (Glendinning & Kirk, 2000). The House of Commons Health Committee (1997) recognises the additional responsibilities, disruption of family life and financial costs of caring for a child at home, but nevertheless reiterates that it is better for children to be cared for at home. Policy such as this influences professionals and contributes to the expectation that parents will care for children who have long term health needs.

**Key policy related to children**

The philosophy of care in the community has developed from a political agenda of reducing inpatient care in acute services (DH, 1988). This was partly to reduce pressure on acute services, but also cost, as community care may be met from informal care and voluntary care, alongside professional agencies. In terms of caring for children in the community, policy has focused on health promotion and reducing health inequalities for vulnerable groups of children. The Quality Protects initiative (DH, 2000) focused on looked after children, with objectives related to improved life chances through better health, education and social care. Sure Start programmes (Department for Education & Employment, 2001) have been developed to target services and resources at disadvantaged children and communities, in an effort to address health inequalities and improve well-being. There are links between health, social and education services in the delivery of Sure Start initiatives with further plans to extend Sure Start Children’s Centres to all areas and ensure all Local Authorities make provision for services in their Children and Young People’s Plan (Department for Education & Skills (DfES) & Department for Work & Pensions, 2006).
The Children’s National Service Framework (NSF) (DH, 2004a) provides national standards to guide future service provision around the needs of children. The final standards were developed by eight external working groups, in consultation with practitioners and users, using evidence based information wherever possible. Chambers & Licence (2005) provide an overview of some of the evidence used to underpin the construction of the Children’s NSF standards, and consider how primary care services can use the NSF to improve services to children. Primary care is particularly important as the Children’s NSF is not disease based, but relates to all children and young people and their families. See Box 1.1 for Standards in England.

**Box 1.1 National Service Framework for Children, Young People and Maternity Services**

Standard 1: Promoting health and well-being, identifying needs and intervening early
Standard 2: Supporting parents or carers
Standard 3: Child, young person and family centred services
Standard 4: Growing up into adulthood
Standard 5: Safeguarding and promoting the welfare of children and young people
Standard 6: Children and young people who are ill
Standard 7: Hospital services for children
Standard 8: Disabled children and young people and those with complex health needs
Standard 9: The mental health and psychological well-being of children and young people
Standard 10: Medicines management for children
Standard 11: Maternity services

(DH, 2004a)

The Children’s NSF underpins the Every Child Matters: Change for Children programme (DfES, 2004), which sets out a national framework to co-ordinate the delivery of services to children and young people. This is supported by legislation in the form of the Children Act 2004, which outlines new statutory duties to clarify responsibilities of children’s services. Nationally, a Children’s Commissioner will raise awareness of the best interests of children and report annually to Parliament, and each Local Authority will appoint a designated lead...