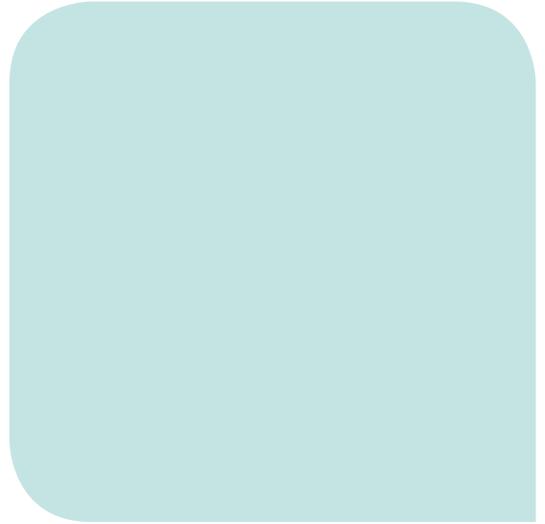


'Necessary stuff':

The social care needs of children with complex health care needs and their families



'Necessary stuff': the social care needs of children with complex health care needs and their families

Ruth Marchant, Michelle Lefevre, Mary Jones and Barry Luckock

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'Necessary stuff' is a direct quote from a young person with complex health care needs who took part in the consultation. It encapsulates a key finding of this knowledge review: dividing needs into health and social care does not make sense for this group of children and young people, and in fact creates extra problems for them and their families.

Front cover images produced by Connie age 6

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Executive summary

This knowledge review set out to identify what is known about the social care needs of children with complex healthcare needs (CHCN) and their families, and about the services designed to meet those needs.

The review was made up of three distinct parts:

- a consultation with children with CHCN and their families
- a review of relevant research
- a survey to identify examples of good practice in service provision.

There is no agreed definition of ‘complex healthcare’ needs among policy makers or professionals and the definition used in this review included children who are disabled, children with special educational needs and children with life-limiting or life threatening conditions. The definition remained flexible enough to allow for the fact that children with CHCN might fit all or none of these categories.

This study has contributed to the growing knowledge base by focusing on the priorities of children and young people with CHCN and their families. While this study supports many aspects of current policy and guidance, it raises some additional challenges and suggests that certain issues remain overlooked.

Service user and carer involvement

Strenuous efforts were made to ensure that the definitions, expectations and experiences of children and young people with CHCN themselves were central to the review - research in this field has to date tended to focus on parents’ views.

The methodology was jointly developed by the review team and the multi-disciplinary Advisory Group, which included as researchers young people with CHCN and their parents. One of the core group members was also a young person with CHCN.

The consultation was conducted expressly to allow an open enquiry into ‘social care needs’ and good practice, from the perspectives of children and young people with CHCN as well as those of their families and friends.

The 25 families involved had 68 children between them; 25 of these children had CHCN and 18 took part directly. They ranged in age from two to 24. Most had multiple health conditions. All used a range of communication methods and six relied solely on non-spoken communication. Eleven siblings and seven other relatives and friends also took part.

Information gathered from the consultation was used to define the criteria for 'good practice' that the practice survey set out to identify.

Rethinking needs; attending to the 'Necessary stuff'

The central finding challenges the very foundations of service provision and practice. Much research, policy and guidance has been based on the assumption that needs for health, social or educational services can be separated out and provided by different agencies. The research review and consultation clearly demonstrated, however, that this assumption does not tally with the experiences of children with CHCN and their families, whose healthcare needs are so much part of their everyday lives that they are inextricably linked with other needs. Attending to the 'Necessary stuff', therefore, requires a blurring of standard professional roles and boundaries.

This knowledge review has not solved these definitional problems but it is clear that we need further work on how we can use the criteria of 'ordinary life' or 'ordinary needs' to underpin services.

Key findings from the practice survey

Many examples of 'good practice' on the part of professionals and paid support workers were identified, which illustrate ways of meeting CHCN with minimal disruption to the 'ordinary' lives/needs of the children and their families.

According to children with CHCN and their families, good practice in service provision:

- demonstrates flexibility and responsiveness to families' individual needs
- actively safeguards their 'ordinary' lives and needs

- works in partnership with families, valuing their knowledge and expertise
- works with wider networks, including family, friends, other services and settings.

Eight services that fulfilled these good practice criteria were selected. Common features included:

- families were perceived as competent experts
- the child and family were acknowledged as partners in defining need
- a high value was placed on individual relationships
- different aspects of a child and family's identity were actively recognised and accommodated
- autonomy was delegated to front line staff
- high levels of flexibility and responsiveness were provided
- tasks such as 'navigating', 'signposting', 'way-finding', 'advocating' or 'key working' were included within the function of the service
- volunteers were creatively used within programmes

The survey also highlighted common difficulties faced by the sample of service providers in their attempts to innovate.

Invisibility of social care work

There was a mismatch between providers' formal remit and the actual services they provided. This meant that neither social care needs nor services were formally acknowledged. Consequently, workers' formal roles were overly restrictive. This led them to 'break the rules' in order to respond flexibly to families' needs. Planners, commissioners and managers need to ensure a better fit between what services are supposed to achieve and what is actually provided. They need to ensure that staff roles are adequate to the remit of their work.

Power and responsibility in commissioning arrangements

Another barrier identified was current commissioning arrangements and associated contracts that focused narrowly on specific needs, usu-

ally clinical. These further led to social care needs and services being overlooked and restricted the power of service providers to redress this imbalance. Planners and commissioners need to consider how services can be commissioned so that flexibility and responsiveness can be built in at the service design stage. They need to be clear about where responsibility for developing services lies in commissioning arrangements. Feedback loops also need to be in place to allow commissioners to learn from service providers in order to improve practice.

Durability of funding arrangements

A third barrier was the short-term nature of funding arrangements. This affected the continuity of service provision and familiarity with professionals that matters so much to families. Planners and commissioners need to explore creative solutions that would allow for longer-term provision of services for children with CHCN and their families.

Key findings from the research and consultation

What matters most

Children and young people with CHCN have the same 'ordinary' wishes and needs as other children. What matters most to them is being able to live at home, go to school, spend time with friends and participate in leisure and community activities with family and peers. This is also important to their families. Other priorities for children and their families include:

- practical issues, such as accessing facilities, getting the right equipment and securing the necessary finances
- the clinical and organisational competence of staff recruited to carry out aspects of care requiring specialist skills.

The priority given to these issues needs to be matched in guidance and practice.

A family-centred approach

The findings strongly support a ‘family-centred’ approach, which considers the needs of all family members, including siblings, both as individuals and as a unit. There is inevitably tension between child and family-centred practice, however, including the potentially conflicting needs of siblings. In order to provide practitioners with examples of good strategic work in action, further exploration of this issue is required.

The current allocation of services to specific children and young people, and not to the family as a whole, means that children with CHCN are unable to enjoy play, leisure or child care with their siblings. Providers need to consider changing these restrictions on service allocation.

Flexibility and responsiveness

Families’ consider flexibility and responsiveness to be very important, including:

- control and direct access to services,
- where and when health needs should be met
- the accommodation of family events, preferences and emergencies.

Providers need to consider how such flexibility and responsiveness can be built into care plans and provision from the beginning, and supported organisationally.

Practitioners need flexibility to work out their roles and responsibilities, so that any one professional can respond appropriately. However, current service configuration tends to reinforce professional boundaries. Providers need to think about how they can change professional roles to allow such flexibility and ensure the training of staff reaches the level and range of skill required.

Inadequate or irrelevant policies, staff training, supervision and support to facilitate flexibility made it difficult to be clear about the worker’s responsibility and accountability. These issues need to be addressed by organisations and in each child’s plan.

Manner and style of service delivery

There is strong evidence that the way in which professionals provide services is as important as the service itself. Parents feel emotionally supported by helpful and compassionate relationships. Organisations need to pay attention to the inter-personal aspect of services and support the development of the skills required.

Duration of services

Families value services they can rely on over longer periods of time, as well as needing services that can respond rapidly when they are in crisis. They want services that can continue even when their child's needs change, rather than having to keep changing the team or the service. Such continuity in service provision allows for familiarity with professionals and home care providers. This is currently hampered by the short-term allocation of services. Planners and commissioners need to explore creative solutions that would allow for longer-term provision of services.

Quality of process

Families still often experience services as sources of frustration and despair, rather than support and solace. Notions of 'fighting' and 'struggling' were ubiquitous. Families talk about 'taking on the system'. Services need to protect the quality of the process by building in ways of handling negotiation and disagreement.

Key workers

There are some indications that families are experiencing benefits from coordinated planning and the keyworker approach, which can relieve families of the burden of coordinating services themselves. However, services need to guard against the risk that key working further marginalises families' participation by relocating the problem one step away from them.

Further consideration needs to be given to the particular competencies that key working for children with CHCN and their families might require, due to the complexity of both families' needs and the service system itself. Organisations need to consider how they can be responsive to families' emotional needs, as well as their practical day-to-day needs.

Finally, the benefits of key working must not distract attention from systemic difficulties that key working is *not* able to address, which include the complexity of funding sources and statutory responsibilities, eligibility criteria for services and geographical differences in service provision.

Introduction

1.1 Aims and approach

The overall aim of this knowledge review was to identify what is known about the social care needs of children with complex healthcare needs (CHCN) and their families and about the social care services designed to meet those needs.

The difficulties and failures of service provision for children with ‘more complex’ needs have been extensively researched and reviewed.^{1, 2-4}

Consequently, we set out to focus specifically on good practice.

We also wanted to ensure that the views of children and young people with CHCN and their families were central to the research. Although this principle now guides health and social care policy, research in this field has tended to focus exclusively on parents’ views. We wanted to place the definitions, expectations and experiences of children and young people themselves at the heart of the review.

The result is a publication that differs from standard Social Care Institute for Excellence (SCIE) knowledge reviews in content and structure. It begins with the results of a consultation that allowed an open enquiry into ‘social care’ needs and good practice from the perspectives of children and young people with CHCN and their families. A more standard review of relevant research follows. The third section consists of a modified form of practice survey that aimed to identify examples of good practice in service provision. Lastly, an integrative analysis brings together and reflects on the findings from all sources. We compare the emerging themes and findings with current priorities within national policy and guidance across England, Wales and Northern Ireland, drawing out implications for policy, practice and research.

1.2 Policy and practice contexts

The knowledge review took place in a rapidly evolving context, which proved both exciting and challenging. In the year leading up to it a number of significant policy initiatives began to impact directly on provision for children with CHCN and their families. Many of these initiatives aimed to improve coordination across services and organisations, following extensive documentation of the difficulties and failures in provision.

Over a 25-year period, there has been striking consistency in the way parents report the negative impact on their family life of poor co-ordination and patchy service provision.¹

Commonly reported experiences included: difficult and confusing assessment processes; lack of information; lack of joined-up services; services that focused on a specific need or condition rather than the whole child and family; multiple agencies and confusing funding sources; long delays in funding decisions; finding out about help 'by accident'; and having to fight for support every step of the way.²⁻⁴

Thus many recent initiatives aim to improve service coordination and multiagency working, for example *The Children Act 2004*⁵ and the *Every Child Matters Framework*⁶; *National Service Framework for children, young people and maternity services*;² *Together from the start*;¹ *Common Assessment Framework for children and young people*;⁴ and the Department for Education and Skills' (2006) guidance on multiagency working. Others were designed to improve the accessibility of services, for example the Prime Minister's Strategy Unit report on *Improving the life chances of disabled people*;⁷ and the extension of the Disability Discrimination Act into schools and colleges.⁸

In the last three months of the knowledge review (November 2005-January 2006), several further major pieces of guidance were launched relating directly to this group of children and families: *For the NHS Commissioners commissioning children and young people's palliative care services*;⁹ *Including me*;¹⁰ *Complex disability – Exemplar*;¹¹ *Removing barriers*;¹² and the White Paper on community health and social care: *Our health, our care, our say*.¹³ Again, much of this guidance emphasised the

need for improved coordination and communication across disciplines and agencies.

After we had completed our review and it was in the editing process, a major review of the funding of children's palliative care, led by the Department of Health, reported on evidence of what works in terms of effective funding mechanisms.¹⁴ HM Treasury and the Department for Education and Skills¹⁵ also undertook a joint review of disabled children's services, the outcomes of which are very relevant to children with CHCN.

This knowledge review thus took place in a rapidly changing context of both policy and provision. This was another reason to focus our work around the priorities of children, young people and their families rather than around specific agencies or services.

Some, but not all, of the issues raised in the consultation and the research review are addressed by current initiatives and this is explored further in the Knowledge review conclusions.

1.3 Stakeholder participation

The knowledge review as a whole was guided by a multidisciplinary advisory group, which included as researchers young people with CHCN, and parents of children with CHCN. One of the core group members was also a young person with CHCN. The review team and advisory group members jointly developed the methodology. Younger children (with and without CHCN) were involved through Triangle's consultative groups in thinking about the issues and about how to approach the consultation with children and their families.

The consultation and the research review proceeded in parallel, sharing ideas, dilemmas and difficulties throughout and children, young people and parents were centrally involved. They participated in defining the focus of the review question and the methodology of the consultation and the practice survey, reflecting on and analysing themes, and critically reading drafts of the report.

The core group met four times across the course of the project; the advisory group met once as a whole group but all members were also involved via email, telephone and individual meetings.

We wanted the views of children and young people to be central because they are so pivotal and yet have so often been absent. The consultation was conducted expressly to ascertain their views as well as those of their families. The practice survey used information gathered from this consultation to define the criteria for the 'good practice' examples of service provision that we subsequently set out to identify. We also searched specifically for children and young people's accounts within the research review, but they were the sole focus of only 9% of the studies analysed, and tended to be the views of more able teenagers and young adults.

1.4 Key definitions

Definitional problems related to the key concepts of this review besieged the team from the start. We struggled with terminology at all levels: in our own discussions, in keywording for the research review, in our contacts with children and families and in our approach to different professionals. At various points it was necessary to remind ourselves that exploring the social care needs of children with CHCN did not require us to adhere to existing definitions of 'social' or 'health' care or 'complexity'. In fact, it became apparent that it was important that we did not.

1.4.1 Conceptualising 'complex healthcare' needs

As noted in the original commissioning brief, there is no agreed definition of complex needs among policy makers or professionals. Our definition of CHCN, therefore, cut across a number of other categorisations, including: children who are disabled, children with special educational needs and children with life-limiting or life-threatening conditions. Yet the definition necessarily retains flexibility; children with CHCN might fit all or none of the above categories.

For us, the boundaries of the definition proved less challenging than the concept of 'complexity' itself. One family's resources and/or competence, for example, may be much greater than another's. Tube feeding might be seen as a routine, everyday need or as a complex, risky nursing procedure, depending on the skill and experience of the family, where they lived and the services that they used. Thus, the definition of com-

plexity proves rather un-amenable to rigid classification but is, to an extent, in the eye of the beholder.

1.4.2 Conceptualising 'social care' needs and services

Definitions of 'social care' used in the research and guidance and by services also varied widely and families, of course, also had different ways of describing their own and their children's needs. Despite the variety of definitions found in research, guidance and services, they all assumed a fundamental divide between 'health' and 'social care' needs and services.

In contrast, from the outset, our discussions with young people and families suggested a much less clear 'division' of needs and serious doubts about the distinction between 'healthcare' and 'social care':

'Social care – that's a tricky one. I must say I don't generally think about it much ... what is a social care need anyway?' (15-year-old with CHCN)

'I don't think of myself as having social care needs. They're just stuff I do.... I don't think of them as a need ... [social care] kind of laps over with things like dressing and eating, I don't really think about it.' (17-year-old with CHCN)

'For me, social care and health care are all bundled together. I need a balance. The social care would include football, computers, going out. The medical care would include meds and nebulisers. If I stop either one of them, the other one gets affected. If I don't go out I get ill. If I don't get medical care, I can't go out.' (22-year-old with CHCN)

'My social care needs are my healthcare needs. When I am eating I need someone to put food in my tube and I need someone to chat with.' (14-year-old with CHCN)

Parents also raised concerns about the distinction:

'It's funny isn't it, how parents have to meet health and social care needs at the same time, but services don't?'

'... they keep telling me you have to separate out his educational needs and his social needs from his health needs. WELL YOU CAN'T. That's his health needs, that's his disability, that's his educational needs.... I try to explain they don't come as separate bits. I don't care who pays for which bit....'

It became evident that the needs of children with CHCN do not fit neatly into the categories of 'healthcare' or 'social care'. The healthcare needs of this group of children and young people are so much a part of their everyday lives that dividing their needs into different categories is deeply problematic. For this group of children and families, therefore, the very idea of 'social care' needs proved difficult to sustain and was often unhelpful. We chose the title of this review 'Necessary stuff' to reflect these definitional problems. It came from a 15 year old who took part in the consultation. She was explaining how fun, friends and a social life were crucial to her quality of life.

It became clear that we needed to redefine and reconceptualise the term that was at the very heart of what we had been commissioned to review. Yet we quickly realised that it was neither possible nor desirable to resolve these definitional problems *before* beginning to review the evidence. Instead, we needed to retain the issue of how best to reconceptualise 'social care' needs and services as a question to be answered. This challenged some of the basics of systematic review methodology, not least the formulation of the review questions.

1.5 Review questions

The issues around key definitions detailed above had serious implications for our formulation of the review questions to be addressed in this work. We began with the question: 'What is known about the social care needs of children with CHCN and their families and services designed to meet those needs?'. An extremely 'open' question, we were concerned that it was too broad to be adequately answered. Subsequently, we attempted to refine it as follows:

- What additional social care needs are created when children have CHCN?

- How can social care services best meet these needs in ways that least disrupt an ordinary social life for children with CHCN?
- What implications follow for policy, practice and research?

Through our struggles with the definitions of key concepts, however, it became apparent that, formulated in this way, these questions made assumptions about the nature of needs, and the division of labour associated with meeting them, that were incompatible with and unhelpful to the lives of children and young people we were consulting with.

In order to be able to explore these conflicts of definition more fully, it was necessary that we returned to the open question that we had begun with, while keeping the three-part focus:

- What is known about the social care needs of children with CHCN and their families?
- What is known about the services designed to meet those needs?
- What implications follow for policy, practice and research?

Consequently, rather than working with predefined terms, a key aim of the knowledge review became to investigate exactly how ‘social care’ needs and associated services are constituted by children and young people with CHCN and their families on the one hand, and in the research literature on the other.

Definitional issues were, therefore, a live concern throughout the life of the project. They are discussed further in the conclusions.

1.6 Remit of the review and limitations

In addressing these questions, we limited the focus of the review in various ways:

- The review focused specifically on children with CHCN in community settings that supported ordinary life in family settings and did not cover children in residential care.
- Knowledge and practice related to siblings was considered only in as far as it was tied to issues of ‘ordinary life’, excluding literature about, and services for, siblings rooted in a ‘young carers’ model.

- The needs of children with CHCN during their transition to adulthood were, similarly, considered only where these linked clearly to 'ordinary life' issues. This tight focus was necessary because the literature on transition is now substantial.
- The searching for the research review was completed in September 2005 and, therefore, we did not engage in detail with any relevant material published after that date.

Further research is warranted in these areas.

Consultation: What matters? What helps? And what gets in the way?

2.1 Methodology

2.1.1 Making contact

We distributed information about the project through a range of routes (clinical, social work and multidisciplinary teams, family support groups, interest groups), using both leaflets for children and young people and letters for families. By these means, families were invited to get in touch with us if they were interested in taking part.

We aimed for a diverse mix of families in terms of geographical location, ethnicity, religion, culture and family make-up. We also aimed for a wide range of children and young people in terms of age, health needs, life experiences and communication methods.

We were aware that some families would require specific and innovative methods of recruitment and we took steps* to ensure that minority ethnic families, families facing poverty, families who found reading difficult and young people who communicate without speech could find out about the project and take part.

* Some children and young people chose to tell us about the things they needed to stay well. We were shown lots of equipment, 'kit' and medicines and several children explained their scheduling to us. Yet several young people chose to tell us little or almost nothing about their health needs or their treatment and care: "I asked if she wanted to tell me more, she said 'no no no ... it's very boring and annoying' and she didn't want to talk about it anymore". Due to restrictions in space we are not able to include material specifically on perceptions and experiences of medical interventions and routines.

Family members participated not as users of any particular service but as citizens in their own right who may or may not currently be receiving formal support of any kind.

2.1.2 Engaging with children, young people and families

We were very aware of the pressures already on these families and tried to proceed throughout with respect and sensitivity. We made the assumption that time would always be in very short supply and we offered every family member:

- an absolute guarantee of anonymity
- total control about whether to contact us and whether to take part
- free choice about where, when and how to be involved
- flexibility and responsiveness to changing needs
- contact at different times
- contact through different routes: telephone, email, visits
- provision of skilled care for any children if required
- a gentle, flexible and responsive 'interview'
- a process that was easy to stop and restart at any time.

Once children, young people and families agreed to involvement we worked carefully with them to plan the best way to gather information about their experiences. This varied from family to family. We saw the majority of children and families in their own home, most often in the evenings or at weekends. Some parents chose to take part by telephone, and/or through email exchanges. Most children and young people were visited individually at home, but some worked in established groups, and others chose to be visited elsewhere (for example, in residential settings, in hospital or at a friend's house).

2.1.3 About the families

We consulted with different combinations of children, young people and parents from 25 families. Between them these families had 68 children, 25 of whom had CHCN, nine male and 16 female with an age range of 2-24.

Twenty of the 25 families were White British (English, Irish and Scottish) and five were partly or completely made up of Black or minority ethnic family members (African, Asian and Eastern European). The families lived across England and Northern Ireland. Our sample included four families who had adopted or fostered one or more of their children, and two families where the parents were lesbian.

Eleven siblings (aged 4-24, from 10 families) and two friends (aged 5 and 7) took part in group or individual sessions. We actively sought to include boys and men and spent time with fathers (7) as well as mothers (12) and brothers (5) as well as sisters (6). We also spoke with grandparents, aunts and uncles from four families. Seven sets of parents took part without their children because the child was too unwell at the time (3), because it was not a good time (1), because it was not possible to arrange (1) or because the child had died (2).

To summarise, in total we consulted with:

- 18 children and young people with CHCN
- 11 brothers and sisters
- 19 parents
- 7 other relatives or friends.

2.1.4 About the children and young people

Most children had multiple health conditions. Some children were well for long periods but could suddenly become very sick; others had long-term conditions and others had progressive conditions or illnesses.

The conditions creating the children's healthcare needs included cerebral palsy, epilepsy, leukaemia, brain tumours, cystic fibrosis, acquired brain injury, spinal injury, diabetes, anaphylaxis, asthma, eczema, immune disorders, lung immaturity and various rare genetic or metabolic conditions. Almost all the children had more than one condition creating a CHCN. Many (21 of 25) of the children also had impairments of hearing, learning, understanding, vision, mobility or communication.

The children's healthcare needs included gastrostomy and nasogastric tube feeding, assisted ventilation, oxygen via different routes, Hickman lines, emergency medication for seizures or anaphylactic shock, resuscitation, cardiac pace-making, complex medication regimes, catheterisation, a range of surgical interventions, chemotherapy, radiotherapy,

physiotherapy, postural management and positioning, monitoring and intervention for apnoea and blood sugar monitoring. For many, this means a hard, endless reality of uncomfortable, painful and invasive procedures.

Most (23 of 25) of the children with CHCN lived all or most of the time in families (including foster or adoptive families). All children had spent time in hospital, some children had lived away from home and some had regular short breaks from home. We included one young man who was living in a hospital environment but attempting to set up his own community-based service and the views of one family whose young child was just beginning to leave hospital.

Eighteen children and young people with CHCN took part directly, ranging in age from 6-24. All used a range of communication methods. Six relied solely on non-spoken communication: signing, eye pointing, gesture and communication boards. The range of healthcare needs was wide and all the children had experienced multiple medical interventions and hospitalisations. In fact, nine of the 18 were hospitalised during the three months of the survey.

2.1.5 The focus and methods

As stated in the introduction, our initial discussions with children and young people with CHCN and their families made clear that their needs did not fit neatly into categories of 'healthcare' or 'social care'. Equally, it had become evident that the division of services according to this split in needs was highly problematic.

In order to avoid imposing these different categories of either needs or services, therefore, in our group sessions and individual visits, we focused on 'needs' more generally. We talked about these in terms of 'what matters' for families, that is, asking about what was important to them and what their priorities were.

Concomitantly, rather than predefine the kinds of services to be discussed, we focused more broadly on 'what helps', as well as 'what gets in the way'. We asked about the 'manner' or 'style' of help, as well as the help itself. We were careful not to focus only on the service system and questions were framed as openly as possible. Barriers, for example, could arise directly from a child's condition or illness, or indirectly from

barriers in the social world or the service system that made it harder for their needs to be met (however defined).

We tried to offer everyone who took part the opportunity to tell as much or as little of their story as they wished.* Often we asked very few questions; we aimed to give the agenda to the children, young people and families as much as was possible. We aimed for open-minded and evidentially careful questioning** and we did not use a structured questionnaire. We worked with visible blank pieces of paper and as far as we could we gave over complete control of the time, the agenda, the paper and the pens. With children we used a wide range of resources and methods to support communication.*** Some families also showed us or gave us photographs, drawings, care plans, ‘passports’,**** letters, reports and tributes.

Those carrying out the direct contacts had long experience of working with disabled children or children with CHCN; some were parents of disabled children or were disabled themselves. The sibling groups were led by experienced adult facilitators, who themselves also had siblings with significant healthcare needs.

* These included: targeting a wide mix of geographical areas; producing information in different formats including using images and symbols; arranging direct approaches and translation and interpretation where English was not the family’s first language; making clear that we would work with any communication method; following this through with visitors using sign, communication boards and play-based methods.

** Some of Triangle’s work involves gathering evidence from children for use in civil or criminal court proceedings. From this work we have learnt much about framing questions carefully and in non-leading ways.^{16, 17}

*** These included laminated photographs of leisure activities, transport and familiar places, symbol and image sets, objects of reference, play and art materials.

**** Passports are accessible, child-friendly summaries about a child and their needs.¹⁸

2.2 The findings

We have combined the views of children, young people and their families, structured by the main themes that emerged on the question of 'what matters' for children and young people with CHCN and their families. Two clusters of priorities stood out.

The first (a) relates to 'people and relationships' and includes relationships with family and friends. These relationships were linked to another important issue both for children and young people with CHCN and their families: (b) individuality and identity, that is, being 'who they are'. With the high levels of support and care needed by these children and young people, relationships with people providing services were also a major part of their lives. The final priorities identified in the consultation relate to issues of boundaries between professional and private relations, that is (c) 'who should care' and (d) the nature of relations with professional care providers.

The second cluster of concerns raised by the children and families consulted related to the issue of 'staying well *and* living an ordinary life'. Here priorities included: (a) professional and organisational competence but also (b) a family-centred approach that is flexible and responsive to an individual family's needs, (c) practicalities and (d) taking on the system.

For each theme we have included things that get in the way and some ideas about things that help. Quotations followed only by the age refer to children and young people with CHCN. For the sake of brevity this is not stated each time. Details of the relationship with a child or young person with CHCN are given in relation to siblings quoted. Quotations made by parents of children and young people with CHCN are identified in the body of the text.

Where children communicated through signs, symbols or word boards, their communication is reported in their own words, whatever the communication route, as summarised by the person consulting. Children using signs, symbols or word boards are producing their own words they are just not saying them. Where children communicated through play, facial expression, gesture, behaviour, or responding to adult questions, this is clarified in the text, making it clear that the child or young person is the source.

2.2.1 People and relationships

Whatever their situation, relationships were crucially important to every single one of the children, young people and families that we met. When asked about their lives, children and young people almost always started with the people that mattered most to them: people they lived with, people they cared about, people who loved them, people involved in their care.

'Family and friends' was also the most common response from parents when asked about what was important in life, what mattered most, what kept them going and where they got their support.

Relationships with people providing services were also a major part of the lives of most of the children and families that we met. Many described professionals who became friends or became 'part of the family'. We explore these different relationships below, and the boundaries are considered in Section 2.2.1.4.

2.2.1.1 Family

Children and young people told us about their families in many different ways. They named, drew and showed us photographs of different family members. Parents were mentioned most often, then siblings, cousins, aunts, uncles and grandparents:

'Mummy. Daddy. Sam [brother]. Nanny. Granddad. Aunty Jo.' (9-year-old)

Relationships with siblings were as mixed as in most families:

'Her little sister winds her up a lot and she sometimes pushes her or pokes her but they also laugh a lot together and like many of the same things.' (parent of a 7-year-old)

Some siblings were unhappy about the amount of time or attention given to their brother or sister:

'He gets all the attention. Sometimes ... and I don't want to be his sister.' (8-year-old sister)

Many wished their brother or sister could get better. These quotes are from three different children:

'I would like sometimes to play with her more.' (6-year-old brother)

'You can't play like other brothers and sisters 'cos you have to be careful.' (7-year-old sister)

'If my brother was stronger... ' (8-year-old sister)

Many siblings were strong defenders of the needs and rights of their brother or sister to be treated 'like everybody else'.

For most parents, their wider family was central in their lives, including but not only as a source of practical support:

'The only way we get a break as a family is my family. I don't think we'd cope without me mum and dad...'

'Her own parents live nearby and are very supportive, but she is concerned that she can only expect this level of support from them for another 5-10 years and is worried about who will help after that.'

This section is short because there was absolute agreement across all groups consulted that family relationships were crucially important and usually mattered more than anything else.

Relationships with family: things that helped

The nurse who did a night shift at granma's, 300 miles away, so the child could be bridesmaid at a family wedding.

The uncle who surfed the internet for helpful information.

The consultant who paid attention to the whole family's needs.

The grandparent who "never judged, even when we wanted to give up".

The social worker who did not try and “whisk him off to respite”.

The physiotherapist who let the little sister join in with exercises too.

The nursing team that taught all four grandparents and two aunts to tube feed.

The grandfather who read stories in hospital for hours on end.

The church who welcomed the whole family, always.

The playground that had “something for everyone”, and safe quiet shade.

The home sitting service that cared for siblings as well.

2.2.1.2 *Friends*

Friends were also extremely important to all the children and young people we met. This was true right across the age range:

‘What children need most is a friend to help and play with.’ (6-year-old)

‘She showed me with her communication book that she had two main friends at school, one in a wheelchair like she is and one who is not in a wheelchair and uses a walking frame.’ (8-year-old)

‘I didn’t want to go to another school with thousands of kids on my own again ... so I chose this school because I knew some kids at this school which is good.’ (13-year-old)

‘I am an organised person, more organised with friends than with other things in my life, because it is more important to me.’ (22-year-old)

Younger children listed brothers, sisters, parents, cousins and pets as friends. Many children named current paid workers as friends, particularly people who visited them at home or were involved in their play. Parents sometimes noted this as well:

'The nurses were wonderful ... they became real friends with our daughter, they were extremely fond of her ... she spoke about them as her friends.'

Some older young people also did this. More often, older young people listed ex-carers/ex-nurses/ex-teachers as friends, describing friendships that had grown out of a previous paid relationship. There was travel in the other direction also, with friends and family who become paid carers. The idea of paid workers as friends was a recurring theme:

'My carers are my friends when I like them, when I don't I see them as a carer.' (21-year-old)

Not everyone agreed that this was a good idea. One father was pleased that his son had:

'... lots of friends so can go to different people for different types of help or support ... so it's less likely he would need his physiotherapist to be an emotionally supportive friend as well as a health worker.'

One family described their sense of loss when a much-valued night sitting service stopped because the child no longer needed tube feeding. Others described how siblings also became attached to carers. This created serious difficulties after a child died:

'Once she died, by and large all the professional people who had been coming regularly to the house stopped coming ... the hydrotherapy swimming stopped ... it was hard to explain to her sister [4-year-old] that these things weren't happening anymore ... it was as if not only had she lost her sister, but some of the people she considered as her friends also went too.'

We return to this theme in Section 2.2.1.4.

A few parents described their children as having ‘lots of friends’ or ‘a good social life’; however, far more frequently parents raised concerns about their child’s lack of friends, particularly friends of their own age:

‘He’s fairly isolated ... his world is pretty much home, plus school when he’s well enough, which means about 50% of the time ... we’re trying to find some kind of life for him outside of home.’

‘She has few friends of her age ... it’s hard ... after school she is at home or with her grandparents. She only sees friends at school really ... a social life outside of school, it would make her much happier.’

Many families talked about how hard it was for their children to access play or leisure activities:

‘... she wasn’t well enough for the rough and tumble of young children plus there was the risk of infection.’ (parent of 4-year-old)

Other parents highlighted the reluctance on the part of schools to take necessary risks as a serious barrier:

‘He was going to go on a school residential trip; he was very excited. They asked me to do the night sitting, the meds and the tube feeds. I said yes because otherwise I knew he wouldn’t be going. Then they sent me this form.... I knew before I filled it in there’d be trouble. They did a risk assessment, they said he couldn’t go.’ (parent of 13-year-old)

‘The school says it can’t be responsible for feeding him at lunchtimes in the canteen because they won’t take responsibility for his allergies. He is being isolated. He has to sit in the corner in a sterile place....’ (parent of 11-year-old)

Some families saw the healthcare demands as a major barrier to friendships:

'At what point do you say he has a social life? There are a certain amount of blocks each day, there are so many things he has to do that he has little choice in the bits that are left.' (older brother of 7-year-old)

Others felt things could be handled differently, for example:

'... less restriction and isolation ... more freedom at school and his 1:1 not following him around ... having young, "cool" support people: he doesn't like having Miss K because she's old, of course he wouldn't say because he is too polite.' (older brother of 13-year-old)

Some children and young people also wished for more friends, or more opportunities to be with the friends they had:

'Once school is finished I get in a taxi and go home.' (12-year-old)

'[To see friends after school] ... I would have to take my pump, my wheelchair and everything and lots of my friends live in flats.' (13-year-old)

'He talked about friendships being "two way" and said it was difficult to get a 50:50 relationship sometimes as it is not always easy to put into a relationship....' (22-year-old)

'She would like to be able to do a sleepover with a friend, she would like more friends but it was difficult to meet people and to keep friendships because she needs someone to help her make the arrangements and help her to go out. Being out late at night was also difficult.' (17-year-old)

Lunchtimes and playtimes at school were very important times for friendships:

'Most helpful was my class teacher, she fixed it for lunches because I couldn't go out at play and I couldn't go on the stairs until everyone had gone. She let me have three friends have lunch upstairs with me and her.' (9-year-old)

'I need the other children not to tease me, to come to playtime club with me if I can't go outside.' (8-year-old)

Relationships with friends: things that helped

The dinner lady who made sure the child never sat alone.

The friend's mother who learnt how to use the epipen so the child could visit.

The physiotherapist who arranged sessions so that the child missed maths instead of playtime.

The friends who kept inviting the family over even though they were never invited back.

The teacher who ate everyday with the child who could not handle the dining room alone.

The friend's family who had nut-free birthday parties so the child could go.

The outreach nurse who was "cool enough to get me into a nightclub".

The youth club that organised a private room for a rest mid-evening.

The cousin who set up MSN messenger and a wireless connection so the teenager's laptop worked in his bed.

The nursing team who "worked cheerfully around the hamsters" in the child's bedroom.

The link family where the child's dog could go too.

The taxi company who offered a flexible, "ring at the last minute", after-school pick-up so the child could stay for after-school clubs when they were well enough.

The head of year who decided the outing was a reasonable risk.

2.2.1.3 *Individuality and identity*

Relationships are crucial to people's sense of who they are. Many children and young people and some families talked with us about different aspects of identity, and the things that helped them 'be who they are'.

Cultural identity: one young person lived in an environment that actively promoted a different religion to his. Despite protest he had been unable to change things that he found difficult and at times offensive. He told us:

'... with me racism is a really big thing.... I hate it. I really hate racism ... other people don't understand that.' (17-year-old)

Two other families told of difficulties in having their cultural needs respected, for example, children being given pork to eat in error or not having their hair or skin properly cared for. Where workers were of the same (minority) ethnicity as members of the family, this was found to be invaluable:

'Through direct payments, we have found it possible to address my daughter's cultural needs, for example with her personal assistants [PAs], we specifically plan for her to be part of Black and Asian culture by attending social events, music events, food, reading books, etc. I also try and ensure that at least one of my daughter's PAs reflects part of her cultural identity. So far, this has been possible.' (mother of 14-year-old)

Identity as a family member: several children and young people clearly felt valued as contributing members of their families:

‘When my little cousin comes [to the campsite] I take him to the club. By myself ... he’s only four.’ (13-year-old)

‘If I was to lose my job, my brother [who supports me] would have to go out to work so it would totally bugger it up basically.’ (23-year-old)

And some told of family friends who were definitely friends of the child as well as the parents:

‘We also have close friends who ... visit her regularly and chat to her and occasionally take her out, all of which gives my daughter a real sense of being valued and loved.’ (mother of 14-year-old)

Some families felt their child tried to minimise the impact of their needs on the family:

‘I think he gets bored but he’d never say.’ (father of 13-year-old)

‘She described how her daughter will blow kisses when she needs her nappy changing, she thinks this is because she “doesn’t want to be a burden, she knows she is a drain”.’ (mother of 9-year-old)

Identity as themselves: the children and young people that we met swim against many tides. As well as the direct impact of their conditions and impairments, they live their lives in a very disabling society where it is often a struggle to get their basic needs recognised and met. Yet we found many examples of children and young people actively managing their identities and finding ways to cope.

‘When I’m most relaxed with myself ... is when I’m watching football, ‘cos then I’m not any different, it’s 45,000 people all in blue.... It’s when I’m in my element. I wouldn’t say it makes me feel normal but it makes me forget.’ (22-year-old)

‘I’m the kind of guy that would do anything at least once. If I don’t like it, I won’t do it again.’ (17-year-old)

'Fun – life's not just for doing 'Necessary stuff'. If you don't enjoy anything you do your quality of life is zero.' (15-year-old)

'I do things I enjoy, I go out with friends and use my computer, I've learnt how to adapt my life around that. I try and think of different ways to do things.... That's what I try and do, I adapt things so I can do things.' (22-year-old)

A younger child was getting increasingly fed up with the things she could not do. Her mother said that she would like to eat sweets, play with toys and look at books by herself like her sister could. The child (aged 9) strongly agreed by nodding, shouting and waving her arms (9-year-old).

One mother described the impact her young daughter had had on many of those involved in supporting her until she died at the age of four:

'Having known her, she made such a great impression, they had seen her so visibly enjoying life despite her immense difficulties, they would always feel differently towards other children who might be similarly disabled.'

Some young people, particularly those with new or progressive conditions, struggled to manage their identities. Help from adults to 'information manage' was appreciated: "The teacher helped by telling people about it" (9-year-old).

Managing one's identity in public environments was not an issue for some young people, but others found it difficult and painful, as did their families:

'I don't think they have a clue ... it feels like we're from outer space.'

'I didn't want anyone to know I had a pump ... I didn't really hide it I was in a wheelchair I had it between my feet like a back pack they didn't really see the lead.... I hid it ... because I was embarrassed ... it was because I was really shy. Sometimes I would finish my pump really quick at home so I didn't have to take it in.' (13-year-old)

Siblings were often very aware of these issues:

‘She needs people to know that she’s six so she doesn’t like being treated like a baby.’ (8-year-old sister)

‘I know he has turned the pump up so it goes quicker so he doesn’t have to go to school with it, he wants to be like everyone else.’ (older brother of 13-year-old)

Identity – shared experiences: several families talked of the value of people with shared experiences, who had children with similar needs:

‘... meeting other families ... the strength in knowing you aren’t the only one who goes upstairs every night feeling just so exhausted.’

‘There was just such a sense of relief – another child with an epipen! A guaranteed nut-free household!’

Some young people also talked about the importance of friends with similar needs or experiences:

‘If I’ve got a problem relating to disability I talk to my disabled friend because she is the only one who understands.... It’s helpful we are both in pain quite a lot, it isn’t good but it’s helpful for each other, for understanding, mutual support, offer suggestions. It’s easier to talk to her because she has a disability, I don’t see it like that though.’ (22-year-old)

One young person with a very rare health condition developed scoliosis as a teenager and found that having a more common diagnosis helped her:

‘It’s good to belong to a group, lots of people have scoliosis.’ (14-year-old)

Some young people had made friends who were ‘different’ in other ways:

'Her best friend lives 50 miles away. Her mum feels they get on well because they both "don't fit in". Because of her different health conditions, her daughter doesn't quite fit in, and her best friend is the kind of child "who chooses not to fit in most of the time".' (mother of 10-year-old)

Individuality and identity: things that helped

The PE teacher who blu-tacked the egg to the spoon on sports day.

The occupational therapist who agreed that skipping was an essential life skill.

The after-school club that allocated 1:1 staffing without question, "as if it was his right".

The godparents who set up an Easter egg hunt all at wheelchair height.

The local education authority who agreed "staying alive" as the child's primary stated need.

The children who stuck up for their brothers' and sisters' rights.

The consultant who involved same-sex parents "without skipping a beat".

The clinic who offered interpreters as routine, and extra time when needed.

The service that actively sought information about a family's culture and religion as routine, in a low-key, relaxed way.

The nursing team who asked the family for skin and haircare guidance.

The hospice that linked families together gently, at the right moment.

2.2.1.4 *Who should care*

All of the children and young people we met needed high levels of support and care to stay well. Most had strong views about who should and should not be involved in providing this support. Many young children wanted their family to carry out most of their care; in fact this was very important to some children:

‘A special person should tell mum, dad or the child how to do it and then after that they should be able to do it, then it should always be someone from the family.’ (8-year-old)

‘Does anyone else (apart from your parents) help you at home? An indignant “No!”’ (6-year-old)

We worked with some young children in a group, thinking about children with CHCN first starting school:

[Interviewer: ‘What would he need?'] ‘His mummy to go with him.’ (7-year-old)

Some of these younger children were also wondering how much they should rely on their friends for day-to-day help:

‘Children should help with some things. A friend should do it, other kids should do it ... yes, your friends like you and are willing to help you.... Probably.’ (8-year-old)

These issues, about friends helping, and people helping who then become friends, was a strong recurring theme. Rigid concepts of ‘role boundaries’

do not transfer easily to this group of children who require high levels of support and therefore have so many relationships to negotiate.

Some older young people were more concerned about the potential difficulties of 'mixing' friendship with paid relationships:

'This is the biggest problem of my life ... people ... they're willing to come talk to you, tell you about all their problems. To me that's cool, but then they get the idea we're best buddies. They've got their job to do and I'm trying to live my life.... I don't know what their game is. They're not my friends – they have nothing to do with my life. Don't think we're gonna be calling each other telling problems, that kind of thing – automatically it brings trouble....' (17-year-old)

Some young people were very clear that roles should not be blurred:

'... I wouldn't have that.... I believe that carers should be carers. Teachers should be teachers – end of story.' (18-year-old)

Some families had used different mechanisms for family members to be employed to provide some of their child's support. With children this tended to be more distant family members but we met with several older young people where close family had been successfully employed in this way:

'On the care side you are not supposed to employ family or people living in the same house as you ... but there are special circumstances.... It should be the young person's choice who to employ, if it's a family member they want, it's a family member they should be able to employ.' (father of 18-year-old)

'My older brother is my primary carer.... He lives in the same house as me, but I have my own living space.... It works.' (22-year-old)

Some parents described struggles with their role. As one mother pointed out it is not always appropriate for the young person to rely on a parent:

'I end up going too, to youth club for example....' (mother of 13-year-old)

And another found that healthcare took a toll on her relationship with her child:

'It's hard being mum making her have all these treatments, and then she doesn't like them and hates me for it.' (mother of 11-year-old)

2.2.1.5 *Relationships with people in 'the system'*

Most children and families described their relationships with people in 'the system' as very important in their lives. The phrase 'the system' was spontaneously used by a number of young people and families, usually to describe a whole array of services.

As set out above, many children and young people named current and previous workers as friends; several parents described workers as 'becoming part of the family'. One parent explained:

'It's not been about ... how any service is organised or delivered ... but is down to individuals who will go that bit extra, not clock watchers more interested in their guidelines than your family....' (mother of 7-year-old)

Although there were differences of view, there were some recurring themes about what mattered, in particular continuity and familiarity, kindness and care, and respect and understanding. These are explored below.

Continuity and familiarity: children and their families valued services and people that provided continuity over time. Those who had known children for many years were particularly valued, not just for their clinical competence but also for knowing and understanding the child and the whole family, for building a relationship of trust:

'At hospital if my doctor is around everything is alright ... he's known me for 15 years ... if I'm given wrong drugs I'm in trouble ... he really understands me.' (13-year-old)

One young child (aged 5) was presenting very challenging behaviour because of his condition; his mother explained that people who knew him well could spot the signs and pre-empt the problems, which avoided escalation to behaviours like spitting, hitting, trashing classrooms and escaping. Other parents also valued professionals with experience:

'I trusted him. I think because he saw her in the middle of a really bad reaction, and he stayed with her in ITU until she was settled. So when he told us what she needed I trusted him.' (mother of 9-year-old)

Parents also valued people who got to know their children:

'You know, there were so many people at that meeting and most of them had never even met our daughter. And those that have, mostly they just look at her for 10 minutes.' (father of 9-year-old)

Children also valued and liked familiar people who they trusted and knew well. Several parents described their young children struggling with meeting so many new people. Older children explained:

'I prefer it when someone I know looks after me.' (13-year-old)

'I would like the person who I most liked to do it because I know them well – it is someone who has been in every single class with me – Mrs C – an education assistant.... I won't cry if she left [sic].'
(8-year-old)

'If it's my usual hospital the nurses know me which is helpful ... I would like the same nurse when I go to hospital because if I was ill I wouldn't have to explain everything.' (11-year-old)

Some families found it preferable to decline support altogether rather than deal with an unfamiliar person:

‘We got to a point where we didn’t want a new nurse to come, without knowing that it was likely that she was going to make a commitment to come regularly ... because my daughter found it frightening having a new nurse. If we had a new nurse offered who was only doing a one-off shift, then we would say we would rather do the night ourselves, because it was stressful for us having a stranger in the house for one night, and even more so for our daughter.’ (mother of 5-year-old)

Children with limited understanding and communication also had very clear preferences for familiar people:

‘Her mother told us that three different helpers come to help her get ready for school. She likes them all but gets on best with Daryl. She confirmed this very clearly with eye pointing and facial expressions, when shown photographs of the different helpers.’ (9-year-old)

Linked to familiarity with individual practitioners was the desire for stability in services themselves; we were told by many families about services that were available for a fixed period of time, usually as a way to manage demand for the service. These short-term interventions were rarely popular. One parent described her fury at a poster offering short-term counselling for families of children with CHCN:

‘... the idea of “short term” just made me want to rip it off the wall. Oh f**k off with your short term ... we’ll dabble dabble with you ... five sessions!! They have to be joking.’ (mother of 7-year-old)

Families valued services that were “robust” and “in it for the long term” and wanted services that could continue even when their child’s needs changed, rather than having to keep changing the team or the service.

One young man (aged 13) told us how hard it was to have to change schools when his health deteriorated: “I went to one school and kept going from school to school”. Another parent described the following:

‘When she was two, a Sure Start area was set up covering our road. They offered me a new health visitor and I said no thank you I want to keep the one I’ve got; she knows us, we trust her. They wrote to me and rang me, and then someone even came to see me to ask me

to change over to the Sure Start health visitor and in the end I said NO, this baby has been in hospital 11 times this year, and Sally knows all about it and I do not have the TIME to explain it all again. They didn't come back, and we kept Sally.' (mother of 9-year-old)

Another family was in transition from children's to adult's services and felt "a bit in no man's land at the moment" (parents of 18-year-old).

Erratic contact from professionals was frustrating for several families:

'We seemed to need to have the idea of weighings to keep her [the health visitor] involved ... there is such an emphasis on having a specific purpose for each family contact.... She made contact again when our child was three because once again she had a role – she was able to tell us about the free nappies.' (mother of 5-year-old)

'Each time he was discharged from hospital they would ring us up, but in between there were long long gaps. I think they had a box to tick.' (father of 9-year-old)

Kindness and care: families and children valued people who cared and were kind, thoughtful, and warm. There was a high level of agreement on this:

'I have 1:1 Miss E ... she's very nice helps when I need help. She's new ... reminds me of my nan.' (11-year-old)

Some relatively young children were very thoughtful about their criteria for who would be best to help with healthcare needs at school. Here is part of a supported conversation between three children aged 9, 10 and 11:

'I think definitely a nurse or a teacher, or the office people.'

'I would choose a teacher, education assistant or school nurse. I know my teacher well. And the people in the office....'

'No not by their job, you shouldn't choose them by their job. It should be how nice they can be, how kind.'

'Yeah, like the office ... the people in the office at my school, they are mean.'

'No, it should be by – do they know what to do?'

Interviewer: 'Can you teach them what to do?'

'Someone can teach them what to do. Yeah, the nurse taught my LSA what to do.'

'My mum showed the teacher.'

'Well, I can tell them most of it.'

Interviewer: 'Can you teach people to be kind?'

'You probably couldn't teach them to be kind, if they're not kind in the first place.'

Another young child named two different helpers at her infant school:

'One for my "button" and one who checks my bloods ... they sometimes help me go to the toilet ... Miss F is better, she's more fun.'
(6-year-old)

Older young people also valued kindness, warmth and people who showed interest in their lives. Parents again spontaneously mentioned the importance of professionals who care:

'One thing that we really liked was those nurses and others who really cared.' (mother of 7-year-old)

'The consultants were all excellent, very caring and very high calibre.'
(father of 4-year-old)

'I didn't have to worry leaving my child with her because she loved her.' (mother of 9-year-old)

'... a lovely social worker ... good at listening, creating a safe environment for discussions, ... promoting the wishes of the family.' (parents of 6-year-old)

It helped one family that they could ring their social worker and feel safe enough to be very honest:

'... and say when we were feeling at the end of our wits.' (parents of 9-year-old)

One support worker who came to see a family in her free time, unpaid, rather than leave them without support, is now a close personal friend of the parents: "She saved my life on more than one occasion". For example, when there was a crisis at home with another child ill, and their daughter was also very sick in hospital, she rang the worker at home on her day off:

'And she said I'll be there in half an hour, so she came to the hospital and stayed with our youngest so I could go home....' (mother of 7-year-old)

Respect and understanding: older young people talked to us about dignity and respect:

'Tricky to measure but an example might be not having personal information blabbed to others.' (15-year-old)

One young man spoke about his previous teaching assistant:

'I could tell him anything, he understood me.' (13-year-old)

Two of the families we spoke to identified the importance of male workers for young men, their brothers and fathers:

'He [male nurse] is his main support, the only person he can talk to and cry in front of.' (mother of 7-year-old, about her husband)

Parents were also very discerning about relationships with professionals and contrasted the very different kinds of relationships they had experienced:

‘Some of them are so jaded ... my daughter knows straight away – she gives me “the look” as soon as she’s in the door ... [but others] show a real interest, and are warm and attentive, and explain exactly what they are going to do so she hardly needs to give me the look at all, unless maybe they do something that hurts her.’ (mother of 10-year-old)

‘[... the doctor] was young and she listened ... she didn’t call me mum and she didn’t patronise me ... she didn’t say “calm down you’re being neurotic”.’ (mother of 9-year-old)

‘Our GP is helpful because she listens to me and works in a way that I like.’ (father of 9-year-old)

‘[The doctors’ basic approach in consultations was:] There is nothing that can be done about it and by the way, your 10 minutes is up.’ (mother of 10-year-old)

Relationships with people in ‘the system’: things that helped

The teacher who regularly ‘dropped by’ the child in hospital on her way home.

The GP who was “calm, collected and helpful and did not just say no”.

The consultant who never made the family feel their child was “one of 100s”.

The headteacher who “kept an eye on things” all the way through primary school.

The support worker who “dropped everything” to be there in a crisis.

The carers who “made it more than just a job” and “took time to help”.

The secondary school who “stuck with” the child, even when his needs changed again and again.

The managers who organised steady provision of care through a changeover of services and teams.

The worker who worked in three different organisations in order to follow the child.

The doctor who “popped in” to the family home with results from blood tests.

2.2.2 Staying well *and* living an ordinary life

By definition these children and young people need a lot of help to stay well. What mattered for these children and their families, however, was not only staying well, but staying well while, simultaneously, living an ordinary life. Clinical issues of competence related to their healthcare needs were, of course, a matter of great importance. However, flexibility and responsiveness were also heavily emphasised in families' accounts of service provision that would enable them to get on with ordinary life individually and together. This related to a range of issues, including control and direct access to services, where and when health needs should be met, the accommodation of family routines, events, preferences and emergencies and the roles/responsibilities of any one professional.

2.2.2.1 Competence

Clinical competence: clinical competence was highly valued by children and young people:

‘I had S [physiotherapist] she was ever so lovely she knew what she was doing.’ (13-year-old)

‘I think it should be an experienced person.’ (9-year-old)

‘You need someone calm ... ready for it ... not all agitated ... not all stressy.’ (10-year-old)

Some young people were anxious about an apparent lack of competence, especially in schools. Three staff had been especially trained to do one teenager’s medicines at school; we asked why:

‘I suppose they are to check one another?... Miss J and Miss T has to supervise all the medication. Last week Miss T wasn’t there and they were looking for someone. Miss A has done the training but she wasn’t in that day ... I missed half my lunch.’ (13-year-old)

‘... well if I had a big asthma attack at school they probably don’t have what I need. They could ring mum to pick me up, or they could send me to hospital.’ (10-year-old)

Others were more confident that their school could meet their needs:

‘My mum and the teacher ... she was careful what I ate, careful of nuts. She would check the food and see what I could eat and I always showed her the food first and she had the epipen and she was the one who banned the whole school from nuts – because there was a scare, someone gave me a biscuit through the fence [between two playgrounds], and no one knew if it had nuts in. I used to learn when I was in reception so I could tell someone.’ (8-year-old)

‘In a way sort of because she was a nurse ... and the other lady ... she has a grandchild who has a gastrostomy too.’ (13-year-old)

Competence was also highly valued by parents; several families described competence as “infectious” – competent people could “spread it about”. One father said he was almost “bursting with hope” when he was shown how to set up a home oxygen system:

'I thought yes I can do this, I can really do this. Until then I thought no, she'll never be able to come home.' (father of 18-month-old)

Parents valued seniority and confidence, especially at times of crisis:

'At a glimpse he [the consultant] could see how sick she was ... it's no good getting stuck with the middle layer, you need somebody who knows.' (mother of 4-year-old)

'... we had plenty of places to be listened to ... we wanted someone to tell us what to do.' (mother of 6-year-old)

One family was left with lots of 'what if' questions after their child died. The outreach nurse wrote down all the questions the family had and sent them to the professor, who replied with answers and gave them choices for times to meet and talked through every issue:

'... until my mind was as at ease as it could be ... and he said if anytime you want to arrange to meet me again it's ok.' (mother of 7-year-old)

Several families commented on the differences between specialist and local services, often balancing expertise against local knowledge:

'The local consultant is not as "expert" as some people in Manchester, but he looks at the whole picture; how her health issues are affecting her life, family life, what can we do that works for you?' (father of 11-year-old)

'We travel to London every three months for a review and IV antibiotics, but then I can do this at home with her for the rest of the time. Because her condition is rare and deteriorating we need the team who know a lot about it.' (mother of 13-year-old)

A lack of competence meant children missed out on important parts of life; one child told us that she could only be fed at home or school, another young person told us that there were only two people who could

get him comfortably positioned at night. Parents and children told us that incompetence was often worse than nothing at all:

‘... if they didn’t know what they were doing she would get upset and then she would get very sick so it was completely counterproductive.’
(mother of 4-year-old)

Organisational competence: the basics of organisational competence were also important:

‘... we’ve got a little physio room [at school] but I haven’t started it yet because they are trying to get their timetables together.... The physio can’t organise the time to train the learning support people to do it.’ (13-year-old)

‘... they don’t seem to have the help he wants when he wants it.... I think that money should be attached to his head and go with him wherever he goes. They get all that money and all that support when he is only there 20% of the time yet when he is there his allocated helper is helping someone else so for example during swimming he can’t go to the deep end because the other child she is helping can’t swim.’ (father of 9-year-old)

Prompt responses were valued, particularly where the child’s future was uncertain:

‘... not knowing how much time you have ahead of you ... you don’t know how long you’ve got.’ (mother of 4-year-old)

Competence: things that helped

The occupational therapist who “really understood what was possible at her developmental stage”.

The outreach team who “just took it all in their stride”.

The nurse who had worked in a hospice and "had so many ideas for the last stages to keep her more comfortable".

The consultant who immediately made the link between his medical condition and his behaviour.

The team of home nurses confident and experienced in respiratory care: "she felt very safe ... we trusted them, she trusted them".

The GP receptionist who saw straightaway "how sick he was, and jumped us to the front of the queue".

The multidisciplinary team who shared information "quietly and quickly, no fuss".

The ex-nurse who did short-term respite in her own home and "didn't mind about all his extra bits".

2.2.2.2 *Flexibility and responsiveness*

Responsiveness to an individual family's needs: many families valued services that clearly listened to their views and were responsive to their needs. Here are comments from eight different families:

'... the help where we wanted it...'

'... it worked best for all of us...'

'... promoting the wishes of the family...'

'... they were able to be guided by what we found to be the problem...'

'... they should find out what works for him...'

'... being willing to look at her as an individual rather than being "determined to make her fit the boxes".'

‘And they can fit in with you ... it’s much much easier.’

‘It means we can work around the medical issues, not let them rule her life.’

However, many services still approach families from their own starting point and not that of the family. One mother described having to “pick a path” through different people’s views on her child and what they felt was important or needed. Another explained that many professionals often had strongly held beliefs, and over the years it had really helped to find people who

‘... didn’t put their philosophy above what worked best for us as a family.’ (mother of 15-year-old)

For children and young people with CHCN themselves, responsiveness to their individual needs was often linked to a sense of personal autonomy and control.

‘She has the help she needs and she was involved in deciding how she was helped, there is usually some choice about which staff help her.’ (14-year-old)

‘I use them like my hands and I get stressed when they do things how they like not how I would do them.’ (21-year-old)

Some young people valued their autonomy and contrasted it with previous experience. One teenager who had been a day pupil in a school that also offered residential care said:

‘There was a nursing team there ... to me it was too suffocating – in the way that the people there seem to have no life of their own. They go to bed when they say, eat when they say to eat... Between them and me it was very different. I saw things very differently to them – the other pupils. The kind of life they’re used to – I’m not used to that life... Might as well put a gun to my head and pull the trigger.’ (17-year-old)

Speaking about having arranged appointments at home, one young man explained:

‘... so I feel less disabled I guess. It’s good for me to be in control.... It’s funny, since I’ve taken full control of my healthcare I’ve been in much better health. I know my body better than anyone.’ (22-year-old)

Some other young people were also very clear about their own contributions to their health. However, many children also valued family involvement in decisions about their care:

‘... my sister has a say in my care. And my mum does.’ (11-year-old)

‘... who decides? daddy [thumbs up].’ (9-year-old)

‘That’s what mums are for, to help you make decisions.’ (sister of 6-year-old)

‘... mummy knows the right thing to choose.’ (7-year-old)

‘... you should start making decisions sooner, it would get you practice for when you’re older.’ (15-year-old)

A family-centred approach, involving working with whole families, including siblings, was identified as important many times. One mother told us about the art therapist from the hospital; she said she:

‘... wasn’t sure how wide her brief was but she made home visits as well including for the child’s sisters. She would come and paint their nails while I went outside and had a good cry.’ (mother of 7-year-old)

Flexibility in service provision: flexibility was crucial in enabling children and young people with CHCN to stay well and families to get on with an ordinary life. This related to the roles and responsibilities of any one individual involved in providing care:

‘The direct payment scheme has really transformed our family. Previously it was a struggle getting the help we needed but since direct payments, we have been able to employ people who are fit, warm natured, happy to be trained by us and willing to work with our schedules, for example starting later on some mornings or accompanying us on holidays.’ (father of 14-year-old)

‘Social services sent a woman who did not want to look after her or do feeds, so she did the ironing and cleaning which was fabulous.’ (mother of 6-year-old)

‘It helped having “flexible individuals” to deal with; some of the people worked in unusual and flexible ways ... people who thought dynamically made a real difference.’ (mother of 4-year-old)

It also related to organisational flexibility:

‘If her [Hickman] line comes out the nurse can come round to see to it ... to fit in with school times. They are really excellent and are very good at working round my daughter and her times.’ (mother of 11-year-old)

‘They could work flexibly, trade hours across the day or night ... we were able to “save up” an hour from each night shift to create two daytime sessions.’ (mother of 4-year-old)

The importance of flexibility was raised in relation to a number of specific issues, detailed below.

Help to stay at home: all of the children and young people had spent much time in hospital; in fact, nine of the 18 directly consulted were hospitalised during the three months of our survey. Hospitals were not popular with the children or their families:

‘I asked if you sometimes had to go into hospital, you screwed up your nose and looked the other way. Your mum said you do and that you were there not long ago but it wasn’t very nice for you...’ (6-year-old)

Many children told us that they hated hospital, and many parents found them difficult and stressful places:

'Hospital admissions were always grim, and often led to things "going completely haywire".' (mother of 4-year-old)

Hospitals were also unpopular with many siblings:

'[Do you have any wishes?] If he wouldn't have to go to hospital all the time and I would have more time with him and my mum.' (8-year-old sister)

Being able to care for children at home, even when they were very ill, was important to many families:

'The best thing was caring for her at home ... you can do your own thing at home, you can watch your favourite video and listen to your favourite music.' (mother of 9-year-old)

'We didn't want her to die in hospital.... I dreaded the idea of having to bring her home, of cuddling a dead daughter. I thought I was going to have to carry her home....' (mother of 7-year-old)

Another child who died at home stayed there until the burial and many family and friends came to see her at home after she had died. The family did not think this would have happened if the child had been elsewhere:

'I think that helped all of us; it helped her sister understand the permanence of it.' (mother of 4-year-old)

Assistance with, and breaks from, caring: some children and young people spent time away from home on a planned or ad hoc basis. Sometimes this became a positive part of their ordinary life, for example, a child who goes one Saturday afternoon a month to another family. We asked what she did there; she used her book to show us:

‘... out/home/out/home/out/home ... mum interpreted that this meant they were out a lot, always on the go at respite. The child agreed strongly.’ (9-year-old)

Other families had declined short breaks that had been unsuitable or even damaging.

Where and when healthcare needs should be met: when thinking about where healthcare needs should be met, one child (aged 7) told us the best place would be at home and the worst place would be at school while another (aged 8) said the worst place would be near crocodiles or in front of school or friends. Privacy and confidentiality were major concerns that seemed to increase with age. Another young person told us the worst place would be somewhere really crowded or at school:

‘I don’t like anything being done at school. I don’t even like it when they line everyone up and look at your teeth.’ (10-year-old)

‘School could be more flexible... I would like taxis to be more flexible and come when I need them if I wanted to do something after school. I couldn’t always let them know before hand if I was late as I sometimes get very tired so might want to go home.’ (13-year-old)

Decisions had to be made about the things children should miss out on in order for their clinical needs to be met. A number of parents were concerned that children were missing lessons: “there’s a lot of stuff that takes her out of school”. On the other hand, a number of young people told us they were delighted to miss lessons:

‘She explained that she could have appointments at times that suited her ... often in school time ... she laughed when asked if that was a problem.’ (15-year-old)

‘You’ve got nothing else to do anyway.’ (14-year-old, laughing)

Although most children and young people reported not minding missing lessons, many preferred not to miss social times at school:

'My last teaching assistant used to do it [gastrostomy tube feed]. He was brilliant he didn't care, he did care ... but it didn't worry him if I left 20 minutes early he preferred I missed 20 minutes of my lesson than 20 minutes of my lunch break.... I would choose to leave the lesson a lot earlier so I didn't miss my lunch break.' (13-year-old)

'I always want my hospital appointments in school time.... But not golden time, that's on a Friday.' (9-year-old)

Direct access to services: several families valued being able to access services directly, when needed:

'Open access to the local hospital and just go straight to the ward was good.' (mother of 4-year-old)

Twenty-four hour availability of support was very important, especially at times of crisis and including after a child had died:

'I was having a low day today and I decided I'll either sand down the fireplace or I'll go up to the children's hospital for a chat and a cry. I'm always welcome there, I can go in and they'll say "hello D, sit in the nurses station and someone will be with you in a minute".'

One mother told us about a service where, she had been told, there was someone there 24 hours a day, seven days a week, if you ever need it. She contrasted this with the bereavement helpline:

'I've never used it because it's not open when I want it. It's not during the daytime because I'm busy myself then, it's ... when I wake up at two in the morning and its raining and she's buried on top of the hill and I want to get her in because she'll get too wet.'

Flexibility and responsiveness: things that helped

The pharmacist who delivered prescriptions until 10pm at night.

The consultant who fixed appointments by email.

The physiotherapist who treated parents' backs in their own home.

The hydrotherapy pool that let the child's little brother swim too, every week.

The receptionist that "jumped through the GP appointments system".

The nurse who dropped in the catheter tubes on her way home.

The hospice team that provided nursing support at the campsite.

The counsellor who visited in the evenings once the children were asleep.

The psychologist who offered an 'as needed' service "just for the bad weeks".

The nurse who organised a cooling machine so a family could keep their child's body at home until the funeral.

The hospital that arranged direct admission to the ward whenever needed.

The service that took the request at face value and did not need reams of paperwork.

The crossroads worker who did all the ironing while the child slept.

The worker who gave parent call me anytime permission.

2.2.2.3 *Practicalities: money, resources, things*

Many families talked about the importance of having enough money, having a suitable place to live and equipment that worked and was useable. Money was crucial; there were many additional costs and often a reduced family income, and a real sense that the family's financial position was at permanent risk:

'... my husband is great but he has to work.' (mother of 9-year-old)

'... there are concerns in the long term, particularly if I fall ill as I am a single mother.' (mother of 14-year-old)

Parents described how they had to take on the role of coordinator:

'... you have to be an incredible organiser.' (father of 22-year-old)

They also talked about the additional time and effort that doing ordinary activities involved:

'There's a lot of faffing around. The morning takes twice as long.

'We can't just go out, even the simplest thing is 100 times worse.

'I can't get them both up alone in the morning, it just takes so long.'
(mother of 9-year-old)

Facilities: accessing and using facilities was an issue for many children and their families:

'[At school] He has to ask for the key to use the disabled toilet, he has been told to wait to use the toilet because there is no one to take him. That's not right; it's embarrassing besides his condition is such that he needs to go now. Once he messed himself and he still had to wait for a keyholder to take him so he could clean himself up.'
(mother of 13-year-old)

‘Computers is upstairs in a tower block ... so I can’t go.’ (11-year-old)

‘Here is just school ... at the campsite I walk out and I can get around to the arcade and clubs and you can just go in if you want. I’ve got about 10 friends there but we always have to come back for appointments.’ (11-year-old)

‘If my sister could go to more places.... We can’t go many places. I get bored. I’d like to go to crazy golf.’ (8-year-old)

Equipment: we were told by many families of struggles to get equipment that suited the child:

‘She indicated strongly that she did not like the picture of the hoist because she did not like being hoisted. Nor does she like using a standing frame.’ (9-year-old)

‘There is a hoist at home but it’s difficult to get her in and out of it.’ (father of 13-year-old)

The family have had ‘bits of equipment supplied but some of it can’t be used.... Her bedroom is like a medical centre, and the bathroom ... it all has a big impact on family life.’ (mother of 9-year-old)

‘The picture of the chair lift into the swimming pool also made her raise her hands and make noises. Her mother explained that she liked to swim but there were no changing facilities at their local pool except ones for babies that had ridges in them that hurt her back and were far too small. I agreed that she was not a baby and much too big to use that kind of changing table. Also the chair lift at the swimming pool had hurt her, so they haven’t gone swimming for a long time.’ (9-year-old)

Even when a child had appropriate equipment it was not always in use:

'My laptop, mum fought for years to get it for me to use in every lesson so I don't have to write and it's much better for me because it makes the difference between me writing one line and half a page ... but when they [school staff] say to bring it in and I bring it in they say we'll do it tomorrow... ' (13-year-old)

'After school I used to be able to chat to my friends on MSN ... but my computer isn't working.' (15-year-old)

Children were often aware that money was tight:

'I love to do horse riding, it's really really good fun ... [but] you have to get a membership and pay lots of money and I don't really want to do that.' (13-year-old)

Whereas professionals were not always so aware:

'.. the OT [occupational therapist] came up with a bath aid that would have been better, and she said oh you might want to think about getting one of these ... meaning you might want to pay ... we had both given up work to be with our daughter, our financial situation was very insecure.' (mother of 4-year-old)

Families appreciated quick responses to requests, and often seemed surprised to have their needs responded to promptly:

'They were amazing – they were used to people bawling down the 'phone, but they didn't just say oh yes that's very sad, they provided practical help quickly and without fuss, they supplied a portable suction machine within 48 hours.' (mother of 7-year-old)

'The financial implications of her additional needs were looked at and an adoption allowance was sorted out "for as long as her needs remain the same". This made lots of things possible: one parent reducing to part-time work; buying equipment; paying for a registered nurse instead of a babysitter.' (parents of 6-year-old)

Practicalities: things that helped

The feed company who delivered spontaneously and “on the dot” every month.

The school caretaker who always remembered to open the wrong (quiet) exit at home time, just for the one child.

The occupational therapy service that offered equipment on trial, to make sure it suited the child.

The neighbour who regularly accepted deliveries including of a month’s supply of tube feed and nappies.

The school secretary who always checked the dates on all the child’s medication at school without being asked.

The disability living allowance fast-tracking system that ensured a response within days.

The cinemas that gave free tickets to carers as routine.

The cafe that blended any dish on request.

The restaurant that guaranteed allergen-free meals.

The shopping centre with an accessible toilet that was always open, and clean.

The buses easily accessible to buggies.

The two teams of undertakers who worked together to organise a child’s burial a long way from home.

2.2.2.4 *Taking on 'the system'*

Even though we actively searched for families with good experiences of services, every single family we met used words like “fighting”, “struggling” and “battling” to describe their experience of the service system:

‘The only thing that winds us up is when we have to fight for things. When we moved I needed a new toilet; we were asked “why?” so I constantly had to justify myself. I’ve learnt to say “I need” not “I want”. I want to go to America. I need to go to the toilet.’ (22-year-old)

‘Well you spend your time going down the housing and then the social and then the hospital and then back again, like round and round in a circle. It’s such a battle. We just wanted her to come out of hospital, to come home.’ (father of 18-month-old)

‘It is a continual, exhausting struggle to get her health needs met in school.’ (mother of 6-year-old)

One teenager told us:

‘What will happen is they will argue between themselves – “this is your responsibility” – and it will always be someone else’s responsibility. They are very powerful people – at the end of the day, you’re one person and they’re a lot.’ (17-year-old)

Some families told us of ‘successes’ in taking on the system:

‘One teenager with long-standing healthcare needs developed scoliosis. The hospital said they would fit a brace in about three months. Her mother “argued strongly” that it was needed immediately and it was fitted within two weeks. This made her feel more confident to challenge services in the future – I know that I know what she needs.’ (mother of 14-year-old)

‘I had to fight with the local PCT [primary care trust] for two years to get physiotherapy ... the key to winning the battle was ... I insisted

the person who made the decision came to see me and explain why I couldn't have it. Now I have it. What I do now, is state my needs, state the consequences of them not being met and give them an idea of cost saving over time.' (22-year-old)

Even families with successful outcomes found the experience demanding:

'Me and my dad have spent hours on the 'phone, and at meetings. My dad does about 10 hours a week paperwork for me with carers, money, appointments – I'm crap at that basically.' (22-year-old)

'The actual paperwork for direct payments was too difficult for me to manage as a full-time parent carer but we now employ someone for a few hours a week to do this.' (mother of 10-year-old)

'The school situation was really tough on her for many years ... we had to go through a tribunal process and as a result we have our say in who is appointed and also an agreement that they are trained up at home before working independently. There is also a proper job description and a more respectable salary reflecting the high level of skills required.' (mother of 14-year-old)

Many young people identified the need for "someone to fight with you":

'And also, probably most important of all, the person needs somebody that doesn't serve the other side's interests. Everyone has a side. You need an advocate or someone that works purely for your interest.' (17-year-old)

'When we take on the system, I try something and if it doesn't get anywhere my dad tries, if he gets nowhere we go to the solicitors.' (22-year-old)

'Usually I have my brother with me. Sometimes a lawyer. Depends how complicated it's going to get.' (21-year-old)

Parents also often wished for someone to “fight their corner with them”.

A number of young people and families had used formal processes to fight for what they needed, including complaints procedures, ombudsmen, tribunals and the court system:

‘The biggest problem is that people really have got to change towards disabled people. In disabled life, yeah, there are too many excuses ... you could pick up a battering ram. To win like that you need a hell of a lot of lawyers ... that makes them back off and start doing their jobs. A lot of places come down to – what’s the word? Bureaucracy.’
(17-year-old)

Another family had gone to court to fight for their child’s rights:

‘I knew she would die there [in hospital] then ... we started to fight back ... it takes confidence...’ (father of 18-month-old)

Taking on the ‘system’: things that helped

The nurse who helped the young person take responsibility for his own health.

The chair of school governors who said “she has a right to be here, we need to sort things out”.

The PCT who funded daily taxis to and from hospital so the child did not have to be admitted, and accepted this as a major cost saving.

The advocate who “wrote letter after letter after letter”.

The headteacher who took the lead and learned to use the epipen.

The charity that developed clear and helpful training materials for schools.

The lawyer who said “it should not be like this, it doesn’t have to be like this”.

The services that found ways to respond to individual needs, even if it meant bending or breaking the rules.

2.3 Conclusions

2.3.1 What matters?

The findings of this consultation show powerfully that having an ordinary life is, in the end, what matters most to children with CHCN and their families: to ‘be themselves’ and to be part of a family, to have relationships, to have a life, to do the things that other children and young people do. There is, in this respect, extraordinary consistency in the things that parents/carers and children and young people want from services: support to lead an ordinary life.

2.3.2 What helps?

Clearly, the conditions and/or illnesses of these children and young people form one (but not the only) set of formidable obstacles to having an ordinary life. Yet, the consultation brought to the surface many examples of people finding a way around these barriers – where children and young people were not identified exclusively by their CHCN and, together with their families, they had succeeded in having the kinds of relationships and doing the kinds of activities that provide an ‘ordinary’ life.

The findings highlight the crucial part that nuclear and extended family members as well as friends play to this end: meeting ordinary needs alongside their CHCN is something that parents, siblings, friends, cousins and grandparents do every day.

In relation to formal service provision, the consultation also identified many examples of good practice on the part of professionals and other paid support workers. Notable in these examples is the significant rear-

range of standard professional–personal boundaries that is often needed. The extent of children, young people and their families' reliance on support services in the most intimate and the most mundane aspects of everyday life, requires professionals and paid workers to engage with families as compassionate human beings, as much as it requires them to draw on their formal skills.

Moreover, the examples of good practice also highlight the redrawing of the boundaries of any one profession that is often necessary. Many examples involved people taking on additional responsibilities and working beyond the formal skill sets usually associated with their role.

Lastly, in the examples of good practice the need for a participative, family-centred approach stood out. The need to work in partnership *with* families is particularly pertinent for this group. Listening *and* adapting to family preferences about their ordinary needs requires a high level of flexibility and responsiveness. Both creativity and risk taking played important parts.

2.3.3 What gets in the way?

All families consulted were able to describe things that helped, including good experiences of services. However, all families had mixed experiences, including examples of things that had not gone well or had gone very badly. The findings of the consultation showed strongly that while ordinary life is often disrupted by a child's CHCN, it is also often disrupted by the service system they then have to navigate. Throughout the consultation, the notion of 'fighting' was ubiquitous.

It is resoundingly obvious that services, as currently configured, are often experienced by families as sources of frustration and despair, rather than support and solace. This has implications for defining 'good practice' that we detail in Section 4.1.

2.3.4 Reconceptualising 'social care'

Service provision is based on the assumption of separable needs, for example, health, education, social care, palliative care and so on. Yet this consultation has shown the way in which the nature of the conditions and/or illnesses of children and young people with CHCN makes any such division of needs untenable. The healthcare needs of this group of

children and young people are so much part of their everyday lives that different subsets of needs overlap and merge in complex and changing ways.

The way families talked about their lives, then, seems to require re-thinking 'social care' needs as fundamentally linked to something like an 'ordinary life'. One possibility, therefore, is to define 'social care' needs and services using 'ordinary life' criteria, that is, relating to children having as ordinary a family and social life as possible.

Thinking about 'social care' needs using 'ordinary life' criteria allowed for a recognition of social care needs as overlapping with and even inseparable from their healthcare needs. A child, for example, may not only be technology dependent for their medical care, but also rely on ICT (information and communication technology) for their social networks. Access to ICT, therefore, becomes a social care need, using ordinary life criteria. Concomitantly, it also allows for recognition that social care needs are not necessarily met by social care agencies and 'healthcare' needs are not necessarily met by health services.

A further benefit of thinking of social care needs using ordinary life criteria was that it allowed individual preference (or subjectivity) and flexibility to be retained at the heart of the definition. What exactly makes up 'ordinary life' clearly varies from person to person, from family to family.

Yet a basic problem remains. What sense does it really make to talk about 'ordinary lives' in relation to a group of children, young people and families whose lives are clearly far from ordinary? In the course of the analysis we have moved to talking about 'ordinary needs' rather than ordinary lives.

2.3.5 Implications for policy and practice

The findings of the consultation, therefore, also raise various challenges to current policy and practice that are worth clarifying here.

Most fundamentally, the fact that 'social care' needs are not necessarily met by social care agencies and 'healthcare' needs are not necessarily met by health services, is not currently addressed by guidance on interagency working and the associated training, nor the fact that other subsets of need such as emotional, educational, financial, are also likely to be inextricably linked. Consequently, the inevitable negotiation

both between agencies and families, and between agencies themselves, is overlooked. Equally, the tension between a child-centred approach and a family-centred approach that this implies currently remains un-discussed.

The emphasis on flexibility and responsiveness in the families' accounts has implications for organisational culture and management. Prioritising this aspect of care planning and delivery would require significant alleviation of procedural constraints. It will also be hard to respond to in a risk-averse culture marked by a climate of fear of personal blame for failing to follow rules.

The consultation also draws attention to the importance of the temporal aspects of social care delivery and the difficulties caused by rationing the period of time for which families can have access to support services. Families need responsive services when they are in crisis, but they also need services on which they can rely over longer periods of time. Current short-term engagement also precludes the development of relations that allow families to feel that professionals 'really care'.

Research review

3.1 Methodology

A systematic review method was used to provide an in-depth review and thematic analysis of the research field. A search strategy was designed that could identify empirical research findings relevant to the research questions. *Inclusion* and *exclusion* criteria were defined to select appropriate studies that were then categorised (*keyworded*) to form a map of the research field. Those that were both particularly relevant and strong methodologically were subject to data extraction and in-depth quality appraisal. Key themes were then analysed thematically.

3.1.1 Inclusion and exclusion criteria

Studies were included at the initial search stage if they were:

- about the social care needs of children and young people who had CHCN, and/or those of their families and services to meet those needs;
- empirical;
- in English (resources were not available for the translation of studies in other languages);
- published between 1987-2005 (some of the major databases do not provide information before 1987; also, prior to this date definitions of CHCN and social care needs correlate less with current definitions).

Papers that looked solely at the needs of siblings of children with CHCN were excluded as this constitutes a fairly sizeable, complex and disparate body of literature that would benefit from separate study.

3.1.2 Initial screening and selection

In accordance with SCIE guidelines, 15 databases were systematically searched by two researchers, identifying literature from a number of disciplines (see Appendix A for details). Input from the advisory group (including children, young people, parents and professionals) and piloting of words and phrases on the databases established the search terms to be used. Studies were electronically selected if they contained a term from each of three broadly defined groups, relating to:

- children and young people
- CHCN
- Social care needs and services.

This database search identified 6,923 citations, including duplications, in which some combination of these terms appeared (see Appendix B for details of citations on each database). Abstracts for each were read by three reviewers applying the inclusion and exclusion criteria. Ten per cent of all abstracts were read by two reviewers for internal quality control. All abstracts identified for inclusion by one reviewer were additionally read by and discussed with another reviewer to determine final inclusion. Any disagreements were referred to a third reviewer. A large number of conceptual and descriptive papers, policy documents and textbooks were excluded at this stage as they did not meet inclusion criteria. This reduced the numbers gained through electronic searching to 222.

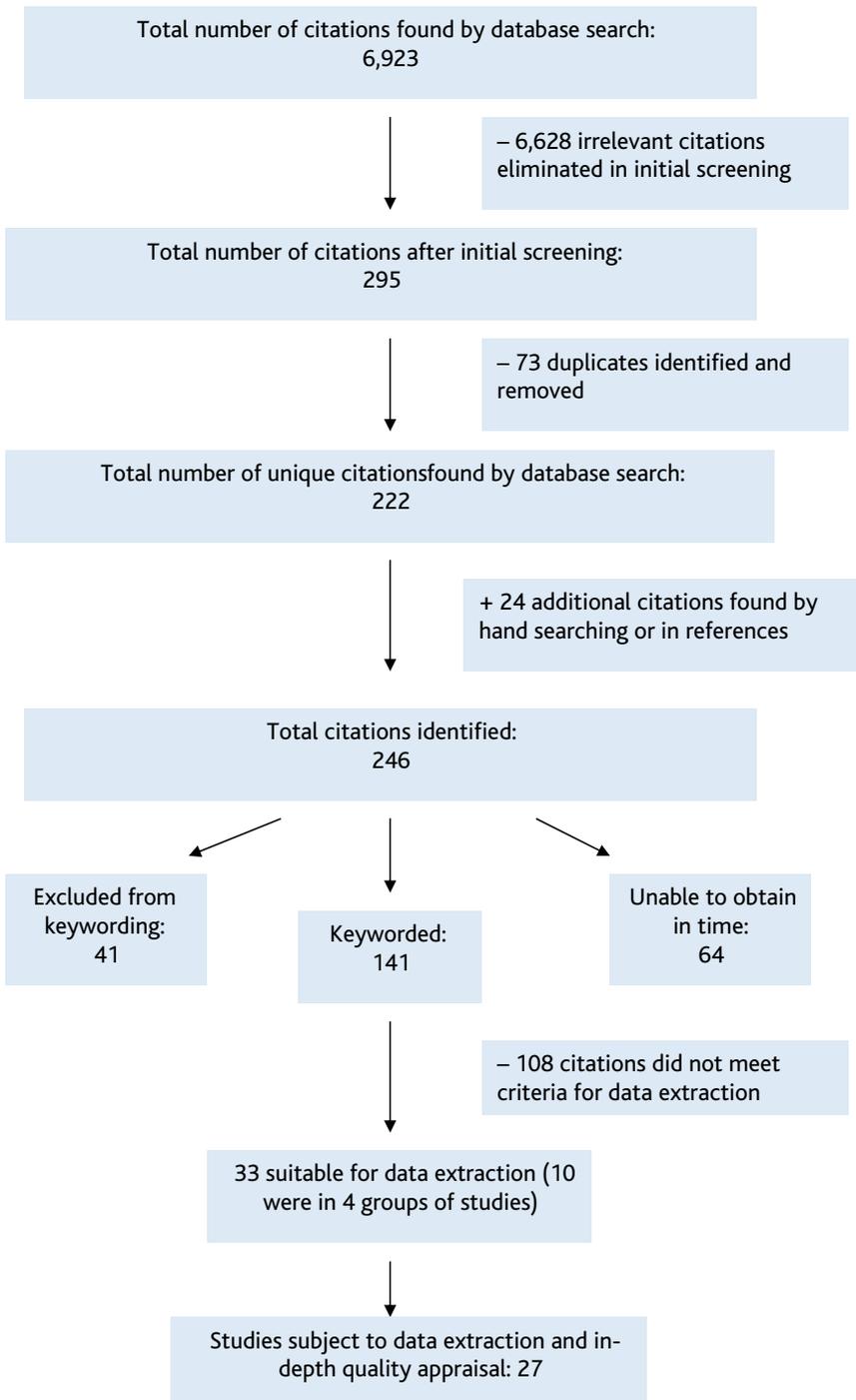
Twenty-four additional references were identified through hand searching of key journals, website searching, citation tracking and through recommendations of stakeholders on the advisory group. This brought the total number of studies included for keywording to 246. These were journal articles (168), theses (38), reports (29) and books (11). References were compiled into a database using 'Endnote 7.0'.

Figure 1 provides a flowchart with further details of screening.

3.1.3 Forming a map through keywording

The keywording strategy draws on the EPPI-Centre (Evidence for Policy and Practice Information and Coordinating) approach to sys-

Figure 1
Flowchart showing screening process at each stage



tematic reviewing (www.eppi.ioe.ac.uk/eppireviewer/guideline_home.aspx?GUIDELINE_ID=GDL146) to form a map of the research field. Information from studies was categorised within a database developed in Microsoft Access using criteria related to both the topic and the nature of the research evidence and concepts presented (see Figure 1).

On detailed reading of 41 studies, approximately 20% failed to meet the inclusion criteria and were excluded. One reviewer keyworded every study. Ten per cent of studies were also keyworded by one or other of two additional team members for internal quality control. Any disagreements in keywording were referred to the third reviewer.

Sixty-four papers could not be obtained in time (most were unpublished dissertations or reports, often from North America). A total of 141 studies were finally keyworded to form the map (shown in Appendix E). Most were North American or UK-based, published as articles in academic journals. The majority were qualitative, with in-depth surveys or interviews with parents and professionals. A quarter focused principally or solely on the social care needs of the child with CHCN, with almost half considering social care needs of the family as a unit and one fifth the needs of parents who were caring for their children with CHCN. The views of children with CHCN were represented in 23% of studies. They were the sole respondents in 9% (mainly older children with less complex needs moving towards independence).

3.1.4 Data extraction and in-depth quality appraisal

Data extraction and in-depth quality appraisal (using an extended version of a SCIE format – see Appendix D) was carried out by three team members in respect of a subgroup of studies. Twenty per cent were evaluated by two reviewers for internal quality control. Any disagreements were referred to a third reviewer.

Papers were included here if:

- they had high relevance to our research questions;
- they were replicable, evaluative empirical studies where the reporting of methodology was sufficiently rigorous and detailed to enable judgements to be made about validity, reliability and the quality of the research design and execution;

- all or most of the children in the study had CHCN, rather than being a small grouping of an overall study.

Ten papers clustered into several groups, in that they reported and discussed findings from the same original study. Those linked together were quality appraised as a group and referenced as one study in the thematic analysis. Four groups of studies emerged¹⁹⁻²⁸. Twenty-seven studies (or groups of studies) were finally included for quality appraisal.

The aims, intervention, study design, main findings and conclusions of each of the quality appraised studies are summarised in Appendix F. A thematic analysis in Section 3.2 highlights the main findings and conclusions from studies included in the overall review with those subject to in-depth review discussed first and highlighted in the text by an asterisk *.

Appendix G provides a rating (from 1-3) of trustworthiness, appropriateness, relevance to this review and overall weight of evidence for each study. The weights draw on the EPPI-Centre approach to systematic reviewing (www.eppi.ioe.ac.uk/eppireviewer/guideline_home.aspx?GUIDELINE_ID=GDL160). Three studies were given an overall high quality rating.^{29*** 77*** 99***} Thirteen were judged as of medium weight.^{20** 24** 27** 42** 47** 52** 67** 76** 109** 121** 138** 142** 143**} Two were classed as medium/low.^{30* 49*} Nine were appraised as of low evidential weight.^{34* 65* 82* 101* 103* 113* 114* 144* 152*} In the thematic analysis, these ratings will be frequently indicated through use of one, two or three asterisks to denote low, medium and high-quality ratings. However, it should be noted that the team felt these numerical ratings do not fully reflect a study's strengths or limitations and Appendix F should be read for a fuller appraisal of each.

More than half of the quality-appraised studies were undertaken in the UK so there is high local relevance.

3.2 Thematic analysis

3.2.1 Introduction

We begin by setting out how the literature defines CHCN and social care needs, then report, through a thematic analysis, the social care needs of children with CHCN and approaches to service provision for them (in Section 3.2.3) and those of their families (Section 3.2.4). The themes chosen to structure this analysis emerged from identifying those that appeared most frequently within papers and/or that had the strongest empirical evidence. Within each subsection, those with strongest evidence (that is, those subject to in-depth quality appraisal) will be reported first and can be easily identified by an asterisk* after each numbered reference. The wider body of literature relating to that theme will then be described.

It will be considered throughout how meeting these social care needs might enable children to achieve the five outcomes that are set for all children within the 2004 Children Act, that is:

- i) be healthy
- ii) stay safe
- iii) enjoy and achieve
- iv) make a positive contribution
- v) achieve economic wellbeing.

3.2.2 Definitions

This section reports the definitions of CHCN and social care needs most commonly used by the empirical studies reviewed. The way in which CHCN bring about social care needs for children and their families is summarised in Figure 2.

'Complex healthcare needs': keyworded studies generally report CHCN to be present where there is a health condition or disability that brings about healthcare needs in order to ensure the child's survival or physical health. Some children's needs are continuous, requiring up to 24-hour-a-day medical, nursing or health supervision or intervention.^{19*} Others are described as moving in and out of a 'zone of medical complexity', with

Figure 2**How CHCN give rise to social care needs in children and families**

Medical/physical condition



Challenge to life and/or death



Brings about additional CHCN, eg

- specialist nursing/medical treatment care
- technological support
- monitoring



Brings about additional social care needs of child and family that must be met in order to promote their need for/right to an ordinary family and social life

health issues moving to prominence after a medical crisis but receding after hospitalisation, monitoring and/or medication adjustments that stabilise the condition.²⁰ These health needs are seen as complex because they require highly skilled, specialised and often invasive procedures usually by others. ‘High-tech’ medical equipment may be needed to supplement, replace or monitor bodily functions such as breathing (for example, ventilators or apnoea monitors), eating (enteral and parenteral feeding via naso-gastric tube, gastrostomy and jejunostomy), and kidney functioning (renal dialysis). These children are often said to be ‘technology-dependent’.^{21** 29** 22** 23** 24** 25* 26* 27* 28, 30, 31-49}

The term CHCN is mainly used by British studies.^{29** 23** 50-54} Other terms used, particularly in North American studies, include ‘medically fragile’ and ‘medically complex’.^{19* 27, 43* 32, 33, 36, 43, 46, 48, 49, 55, 56} Severe or unstable forms of other *chronic illnesses* or conditions bring about CHCN for some children so were included in this review, for example, sickle cell anaemia,^{57** 58* 59, 60} diabetes,^{61-68, 76**} cystic fibrosis,^{69*** 62, 63, 67, 70-72}

spina bifida,^{73*} 62, 63, 74 cerebral palsy,^{55, 71, 74-88} osteogenesis imperfecta,^{71, 89, 90} and muscular dystrophy.^{67, 78}

Until recently many children born with high levels of CHCN did not survive beyond early childhood. Most who did were cared for in hospitals or other institutions. Current medical advances mean that many children now live into adulthood and can remain within family settings if the CHCN and the additional needs that are created for children and families are adequately addressed.^{91*** 29** 23** 24** 25* 38}

'Additional needs': children with CHCN have the same 'ordinary' needs as all children. CHCN give rise to a range of additional needs for children with CHCN (for a physically safe environment at home and in school, for attention to emotional, educational and social needs). A consistent message from studies reviewed is that these must be met if children are to have as ordinary a family and social life as possible, enabling them to live at home, go to school, make friends and take part in community and leisure activities.^{29** 91*** 99***} This is a focus consistent with both children's rights and wishes.^{29**}

'Social care' needs of parents and carers: while professionals and other paid workers can and do provide direct health and social care services to children, this review will go on to identify how family members (usually mothers) undertake most social and other care for their children with CHCN. The particular demands of this role will be shown to give rise to social care needs for parents and family carers (for preparation for the enhanced caring role, assistance with/breaks from caring, emotional support, financial support). The extent to which social care needs must be met and parents actively supported if they are to continue to meet their children's needs for a stable, safe and positive family and social environment will be discussed.

'Social care' needs of children with CHCN: determining what constitutes social care needs for children with CHCN has not been straightforward in this review. There is considerable ambiguity regarding what might constitute social care needs as opposed to health, mental health, social and educational needs. For example, parents and other workers (such as teachers) who are not medically qualified often need to acquire medically

specialist skills and knowledge to enable children to live at home^{22** 23**} and attend school.^{91*** 43*} This ambiguity matters less to children and families who do not experience their needs as individual elements but rather as part of a seamless whole. Children in a highly rated study who are ventilator-dependent, for example, prefer professionals to work across discipline boundaries so that fewer people are involved with their care.^{29***}

Where definitions will be seen to have been significant and problematic, however, is in relation to responsibility for funding with agencies attempting to distinguish individual needs in accordance with service boundaries in order to determine accountability for provision of resources.^{29*** 24** 103*}

3.2.3 Social care needs of children with CHCN

This part of the thematic analysis reports on the social care needs of children with CHCN. Six themes are isolated and analysed:

- i) children's physical wellbeing
- ii) emotional wellbeing
- iii) an ordinary family life
- iv) school inclusion
- v) social participation
- vi) moving towards adulthood.

These themes were selected as they appeared most frequently and had most empirical support. Findings from studies subject to data extraction and in-depth quality appraisal are generally reported first within each section, or are at least highlighted.

3.2.3.1 *Physical wellbeing*

Three quarters of all keyworded studies were concerned, at least in part, with children's physical health (outcome [i], 2004 Children Act). The samples of children reflected a wide spectrum of health and illness. At one end there were children who were medically very fragile with frequent medical emergencies placing their lives at risk⁵⁵ and/or who were not

expected to live into adulthood.⁴⁵ At the other were children who were mainly well but needed monitoring and oversight to maintain health or particular interventions as a result of a severe disability (for example, children with severe cerebral palsy who might require tube feeding).⁸⁷

In the quality-appraised studies, it was found that, depending on the level of their healthcare needs, children required support and assistance in a number of areas. A study given a high evidential rating found the monitoring of the child's symptoms and bodily functions^{92***} to be important. Three studies of medium rating reported how some children needed bodily functions such as breathing, eating and digestion supplemented through manual caregiver intervention and/or use of specialised equipment (for example, mechanical ventilation, tube feeding).^{21**23**24**} The need for medication (including intravenous) to be provided on both a regular and emergency basis^{25**93*} and transportation to hospital for appointments and in emergencies^{94*} were also noted.

Supplementation of bodily functions,³⁸ a need for monitoring,^{28, 32, 39, 55, 66} provision of medication^{55, 95} and transportation^{59, 75, 96} were also discussed in other keyworded studies. Keyworded studies additionally described the importance of children receiving education and support in learning to understand and manage their condition through modifying their behaviour, controlling their symptoms, complying with treatments and being alert to the meaning of any changes.^{60, 70, 72, 97}

Despite the immense stresses on parents no studies were identified regarding potential intrafamilial risks of abuse or neglect to children with CHCN. This contrasts with research on disabled children more widely that has considered their particular vulnerability. One keyworded study does, however, assert the importance of professionals at discharge planning ensuring that parents have adequate general parenting skills and that any pre-existing family problems that could mitigate against appropriate and reliable caregiving under stress are dealt with.^{32, 98}

3.2.3.2 *Emotional wellbeing*

Almost a third of keyworded studies considered children's emotional health and wellbeing, with many identifying sources of stress or difficulty for children. Findings and suggestions relate to outcomes (i), (ii) and (iii).

Two quality-appraised studies (one medium-rated, one low) show that most children report good levels of emotional health, have normative global self-worth scales and want the same things as other children to promote their emotional wellbeing: friendships, peer social supports, parental support, to be treated with respect and dignity.^{29** 73*} However, children also reported stressors that had a negative impact on their wellbeing. Lengthy hospitalisations caused distress as children were separated from family, friends and community.^{91***} Stigma, discrimination, prejudice, and teasing about being different due to their CHCN were found to be significant.^{69*** 91*** 58*} Many children felt insufficiently consulted and informed about their care and support.^{91*** 29**} Children felt there to be restrictions on developing their independence due to the demands of their CHCN and felt too reliant on their families to meet their needs.^{69*** 29**} They often ended up with insufficient opportunities for time alone with friends and restrictions on ordinary leisure/recreational activities.^{29**} Pain and fear from their illness/condition and/or healthcare interventions were distressing.^{93*}

Such stressors compromise children's emotional health. Although apathy, low motivation, low self-concept and conduct disorder were not often reported, symptoms of distress and behavioural difficulties such as anxiety, depression, shyness and isolation were found.^{58*} Children appear to have few outlets or opportunities to describe and express the discomfort and distress they experience.^{29**} Some parents say they become so preoccupied, exhausted and overwhelmed by the physical nature of the CHCN and the attendant stresses that they are unable to sufficiently meet their children's other socio-emotional requirements.^{97, 99***} Although some children are said to need *counselling*¹⁰⁰ there is little evidence that they receive it.^{29**} While many professionals seem to concentrate on health needs at the expense of emotional ones, volunteers in one study were found to have helped children more informally with fears and worries and to engage in fun activities.^{101**}

These issues are also discussed in keyworded studies.^{21, 39, 44, 63, 87, 102, 103*} It would appear that the nature and extent of emotional needs of children with CHCN and how best to meet these needs requires determining further, both in respect of individual children and more globally to aid service planning if 2004 Children Act outcomes (iii), (iv) and (v) are not to be compromised.

3.2.3.3 *An ordinary family life*

Children with CHCN have a right to live with their families and affirm strongly that this is their wish.^{91***29**} It has been found that for children's CHCN to be managed in the family home so that they can remain safe and healthy *specialist caregiving* needs to be in place from carers (paid or family) who are sufficiently skilled and knowledgeable to understand and manage their needs.^{91*** 104*} Prompt and in-depth *assessments* are necessary to this, ensuring that efficient resources are available and that all carers are adequately trained and able to meet the child's needs.^{91***29**} Keyworded studies also discuss these issues.^{32, 38, 55, 89, 98, 105-108}

However, there is strong evidence that ordinary family life is often disrupted, with homes becoming 'hospitalised', dominated by monitoring, treatment regimes, medical crises and care provision, invaded and intruded on by a range of professionals and paid carers.^{91*** 26* 25* 93* 94*} This is also discussed in keyworded studies.^{30, 36, 49, 109, 110}

Children and their families provided strong evidence that many children remain too long in hospital, with delays for no good medical reason but due to insufficiently qualified or trained carers being available or because funding could not be agreed or arranged in time to provide carers, equipment or necessary *housing adaptations or moves*.^{91***111**29**104*} Young people reported that this was unwelcome and distressing; getting home was very important to them, particularly as they did not feel involved in their care or listened to in hospital.^{91***} Delayed discharge compromised their capacity to maintain adequate contact with their families, first language, culture, nationality and religion.^{91***} This is also described in keyworded studies.^{38, 50, 71, 86, 89, 90, 98, 100, 106, 112-115}

There was some evidence that children and their families want to be able to spend social and leisure time together but experience difficulty finding recreational and social activities that the whole family can participate in outside their home.^{29**} The demands of adhering to treatment regimens mean that extraordinary levels of planning and creative adaptability are required to ensure the child's health is not compromised.^{93*} Some children need holidays to be organised near specialist hospitals in case of a medical emergency.^{25*} Those who are technology-dependent often need cumbersome equipment with them at all times which requires specially adapted *transport; financial support* will be needed to purchase an appropriate vehicle or to enable ready access to adapted

community transportation.^{25* 93*} Some children and parents found it too embarrassing performing procedures like gastrostomy feeding or tracheostomy suctioning in public due to attitudes of the public or staff at facilities.^{25*}

These issues are also discussed in keyworded studies^{39, 44, 49, 70, 71, 116-118} and are thought to be important as increased contact with relatives, friends and the wider community is believed to be associated with improved emotional and social wellbeing for all family members.^{39, 44, 103} Improvements in accessibility and oppressive or prejudicial attitudes from members of the public or staff at social amenities will depend in part on the extent to which local authorities and the private sector meet their responsibilities under the 1995 Disability Discrimination Act.

It can be seen, then, that failure to provide supports to enable children to achieve the more fundamental outcomes ([i] and [ii]) can seriously impact on 'higher-level' outcomes ([iia] 'enjoy' and [iv] 'make a positive contribution').

3.2.3.4 School inclusion

Eleven studies subject to in-depth quality appraisal^{91*** 29** 21** 19* 26* 58* 25* 27* 107* 73* 94*} and nine other keyworded studies considered what is required to ensure a child's participation in education.^{20, 38, 43, 63, 86, 113, 119-121} Education is a fundamental part of helping children achieve 2004 Children Act 2004 outcomes (iii), (iv) and (v).

Until recently children with CHCN could not always participate educationally with their peers as schools were unable to meet their significant needs for technological, medical and care support.^{19* 27*} Care needs are often substantial. Although on average children were found to need three helpers at school,^{29**} those attending special schools had up to 14 different professionals providing aspects of their care.^{107*} Positively, three studies report more recent progress in school inclusion through supplying sufficient appropriately trained carers and equipment;^{27* 107*} in one all children of school age with CHCN were going to school or nursery on a regular basis and most were accessing the full curriculum.^{29**} *Coordinated, keyworker*-type approaches are reported to have made an important contribution, facilitating multi-agency planning alongside parents and pupils to ensure that all needs are met.^{21** 26*}

However, there is strong evidence of difficulties. Limited finance and funding disputes between health and education cause delays for many regarding adaptations to buildings to make them more accessible,^{91*** 25* 94*} provision of equipment,^{29** 19* 107*} specialist care, and transportation to school.^{21** 26* 94*} Just over one third of children in a recent UK study had school inclusion delayed by up to eight months due to a lack of suitable carers being available.^{107*} In the same study, despite the Department of Health 1996 Health Care Plan approach being described as helpful by parents and school carers, none of the children had the recommended Plan. Illness and pain caused some children to struggle academically and with attendance.^{58* 27*} Children are often excluded from school trips, in part because of a lack of suitable carers,^{107*} resulting in parents stepping in to support their children while feeling that schools were not meeting their statutory responsibilities.^{27*}

Many schools have limited experience of including children with some CHCN, (such as ventilator dependence) and must learn anew with each family, so there is strong evidence of a need for training, policies, support and supervision.^{91***} Responsibilities for tasks are not always well defined and professional boundaries may be blurred. Whereas school nurses generally provide medications, supervise others in doing so, or provide skilled respiratory care, such as tracheal suctioning, other staff such as teachers are often taught how to provide repetitive, routine yet skilled care, such as gastric tube feedings, or supervising the end of a nebuliser treatment begun by the nurse.^{43*} Young people say they value such flexibility in professional roles as the number of different caregivers is then limited.^{91***} However, unclear policies regarding *role and accountability* may create a lack of clarity with workers being unsure about responsibilities and inadequately trained for tasks, so it is advised that these are clearly identified within each child's plan.^{26* 27*} Additional needs regarding training for professionals are implied by parents needing to train school staff in meeting their children's CHCN to ensure their inclusion.^{27* 107*}

These school inclusion issues are also discussed in seven keyworded studies.^{20, 43, 63, 86, 119-121}

3.2.3.5 Social participation

Children with CHCN are described as having the same rights to and desires for social inclusion as other children, that is, to have friendships, social stimulation and be able to participate in social activities with all peers, not just other children who are disabled or have CHCN.^{40, 63, 75, 100}

This supports all five of the 2004 Children Act outcomes. However, there is strong evidence that many children find that their choice of leisure activities is restricted and they have less chance to make friends.^{91*** 29**} This is also discussed in keyworded studies.^{21, 63, 71, 87, 117} As well as those reasons given in Section 3.2.3.3, some children are too ill or fragile to participate with peers in social, leisure or community activities, or their parents fear they are and restrict their inclusion.^{58* 89} There is some evidence that psychosocial education for parents about the need for their children to develop independence may be useful.^{58*}

Supporting the development of peer relationships is also important here. Some children experienced prejudicial attitudes^{91***} and teasing^{58*} by peers because they were, or were perceived to be, different as a result of their CHCN. One study advises that children could be helped to cope with these challenges through *psychosocial interventions*.^{73*} This is also described by keyworded studies that suggest that these will help children develop social skills and normative friendships that will promote their inclusion in social activities.^{50, 54, 70, 122} Teaching children about their condition and helping them explore its meaning for their lives is thought to help with symptom control that has a knock-on effect for how they might more confidently form relationships and interact with their peers.⁷⁰ This appears to be easier for children to appreciate and manage as they mature.^{93*} Improving self-esteem and confidence about their difference is found to be necessary^{58*} as children with CHCN need 'higher-than-average levels of self-esteem to counteract the physical and attitudinal barriers they face throughout their lives'^{73*} (p 172). This is also discussed in⁷⁰. Work at a larger systems level was also advised to reduce these barriers through challenging all pupils' attitudes and promoting inclusive activities in schools.^{73*}

3.2.3.6 *Moving towards adulthood*

Fourteen studies, three of which were quality appraised^{69*** 91*** 123*} and provided good evidence, focused on what enables young people to make successful transitions to independence and/or from paediatric to adult-centred services.^{59-61, 67, 72, 74, 124-127, 159} Three quarters of these included the direct voices of young people with CHCN themselves; in just under half they were the sole respondents. All were classed as primarily focused on the needs of the young people rather than their carers/family.

Transition services are reported as aimed at increasing young people's autonomy, responsibility and capacity to manage their illness and meet their own social care needs as adults wherever possible so they can participate as fully as possible in social, community and economic life^{59, 60, 72, 126, 127} (meeting 2004 Children Act outcomes [iii], [iv] and [v]). Successful transitions are associated with young people taking responsibility for their health, increased optimism and decreased anxieties about the future, and improved mental and emotional wellbeing^{69*** 72} (outcomes [i] and [ii]).

The clearest message from young people in one study was that they want the same things as any other young people as they grow into adulthood – “friends, sex, money, a place to call their own, and the freedom to do the things they enjoy doing” – but that the way services are delivered can be a barrier to achieving these things (¹⁵⁹ p 137). Service coordination is found to be helpful; it can ensure continuity of communication and information between paediatric and adult service sectors^{69*** 123*} (also suggested in^{60, 61, 67, 159}). However, it appears that there is not always sufficient *planning* for this transition with young people themselves.^{91***} Many have little or no preparation or opportunity to discuss decisions, plan their transfer to adult services or practice managing their care.^{69***} Some young people say they want more up-to-date knowledge of their condition and treatment and ways of managing it⁵⁹⁻⁶¹ as it makes them feel more independent and autonomous.¹²⁵ There is evidence that such feelings correlate with improved adherence to treatment and condition management^{69***} (promoting outcome [i] into adulthood).

There are concerns that young people may hinder their own successful independence by prioritising their social needs above their health needs and treatment regime. They are subject to the same pressures as other

adolescents to engage in social activities that can negatively affect their health, for example, smoking, drinking, using drugs, but, for them, this may have catastrophic consequences health-wise.^{69***} Health and social care workers are advised to recognise this, working in partnership to engage young people in developing and managing their own treatment regimes^{69***}. This is also suggested in⁷². Practising life skills required to effectively manage their care, as well as adopting behaviours favourable to their health may be useful and could be more likely within a therapeutic environment that is safe, supportive and encouraging.⁶⁰

Professionals believe that lack of funding and access to key staff can impede successful transitions.¹²⁶ Some suggest that parents, too, may provide barriers if they are ambivalent about their offspring's independence; they may need support and education to encourage them to participate in autonomy-building activities.^{59, 127}

3.2.4 Social care needs of family carers of a child with CHCN

For all children it is their parents and other family members who have the primary responsibility for ensuring their health and safety in the family and promoting their active participation in school and the wider

Figure 3

Types of support and approaches to service provision required by parents

Support needed by parents

- preparation for the enhanced caring role
- assistance with/breaks from caring
- emotional support
- financial support

Support needed by parents

- that their efforts and needs are recognised, valued, and accepted by professionals
- that the services are available (for example, trained staff)
- that provision of services and resources are coordinated with joint agency funding agreed
- anti-oppressive service structures and individual approaches

social world. When children have CHCN these caring responsibilities are significantly increased. If parents and family carers are not supported in this role their capacity to meet their children's social care needs is reduced with the result that the child's wellbeing is seriously compromised. This review identified the *support* required by parents and *approaches to service provision* that might be most effective (summarised in Figure 3). These two aspects cannot be disentangled completely.

3.2.4.1 *Preparing parents to provide specialist care*

If a child with CHCN is to be safely and adequately cared for in the family home, sufficiently skilled and specialist nursing and personal care must be available to provide the conditions specified in Section 3.2.3. There is evidence that there are insufficient formal services available to fully meet the requirements of children with continuous needs, particularly those who are technology-dependent and need a very high level of supervision and care.^{26* 104*} This is also suggested in.^{100, 105} Consequently parents, willingly or under pressure, become the primary carers for most children with CHCN as the alternatives appear only to be continued hospitalisation or local authority care for the child.^{25*}

There is strong evidence that parents need to be trained and prepared by nursing or medical staff for the specialist caregiving tasks they will be undertaking in addition to general parenting^{92*** 22** 19* 26* 25* 107*} (also proposed in^{109, 122, 129}). The level of skills they learn would normally be the province of medical staff, with some CHCN requiring very specialised techniques outside the experience of most GPs, community nurses and even local hospitals.^{25*} Parental competence in these must be assessed prior to hospital discharge to ensure the child's health is not placed at risk^{91***} (also put forward in^{32, 98}). However, not all parents receive training that is sufficient^{19* 107*} or of the appropriate nature, that is, some was reported as insensitive as, by concentrating exclusively on procedures, the emotional effect of having to do intrusive and often painful tasks to one's own child was ignored.^{94*}

Parents require information and explanations about the child's condition (that is, prognosis and treatment) and practical advice about daily caregiving as well as how to respond to emergencies.^{57** 92***} Information needs to be provided in ways that can be understood and may need to be repeated as parents become familiar with their child's diagnosis.

^{93*} However, inadequate, inappropriate or contradictory information is often received.^{25*}

Many families say they do not know where to find out what they need to know⁹⁰ and welcome introductory materials such as leaflets and booklets¹³⁰ and being able to access information through the internet.^{131** 109} However, there are risks of using such information in isolation as it may not be accurate or applicable in a particular instance.^{131** 130} Verbal explanations and advice are successfully provided by telephone helplines^{22*} and keyworkers.^{29** 24** 57, 130* 94*} Mutual advice/information sharing was welcomed, too, with good evidence for using internet-based support groups.^{131**} Local parent support groups were also thought to be useful.^{116, 132} Suggestions regarding information were also made in keyworded studies.^{52, 62, 79, 85, 110, 116, 122, 130, 133}

Provision of such information and advice is associated with enhanced parental emotional wellbeing, improving control, empowerment and coping.^{25* 93* 24**} It is also thought to improve parental relationships and stability of family life.⁶⁴ Through this parents become extremely skilled and knowledgeable and can often detect potential health problems earlier than professionals who do not know the child so well^{25*} (also suggested in¹¹⁶).

3.2.4.2 Assistance with/a break from caring

Some parents find life caring for their child with CHCN to be a constant, daily struggle.^{92*** 22**} The rigours of highly scheduled 24-hour treatment regimes, heavy lifting and the need for constant availability to monitor symptoms and manage complications or emergencies can cause sleep deprivation and extreme physical exhaustion.^{92*** 68** 29** 21** 25*} Where this level of fatigue is not assuaged it can have potential long-term consequences for parental health. Not only is this damaging for parents as individuals but it might mitigate against the parents' capacity to continue as caregivers.^{92***}

Numerous studies discussed the need for parents to have some form of assistance with or break from these ongoing responsibilities and demands.^{37, 41, 42, 44, 50, 51, 55, 75, 95, 110, 134} As CHCN require particular or specialised skills on the part of the caretaker, naturally occurring opportunities for assistance or breaks are less available.^{21** 25*} Relatives and friends are unable or lack confidence to assist^{50**} unless they have undergone

formal training,^{25*} and this is rarely available.^{94*} Parents are thought to be reluctant to ask them because of fear of over-burdening them with such physical and technical demands.⁵¹ Only where school inclusion is successful do parents receive a natural break from the demands of care in a way that does not disrupt the child's ordinary social and family life.^{29** 27*}

Many parents need additional *nursing*,^{26*} *ancillary care*^{94*} or *sitting* services to be provided in the home^{29** 143** 25*} so that they can cope (also suggested in^{33, 38, 46, 52, 108}). These services enable parents to rest, sleep, have a bath, go shopping, spend time with their partner and participate in work, leisure, religious, cultural, social or community activities. There is very strong evidence that this supports and replenishes parental morale, energy, mental health and emotional wellbeing that have been depleted due to the stress and exhaustion caused by the emotional, physical and practical challenges of constant caregiving and vigilance^{91*** 92*** 21** 22, 32, 33, 50, 51, 68, 75, 79, 82, 90, 95, 110, 135** 136** 137** 26* 138*} (also discussed in^{32, 33, 50, 51, 68, 75, 79, 82, 90, 95, 108, 110, 135, 139}).

Some parents found this in-home provision of a break for them to be more flexible, responsive and less disruptive for their children.^{21** 25*} The child remains in his/her own familiar environment; equipment does not have to be transported, the risk of cross-infection is reduced and trust is built up with one carer or a team of carers over time who have been specially recruited and trained, although not all parents receive provision appropriate to their needs. Parents want services to be sufficiently responsive to accommodate family events, preferences and emergencies but this is rarely available,^{137**} for example, no night-time sitting services.^{25*} Keyworded studies make similar comments.^{71, 77}

Despite their benefits, the continuous presence of home carers can be stressful and invasive, disrupting family life and limiting families' privacy.^{94* 25*} There have also been difficulties in identifying enough knowledgeable and skilled home care personnel who are able to meet the child's care needs; this has implications for local authorities' *recruitment*, *training* and *supervision* procedures.^{26* 25* 94*} Keyworded studies suggest parents need to be confident in formal carers' abilities as a change in worker disrupts routines and provokes anxiety.^{49, 88} Multiagency agreement about funding these services within care packages needs to be planned early if hospital discharge is not to be delayed or parents required to do more than they can manage while waiting for the appropriate level

of home care to be agreed.^{25* 104* 94*} Wide disparities have been reported in the amount of home support received by families with similar needs in the UK, possibly relating to local policies.^{25*} Some parents say they carry high levels of responsibility in the absence of sustained support.¹³⁸ Further national clarity on *eligibility criteria* appears to be called for to ensure equity of service provision geographically.

Such home-based services do not always offer parents a sufficient break away from routines to refresh them emotionally and physically and many parents prefer the child to be cared for outside of the home for a few hours or days^{137**} (also suggested in⁵¹). Pros and cons were reported for different forms of break. Those within alternative family settings, including suggestions for link-family schemes,^{50,95} were generally valued highly by all family members including children with CHCN^{92*** 21**} (also discussed in^{51,75}). Some parents received personal support through the relationship built up with the carer.^{92***} Proposals in keyworded studies were that at least one night if not more was generally needed to provide parents with sufficient rest given their potential exhaustion.⁵¹ Pre-planned, 10-day stays away were said to increase mothers' feelings of wellbeing, reduce depression and improve caregiver–child interactions.⁷⁶

Some families and professions reported that institutionally based short breaks were less preferable due to risks of cross-infection, disruptions to children's routines and excluding children from ordinary family life.^{21** 25*} However, there were indications that parents in a keyworded study preferred their children to stay in a hospice feeling that their children were safe, comfortable and happy there.¹³⁸ They were particularly reassured that the alternative carer would be a nurse and, consequently, have sufficient medical skills.

There is evidence that some families have to find, train or orient their own short break carers themselves.^{92***} It is advised that the families' need requirements are determined *in advance*, not in response to a crisis, since the process involved in agreeing funding and recruiting and training specialist carers for particular families is lengthy^{91*** 24** 21** 136** 26* 25*} (also suggested in^{37, 44, 50, 77, 89, 96, 140}).

Some parents and professionals worry that children have been placed in inappropriate settings, and are concerned about physical safety and possible psychological damage to children through a lack of consistent care, and carers.^{138*} Not all parents took advantage of short-break or sit-

ter services as they worried that their child's health needs, particularly medical emergencies, would not be adequately dealt with and their child would find breaks away or changes of carer difficult to deal with^{68**} (also proposed in^{44, 95, 141}).

Some further proposals were made in the keyworded studies. Some parents who objected to the label of carer, perceiving themselves simply as parents, were happy to use child support services but felt if they used a parent-support service it was an admission of failure, that they could not cope.¹⁴¹ Very few studies discuss the overt advantages or risks for the child of having a break from their usual carer. Time out of the household with a link family⁵⁰ or in a holiday play scheme¹⁰⁰ is thought to offer children possibilities to participate in community life, have fun, make friends and develop independence. Nurses in one UK study thought children needed as much a break from the usual routines and faces as their parents.⁵¹ The point was continually made by parents and professionals that short breaks *do* promote family life for children with CHCN as they enable parents to cope and continue successfully with the care-taking role. Only one out of a sample of 10 families said that the situation worked well without any breaks being provided.⁹⁰ Another family placed their child in foster care for a year due to parental stress and exhaustion.⁵¹ However, much more needs to be known about children's views and preferences here.

3.2.4.3 *Emotional support for parents/primary carers*

A number of studies report high levels of emotional and psychological stress experienced by parents of children with CHCN. Difficult decisions need to be made;^{92***} two keyworded studies described decisions about medical treatments being stressful.^{44, 66} Some parents felt pressured to become long-term carers regardless of whatever expectations they might previously have had for gradually relinquishing the caring role as their child matured.^{25*} Continually meeting the child's physical or medical needs and monitoring their symptoms was said to cause exhaustion, overload and social isolation^{57**} (this was also discussed in^{44, 45, 66, 102, 109, 110, 117, 141-143}, particularly for mothers who tend to be the main caregiver).^{143, 144}

A number of issues believed to contribute to this were discussed in keyworded studies: frequent change, unpredictability, fears and uncertainty about the future,^{37, 39, 102} seeing the child in pain or suffering,¹⁴¹ and

chronic grief¹¹⁷ and anger about losses, for example, of dreams for their child, of relationships with extended family and friends,¹⁴⁵ of privacy and personal space, of the opportunity to be creative and reflective, of freedom of choice in personal and family matters, of leisure activities including holidays.¹¹⁰ Significant financial strains are reported below (see Section 3.2.4.4). Such continued stress was thought to inhibit parents' capacity to meet certain of their children's needs, for example, giving appropriate boundaries^{97, 99**} or providing emotional support.⁸⁵ While some parents report that their child's needs have brought them closer together, others talk of conflict and disharmony in the parental relationship due to limited leisure time together as a couple, arguments about role and task distribution and exhaustion.^{33, 36, 39, 84, 97, 102, 103*, 141} Some parents asked for their parental relationship to be supported in order to avoid family life being disrupted for children³⁹ and others *relationship counselling*.³³

There is strong evidence that many parents experience a range of physical and emotional symptoms such as anxiety, anger, frustration, despair, powerlessness, depression, exhaustion, irritability, migraines, anaemia and insomnia^{91*** 57** 68**} (also considered in^{36, 45, 46, 95, 109, 144, 145}). Two keyworded studies suggest some symptoms reach clinically significant levels^{83, 84}) and more than half of respondents in another reported enough symptoms to classify them as needing psychiatric intervention.³⁰

There is some evidence that parents had their own preferred ways of coping that included: gaining concrete and emotional support from family, friends, others in a similar situation and professionals; comfort from religion, spiritual beliefs and prayer; cognitive techniques (reprioritising lifestyle, normalising, problem solving, information seeking, taking control, planning); physical outlets (for example, crying, drinking, smoking, physical activity); self-maintenance (venting emotional distress, having other interests, self-indulgence); approaches to life (adaptability, taking one day at a time, not dwelling on difficulties, acceptance, hope, comparing self to others worse off, refusing to give up, forming positive meanings from the experience, 'getting on with life' and moving forward); a good relationship with the child; helpful policies; own financial resources; and job flexibility^{22** 57** 26*} (also discussed in^{36, 39, 46, 102, 141, 144, 146}). Improved coping was associated with parents feeling more control in their lives, no longer being overwhelmed by their emotions, improved parent-child relationships and capacity to continue caregiving.

Some parents report having needed professional *counselling*.^{28* 108} Individual, family and group counselling were all thought to be beneficial⁹² with needs at diagnosis particularly mentioned.⁸⁷ There was strong evidence that parents feel *emotionally supported* by helpful and compassionate ongoing relationships with professionals and home care providers in which they are able to discuss their feelings and contact them at any time with problems/issues.^{29*** 42** 24** 28*} This suggests that the way in which professionals provide services is as important as the service, for example, manner, approach, emotional availability and sensitivity. It was suggested, however, that boundaries need to be attended to, as uncertainty, confusion and frustration may occur when these are crossed; contracts setting out boundaries^{111, 153} and worker self-awareness were proposed.³⁸

Conversely, parents feel unsupported when professionals do not recognise their needs and difficulties, view them as difficult, demanding or manipulative, without recognising the difficulties they face, appear unsympathetic, and/or disinterested in their child's suffering^{67** 49*} (also discussed in^{45, 106, 151}). Keyworded studies suggested good communication between workers and families was important⁴⁸ to deal with conflicts about parents feeling need is not addressed,¹¹⁷ where there are disagreements about treatment or care approaches, or because parents resent paid professionals being able to go home when they get little break.⁴⁰ There was evidence of benefit in assisting mothers to learn skills to help them manage their relationships with professionals.^{42**}

Organisations that enabled parents to mutually share information and give/receive social and emotional support (either face-to-face or 'virtually') were found to be beneficial.^{138** 34* 139, 54} One internet group was found to reduce anxiety and depression, helped restore emotional balance or stability and improved caregiver-child relationships for some parents.^{138**}

3.2.4.4 *Financial needs*

Many families where there is a child with CHCN experience report increased financial hardship. The demands of the caregiving role prevents parents putting time and energy into furthering their careers and the majority of mothers give up paid work^{20** 24** 28* 101* 103*} (also discussed in^{51, 53, 63, 125, 147 33, 74, 147 92, 117, 110, 79}). The need for home adaptations, house

moves and equipment has already been reported; many families cannot get charities or the local authority to meet the full costs and have to fund them themselves.^{24**} Keyworded studies suggest additional costs include travel to, and parking fees for, appointments,¹⁰⁶ higher electricity bills to run equipment, higher home insurance, mobile phones in case of medical emergencies and refreshments for home carers.⁴³ In countries where there is not a national health system to pay for home care and medication (for example, North America) further financial hardship was experienced.^{34* 33, 40, 51, 74} This combination of low incomes and caring was believed to isolate families and restrict lifestyles, consequently detrimental to the child and family's social inclusion and emotional wellbeing.⁷⁹ Provision of *additional financial resources* that would lessen the stress and impact on the family system were proposed.^{37, 136}

3.2.4.5 Other family support services

Families want to do leisure activities together but regimes and equipment to meet CHCN often prevent this^{99***} (also described in ⁵⁷⁻⁵⁹). There is evidence for a *family-centred* approach to service provision that considers the needs of all family members both as individuals and as a unit,^{99*** 42** 24** 152*} (also proposed in ^{40, 63, 73, 154}). This promotes positive, loving relationships between parent and child that mediate the stress of being a carer, enabling parents to view their situation more positively and to maintain commitment to caring through difficult times^{42** 67**} (also discussed in ^{51, 147, 107}). Ambivalent and resentful feelings persist when stresses and difficulties are not supported and parents are pushed into being carers rather than choosing this role^{67*} (also considered in ^{141, 147}). It is believed that parents are then less able to provide emotional support to their children, which inhibits the development of children's self-image and self-worth.⁹³ Conversely, where family support services are boosted parents can cope better and parent-child interactions are seen to improve^{82*} (also described in ^{93, 147}).

Suggested services in keyworded studies include early intervention programmes thought to reduce stress and improve parenting skills to deal with particular challenges¹⁵⁵ and home visitors who provide play and educational activities for children as well as supportive conversations, assistance and short breaks for parents that are believed to reduce parental concerns, stresses and fatigue and improve general spirits.¹⁵⁶ A range

of other family support needs were also reported, some of which were evidence in quality-appraised studies including *advocacy*,^{28* 63, 86, 106, 151, 157} *information* on services and benefits available,^{28* 85, 86, 93, 98} *home helps*^{43, 86} and *transport*.^{29*** 79, 90, 115, 125, 126, 124} There are suggestions, however, in one keyworded study, that some parents are reluctant to use support services for themselves if they do not benefit their child directly.¹⁴⁷

Keyworded studies suggest that the needs of the child with CHCN and their *siblings* may sometimes clash and a whole-family approach to assessment is needed to assess these potentially conflicting needs so parents can manage simultaneous demands.⁷⁹ Some siblings without CHCN have become carers themselves and are affected by similar stresses and strains to those reported by parents.¹¹⁷ Others may feel left out of the family and less important to their parents because there is less time, attention and energy for them.^{40, 151} In some cases their education, social lives, routines, behaviour and emotional and mental health is found to be affected^{30*} (also described in^{40, 53, 126}). It is proposed that specified outcomes for children must also be promoted for siblings, too, so costs and benefits need to be weighed not just for the child with CHCN but for the whole family.^{40, 59, 73, 147}

The particular needs of minority ethnic families for support are not always addressed. There are said to be professional assumptions that services are not required within minority communities as extended family support is available and preferred. In fact Pakistani and Bangladeshi parents were described as having a lower level of extended family support¹³⁰ than those in a national study of mainly white families.¹⁰⁸ Additional stressors for minority families described included the combination of disadvantaged circumstances and difficulties in securing access to appropriate services because language barriers and inadequate levels of communication left families not always able to understand how services and benefits were organised, what was available to them and how to challenge or even negotiate with service providers.^{93, 148} South Asian families preferred services that were sensitive to cultural and religious needs.⁹³ Pakistani and Bangladeshi families specified workers of the same ethnic origin so they could speak the same language.¹⁴⁸ It was found that some parents believed that if haemoglobinopathies (for example, Sickle cell disorder and thalassaemia) affected more white children there would be better service delivery.^{67**} It seems advisable that agencies consider

institutional racism as part of *anti-oppressive* service planning and delivery.^{67** 148}

3.2.4.6 Service coordination

Numerous professionals from a wide range of disciplines become regularly involved with families where there is a child with CHCN.^{28*} Many parents have complained that service provision has been fragmented leaving some feeling they are the only ones who are seeing or caring about the whole child.^{99***} A lack of coordinated planning means that difficulties with accessing services, overload from unsynchronised visits from different professionals and confusion about their roles, insufficient information and feeling isolated and unsupported are common experiences.^{28*} Having to organise service provision and equipment themselves leaves parents with little time for ordinary family life and creates additional pressures over and above those of caring for their child.^{99*** 28*} There is strong evidence that coordinated systems of case management and joint collaborative working that tailor approaches to the child and family's needs rather than trying to fit them into pre-existing unhelpful structures are preferred by families and professionals.^{99*** 20** 24** 47** 52** 34* 144* 50* 103*} These issues are also considered in^{41, 79, 108, 136, 151, 158, 85}.

Disputes between agencies, and sometimes professionals, about responsibility for funding services appear to cause considerable stress to parents^{103*} and highlight the need for clear responsibilities through *Joint funding* procedures.^{28* 86} In the UK NHS guidance EL(95)5 has clarified responsibilities for funding technologies, and the use of commercial companies to provide an integrated service directly to families' homes. As a result funding appears to have become more reliable, efficient, responsive and integrated, benefiting families.^{29*** 28*}

Integrated systems of multiagency working are being introduced in the UK in line with the requirements of the 2004 Children Act. Here a lead professional must be identified for each child who should: provide information, signposting and emotional support; coordinate the multi-disciplinary services provided; monitor and review the care plan and ensure its effectiveness; and make proactive contacts with the family to assist in the identification of needs and preparation for review meetings, including helping the child to communicate his or her wishes.⁵⁵ This more coordinated approach appears to have resulted in observ-

able improvements to the system that a number of families feel has become more efficient, effective and simpler to deal with. These include: greatly enhanced coping,^{67**} a reduction in the negative effects of care routines,^{20**} improved communication, more involvement in the care planning process, solving of previously intractable problems, identification and addressing of needs, and provision of information, advice, and emotional support^{24**} (also described in⁵⁵). One keyworded study also suggests children are being discharged earlier from hospital.⁶⁰

In one medium-rated study^{24**} there is evidence that parents felt more emotionally supported as they were less exhausted even though keyworkers were not necessarily dealing directly with their emotional needs. The role expansion and blurring following the adoption of keyworking seems to have been experienced positively by frontline workers as it was providing an opportunity to work in new ways. However, many social workers felt medical and healthcare issues dominated and threatened the social model of disability. The study authors advise alertness to workers stepping too far outside their area of expertise. Another study reports strong evidence that a keyworker should be appointed for every child with CHCN.^{52**}

3.3 Conclusions

3.3.1 What is the research evidence about the social care needs of children with CHCN and their families and services designed to meet those needs?

The findings of the research review are consistent with those of the consultation. In particular both verify that children with CHCN have the same 'ordinary' wishes and needs as other children, that is, to live at home with their families, go to school, spend time with their friends and participate in leisure and community activities with family and peers.

Children and their families require any or all of a range of services to enable this, including specialist home care, equipment, housing adaptations, transport, psychosocial interventions, emotional support and counselling.

Despite some more recent improvements, however, these services are not always provided without significant delays and/or battles on the

part of families as funding is not always agreed readily or on request. Without this children's health and safety cannot be guaranteed at home or school. The result is that some children still experience significant delays in being discharged from hospital and attending school.

Both review and consultation highlight how it is parents who provide most daily care for their children. Ongoing monitoring and caregiving can be stressful and exhausting. Meeting the parental needs outlined in this review can enable them to cope in the longer term and consequently promotes child-focused outcomes. A family-centred approach to service provision is strongly supported empirically; this includes home support services, emotional and relationship support, access to employment and additional financial resources. The implications here, then, relate both to type and amount of services provided to meet needs.

Families, however, experience further difficulties regarding the availability and flexibility of such services due to the lack of suitably trained personnel. This suggests issues with both recruitment/retention and training of formal carers.

Ordinary family life is frequently interrupted by the fragmented nature of service provision currently. Families may fall through the gaps in between and struggle to ensure agencies take responsibility for funding the services they need. A 'postcode lottery' regarding service provision adds further stress to families.

Early indications from the moves towards integrated service provision under the Change for Children agenda are positive with some families experiencing benefits from the lead professional approach with coordinated planning/commissioning and a coherent 'team around the child'. Improvements are not only in speeding up and simplifying assessment and service provision but in providing the kind of ongoing relational and socio-emotional support so valued by families.

One significant limitation of the existing research base is that the voices of parents and professionals have been heard more than those of children with CHCN in this review, particularly in respect of younger children and those with the most complex needs. This does not fit with the aspirations of the current policy and legislative context that emphasises the importance of seeking children's views to inform service planning and delivery to meet social care needs. The achievement of outcomes should arguably be measured by children's desires and aspira-

tions, what they want and need, and relate to the policy agenda, rather than what resources currently dictate.⁶²

Further empirical research regarding children's views on their social care needs (for example, in respect of emotional support or how they view short breaks outside of the family home) is recommended to ensure that children's emotional and social needs are not marginalised by professionals concentrating on their health or on their parents' needs. A separate research review of the needs of siblings in their own right would be advisable to ensure that they are also able to achieve the outcomes specified for all children in the 2004 Children Act.

3.3.2 How does research evidence compare with the findings of the consultation?

As stated above, many aspects of 'ordinary life' featured both in the research literature and in the consultation as things that matter most for children and young people with CHCN and their families.

3.3.2.1 Issues of manner and mechanism, process and outcome

In certain respects differences seemed to relate to the framing of issues rather than constituting contradictions in substance. Things that matter in the consultation were sometimes articulated more as matters of process as opposed to the outcome focus of research. For example, the importance of relations with family and friends and access to play and leisure activities were highlighted in both parts of the review. The themes they fall under in each, however, are significantly different: 'people and relationships' in the consultation in contrast to 'emotional wellbeing' in the research review.

The consultation generally framed issues with an emphasis to the 'how' or the 'manner' of service delivery as opposed to the mechanisms. For example, flexibility and responsiveness were highlighted in both as matters of importance to families. In the consultation this was a theme in its own right, in contrast to the research review in which these issues featured under 'assistance with and breaks from caring' and 'service coordination'.

Consequently, certain priorities stood out more strongly in the consultation, compared with the research literature. These include:

- the importance of friends for children
- the nature of relationships between professionals and families
- when and where health needs should be met
- enabling children to have a positive sense of themselves.

While these aspects do appear in the research review, they do so among a number of important themes rather than being one of a few key themes in the consultation.

Conversely, the weight given to systemic difficulties and solutions in service delivery in the research review tended not to be highlighted in the consultation. For example, the focus on funding issues in the research was not mirrored in the consultation. Again this seems to be a matter of the framing rather than substance of issues because in both the consultation and research review, families rarely talked about who funds or provides services, other than as another barrier to provision.

3.3.2.2 A *'family-centred'* approach

Perhaps the most striking differences between evidence produced through the consultation and that of the research review relates to parents and siblings of children and young people with CHCN. While both highlight how it is parents who provide most daily care for their children, parents in the consultation made little of the constant daily struggle and the high levels of emotional and psychological stress linked to caring for a child with CHCN, that featured strongly in the research review.

Parents in the consultation made little of their own support needs, compared with the attention this issue receives in research literature. The only issue in common seems to be that of 'assistance with, and breaks from, caring' that features in both. Yet in the consultation it illustrates one aspect of the 'flexibility and responsiveness' that families want from services rather than being a means of stressing the importance of parental support needs as distinct from that of their children with CHCN or their siblings.

In relation to siblings, similarly, evidence from the research literature highlighted the clashes that sometimes occur between the needs of the child with CHCN and those of their siblings. Evidence from the consultation gave a more nuanced picture that indicated that relations between siblings were as mixed as in most families. The positive

aspects of siblings' understanding of, involvement in and compassion for their brother/sister with CHCN stood out strongly. Equally, the value of services that included siblings whether in hydro-therapy swimming, art therapy or home-sitting, was also central.

While a 'family-centred' approach is advocated in both sets of evidence, the consultation evidence seems to emphasise the needs of the family unit over and above the needs of individual family members as individuals, while this emphasis is reversed in the research review findings. Clearly this difference speaks to the inevitable tension between a discourse of child-centredness (whether child with CHCN or sibling) and one of family-centredness. Unfortunately the findings from the research and consultation indicate that to date this remains under-explored.

3.3.3 Reconceptualising social care

Service provision is based on the assumption of separable needs, for example, health, education, social care, palliative and so on. Yet analysis of definitions of social care needs most commonly used in research literature concerning children with CHCN revealed considerable ambiguity regarding what might constitute social care needs as opposed to health, mental health, social and educational needs. This reinforces the urgent need to reconceptualise 'social care'.

The way families talked about their lives in the consultation seemed to require rethinking 'social care' needs as fundamentally linked to something like 'ordinary life'. The findings of the research review corroborate this and, therefore, the potential in reconceptualising social care needs from an 'ordinary needs' or 'ordinary lives' perspective.

3.3.4 Implications for policy and practice

The findings of the research review, therefore, also raise various challenges to current policy and practice that are worth clarifying here.

The CHCN are likely to give rise to a range of what, in the current policy context, are termed 'additional' and 'complex' needs.^{2, 160} However, both review and consultation also remind us that the primary

focus must always remain on the ordinary needs of these children if children with CHCN are to lead ‘ordinary lives’.

Barriers to this derive initially from the CHCN themselves but the research evidence indicates various ways in which they reinforce rather than reduce by current service design and delivery. According to the National Service Framework disabled children’s standard services should be coordinated, high-quality and family-centred and based on assessed needs in order to promote social inclusion. Yet the research review indicates that crucial practice issues related to implementing and embedding such policy and guidance remain.

The research review suggests that the coordination remains problematic, particularly related to funding. Yet the current framework for joint planning and commissioning of services (www.everychildmatters.gov.uk/planningandcommissioning) is silent about the complex service needs of this group of children. Current commitments to ensure better integration of service governance and strategy (www.everychildmatters.gov.uk/delivering-services/integrated-working/), including joint commissioning, urgently need to be prioritised and actualised. Joined-up planning at the level of the individual child and family is needed so that families can access seamless services.

Research evidence also indicates that the availability and flexibility of services of adequate, let alone high-quality, also remain problematic due to the lack of suitably trained personnel. The Options for Excellence Review of Social Care recommendations (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4139958) may go some way towards tackling this in a range of ways if they are realised by the Children’s Workforce Development Council (CWDC)*, for example, promoting career pathways and formalising and standardising training through an Integrated Qualifications structure.

Parents’ and foster carers’ needs for training, advice and information to prepare them for often highly specialist health procedures so that the

* The CWDC is one of five bodies forming the UK Skills for Care and Development Sector Skills Council and coordinates the Children’s Workforce Network. It aims to ensure that the people working with children have the best possible training, qualifications, support and advice.

child can be safely cared for in a family setting are also recognised in the Options for Excellence recommendations and must be pursued.

As indicated earlier, the research review draws attention to the inherent tensions at the heart of a 'family-centred' approach. Much more needs to be known about this area if it is to benefit children and young people with CHCN and their families.

Lastly, research evidence suggests strongly that the value of basing services on assessed needs is significantly diluted if it is not backed up by universal or eligibility criteria.

Practice survey

4.1 Methodology

To supplement the research review, the practice survey aimed to identify development work, knowledge and examples of good practice in meeting the needs of children with CHCN and their families.

If there is normally a dialogue between the research review and the practice survey in SCIE knowledge reviews, the question of how best to conceptualise social care needs and services at the heart of this particular review required an even more direct connection between different parts, as described below.

4.1.1 Conceptualising 'good practice'

Undertaking a practice survey in England, Wales and Northern Ireland to identify services and settings that have made progress on meeting the social care needs of children with CHCN and their families required us first to define 'good practice'. We used findings from the consultation to do this.

The practice survey used information gathered from this consultation to define the 'good practice' examples of service provision that we subsequently set out to identify.

The key criteria that emerged from the consultation included services that:

- demonstrated *flexibility and responsiveness* to the individual needs of families;
- recognised the *ordinary needs* of children and families as crucially important;
- worked *in partnership* with families, valuing their knowledge and expertise;

- worked with *wider networks*, including family, friends, other services and settings.

We excluded services that focused only on one member of the family, who worked only in one setting, or who defined their role as solely clinical. This is not to say there is no place for such targeted services, but our focus was on services who were responding flexibly to the needs of whole families. We also wanted to locate services that had found ways to actively safeguard families' ordinary needs.

During the course of the review, we learnt more about families' experiences and the barriers they faced in getting their ordinary needs met, in getting the support that would allow them to lead 'ordinary lives'. Consequently, it seemed clear that defining 'good practice' in terms of meeting children's complex needs in ways that *least disrupt* their ordinary needs no longer seemed adequate. Instead, it became clear that 'good practice' required meeting children's complex needs in ways that actively safeguard their ordinary needs, and those of their families. Lack of disruption to ordinary needs was not enough, because the barriers faced by families in getting their ordinary needs met were so formidable.

4.1.2 Identifying services

We gathered information about a wide range of services in our consultations with families and our original plan was to use this input to identify examples of 'good practice'. However, this raised challenges in terms of maintaining the anonymity of participants, given that we were targeting such a specific group of children. Consequently, we decided to widen the search base for services by advertising our search on a range of national electronic forums in order that the services identified were no longer exclusively in the areas from which families taking part in the consultation were drawn.

We followed up as many of these services as possible and selected eight that fulfilled the criterion of 'good practice' detailed above.

4.1.3 Data collection

We spoke in person to a senior or lead person of every service, and read a range of information produced by the service. For almost all, we spoke

directly to at least one family who had used the service. Where possible we met with some or all of the staff team, read internal and independent research about the service, gathered views and stories from families and staff, spoke to commissioners and referrers as well as reading published books and materials.

We had hoped that our descriptions of initiatives would cover the background and aims, how they work, what has been learnt, what made them work and their general ability to fit other settings or localities. However, confidentiality issues arose that prevented us from providing this level of detail – as we explain below.

4.2 About the services

The eight selected services are provided very differently:

- from within the NHS (3)
- local authorities (1)
- voluntary organisations (4).

Some of the voluntary organisations are contracted by statutory authorities; some are independent. All the services offer direct provision of some kind to families.

They serve very different areas:

- primarily rural (2)
- primarily urban (2)
- mixed (3)
- national (1).

Five are in England, one in Wales, one in Northern Ireland and one works across the UK.

All of the services are multidisciplinary, but across an extremely wide range of disciplines: medical, nursing, care, social work, advocacy, financial and employment advice. Several of the services have volunteers within the teams.

There are, no doubt, other services across England, Wales and Northern Ireland that respond flexibly to families' needs, some because this is their designated function, others because individual staff have

identified the need for flexibility and responsiveness in their direct work with a family. The methodology adopted by the review team to identify services obviously restricted the services potentially included. Therefore, our selection of eight is not meant to imply that these are the only eight.

Below are brief descriptions of the eight services and the features that we found most significant for each. Full contact details are given to enable further information to be easily located.

Name of service	Demelza James Hospice at Home Team
Contact name and role	Corine Koppenol, Team Leader
Postal address	Red Lion House, Magham Down, East Sussex, BN27 1PN
Telephone/email	01435 868507 corine.koppenol@demelza.org.uk
Website address	www.demelza.org.uk
Aims of service	Demelza James Hospice at Home provides a team of specialist children's nurses to support families who have a child with a life-limiting condition, providing ongoing nursing care and a wide range of palliative care support at home
Key features	The team provide care, crisis intervention, an on-call service and respite. The service enables the family to live life as a family in their own environment. The service works extremely flexibly in the child's own home, in the homes of other relatives and friends, in schools, nurseries and leisure settings and when children are on holiday. The team describe 'rewriting their job descriptions' for each new child and family, and over time with the same family

Name of service	Children's Home Care Team (CHCT), Medway Maritime Hospital
Contact name and role	Jacqueline Duffy Specialist Social Worker
Postal address	CHCT, Paediatric Unit, Medway Maritime Hospital, Windmill Road, Gillingham, Kent ME7 2RW
Telephone/email	01635 825144 Jacquie.duffy@medway.gov.uk
Website address	
Aims of service	To provide holistic local support to a child or young person who is seriously ill, so that they can be cared for at home by their parent/carer. The team aim is to be child and family-focused and to ensure that the child or young person's medical needs are considered alongside the social, educational and emotional needs of the child and their family
Key features	The team work flexibly with the child's own and substitute families including grandparents, aunts and uncles, best friends and neighbours. The service enables parents to be involved in all aspects of their child's care and takes an inclusive/whole family approach such that families feel supported and able to make informed decisions about their child's care

Name of service	The Nigel Clare Network Trust
Contact name and role	Mairi McElhill Putt, Director
Postal address	The Nigel Clare Network Trust, The Watchhouse, 10 Giltspur Street, London EC1A 9DE
Telephone/email	0208 769 0941 postmaster@nigelclare.org.uk
Website address	www.nigelclare.org
Aims of service	To enhance the quality of life for families caring for children and young people with conditions that limit their lives by length, by quality or by both; to provide practical, relevant aid to self-help that will reduce or negate hardship caused to families in these situations; to raise awareness among employers, professional and voluntary sector carers, statutory authorities and others of the value of maintaining the family as an effective unit by providing equality of opportunity to make a living; to develop models of excellence of service for replication throughout the UK and beyond
Key features	To deal with a family's economic and practical needs, by providing advice and support to enable parent-carers to find a life-work balance; to protect the family's economic situation

Name of service	Northern Ireland Children's Hospice Community Team
Contact name and role	Hilary Maguire, Care Manager
Postal address	Northern Ireland Children's Hospice, 18 O'Neill Road, Newtownabbey BT36 6WB
Telephone/email	028 9077 7635 hilary.maguire@horizon-house.org
Website address	www.nihospicecare.com
Aims of service	The Children's Hospice Community Team is part of the Northern Ireland Children's Hospice, and aims to be flexible and responsive to an individual child and family's needs; to provide support and advice to the child and family, emergency/crisis specialist respite at home, terminal nursing care at home and bereavement support; to improve and enhance respite and nursing care to children with life-limiting illnesses and their families in their own home
Key features	<p>The team is multiprofessional: nursing, care and social work, and provides flexibility and choices to life-limited children and their families. Care can be provided in the child's own home or other community settings as required.</p> <p>Children are not treated in isolation. Care encompasses their families and friends and includes helping them to come to terms with life-limiting and life-threatening illnesses. Service provides flexibility and choices to life-limited children and their families</p>

Name of service	The Ryegate Home Care Team
Contact name and role	Mr John Reid, Director of Clinical Operations and Nursing
Postal address	The Ryegate Children's Centre, Tapton Crescent Road, Sheffield, South Yorkshire S10 5DD
Telephone/email	01142 260600 Karen.Obrien@sch.nhs.uk
Website address	www.sheffieldchildrens.nhs.uk/
Aims of service	To provide high-quality care and support to families who have a child with complex needs/ a life-limiting condition in the home. A multidisciplinary team consisting of a consultant, psychologist, nurses and support workers who provide support, advice and nursing care to children with neurodisabilities who require specialist support and nursing care. Also provides a 24-hour on-call service
Key features	<p>The team believes in a flexible, caring approach tailoring the nursing needs to each individual family. The team aims to support, give advice and provide hands-on care. The team tries to improve the whole families' quality of life.</p> <p>The team offers holistic care, which focuses on the enhancement and quality of life for the child by embracing physical, emotional, social and spiritual elements of care</p>

Name of service	SSSH (Specialised Sitting Service at Home)
Contact name and role	Tracy Young/Helen Burley, Specialist Health Visitor/Modern Matron Children with Special Needs, The MacKeith Centre
Postal address	The MacKeith Centre, Royal Alexandra Hospital, Dyke Road, Brighton BN13JN
Telephone/email	01273 328145 Ext 2249 Tracey.Young@southdowns.nhs.uk, Helen. Burley@southdowns.nhs.uk
Website address	www.southdowns.nhs.uk
Aims of service	SSSH is a flexible service that supports parents/carers and families, by providing a break from caring so that parents can spend some time together and/or spend some special time with their other children
Key features	Wide professional background of sitters; emphasis on giving as much autonomy as possible to the family and the sitter; about what happens and when and with whom

Name of service	Southend Social Care Children's Disability Team
Contact name and role	Laura Clarke, Senior Practitioner in Social Work
Postal address	The Lighthouse Child Development Centre, Snakes Lane, Southend-on-Sea, Essex SS2 6XT
Telephone/email	01702 507153 LauraClarke@southend.gov.uk
Website address	Children's Information Service www.childcarelink.gov.uk
Aims of service	Helping children with disabilities to get as much out of life as possible can be a bit like a jigsaw puzzle. All the agencies are like small pieces of the whole picture. Sometimes it can seem difficult to fit them together and sometimes the pieces seem scattered and hard to find. The social care team can help you put the pieces together
Key features	Enabling families to 'put the jigsaw together'. Also, basing the team in the same building as the medical services has enabled multidisciplinary working to develop

Name of service	Ty Hafan Family Support Team
Contact name and role	Shirley Valentino Family Support Team
Postal address	Family Support Team, Ty Hafan, Hayes Road, Sully, Vale of Glamorgan, CF64 5XX
Telephone/email	02920 532200 Shirley@tyhafan.org
Website address	www.tyhafan.org
Aims of service	The team works with families in a variety of ways, undertaking planned therapeutic interventions that can be practical, emotional, psychological, social or spiritual
Key features	The team is made of people with many different backgrounds, but all share a commitment to working with children and their families and to representing the views, wishes and needs of children/young people to decision makers and helping them to navigate the system: 'if there is a law or entitlement concerning our families we need to know it'

4.2.1 What can we learn from these services?

As stated earlier, input from families involved in the consultation had been used to define 'good practice' and families themselves had identified some of these services as positive examples of good practice. However, matching up the themes that had emerged in the consultation with their working practices turned out to be a far from straightforward exercise.

Far from exemplars of organisational arrangements that allowed professionals and carers to operate in the flexible manner, responding to the individual needs of the child and the family *as a whole*, as children with CHCN and their families had told us they needed, many of these services faced significant difficulties in doing what they deemed necessary to do. Speaking to people of the various services brought things to the surface that hindered their good practice as much as things that helped. In spite

of the evident dedication, skill and responsiveness of staff to individual and familial need, it proved impossible to use these services to build up a model or models of best practice.

4.2.2 Things that help: common features of good practice

Despite the difference in purpose and structure of these services, some common features were evident.

Across all services, there were similarities in ways that children with CHCN and their families were imagined, that helped in the nature and manner of service provision. Firstly, families were perceived as competent experts. Secondly, there was common acknowledgement of the child and family as partners in defining need.

Crucially, many of the services placed a high value on individual relationships and actively recognised and accommodated different aspects of a child and family's identity. What helped notably, in this regard, was the delegation of autonomy to frontline staff. Equally, the inclusion, within the function of the service, of tasks such as 'navigating', 'signposting', 'wayfinding', 'advocating' or 'keyworking' also proved helpful.

4.2.3 Things that hinder: common barriers to good practice

Pertinently, not one of the eight services defined its focus as wholly about 'social care'. Indeed, 'social care' is specifically mentioned in the description of only two of the services. However, when asked, all agreed that meeting social care needs was an essential part of their role.

This turned out to be more than a simple issue of terminology. We were surprised by how many examples of helpful service interventions seemed to involve people 'jumping the system' in some way: many people providing and managing the services spoke openly with us about 'breaking the rules' to meet families' needs. For example, as one professional explained of another:

'Not sure how wide her brief is. She wasn't really supposed to take his brother too. Technically not meant to use the system like this. Didn't put that on the timesheet. Bent the rules. Looked the other way. There are always special circumstances. We didn't put that on the timesheet

either. Some of what we do would be seen as an unacceptable risk ... but what the eye doesn't see the heart doesn't grieve over.'

Parents were also aware of this 'rule-breaking' behaviour:

'She told me what to put on the form so we'd be eligible. It wasn't exactly in her job description. He was only meant to work in our house, not at the park. You could see she wanted to get around the system for us. He didn't exactly break the rules...'

'What we do is a sort of informal exclusion, ie I just take him home if school ring up and he goes back the next day or the day after ... technically not supposed to use the system like this ... but it works fairly well.'

'... well the school ring me if they know they have a lot of kids off with a bug and then I keep him home.... We're not meant to do that but it works.'

Commissioner/provider divisions were often deemed to hinder their work. Many services were navigating complex commissioning arrangements on behalf of individual families, and struggled with contracts focusing on specific needs (usually clinical) when they saw that what families needed was much wider than this. Other services had moved towards rewriting the rules of their own service but were finding these actions blocked by commissioning agencies.

Another factor that hindered good practice in service provision was the fragility of teams due to short-term funding arrangements. The services selected were not particularly well resourced and many of them have uncertain futures and are dependent on funding that is time limited or renewable annually. This was reported as a major stressor for services, and obviously impacts directly on the continuity and familiarity that matters so much to families. There was awareness among many workers and families using the services that resources are not infinite – for example, families recognising the need to have services cancelled to allow crisis intervention for others as well as the need for creative use of volunteers in programmes.

The sensitive nature of the difficulties faced by these service providers caused a serious conundrum: how to write about these difficulties without compromising providers' anonymity. The result is a broad-brush stroke of practice provided in the tables above, as opposed to the detailed examples we had hoped to provide.

4.3 Conclusions

The practice survey confirmed that examples do exist of services that demonstrate flexibility and responsiveness to the individual needs of children with CHCN and their families, use ordinary life criteria to define needs and work in partnership with families as well as working with wider networks of family, friends, other services and settings.

Common features of these services included:

- families were perceived as competent experts;
- the child and family were acknowledged as partners in defining need;
- a high value was placed on individual relationships;
- different aspects of a child and family's identity were actively recognised and accommodated;
- autonomy was delegated to frontline staff;
- high levels of flexibility and responsiveness were provided;
- tasks such as 'navigating', 'signposting', 'wayfinding', 'advocating' or 'keyworking' were included within the function of the service;
- volunteers were creatively used within programmes.

Our consultation work identified what helps and what gets in the way of providing the kinds of services that children with CHCN and their families told us they needed. This section, in contrast, has highlighted some points about what *helps* and what *hinders* from service providers' perspectives.

Three key and common barriers were identified. Firstly, the mismatch between the formal remit of these providers and the actual services that neither social care needs nor services were formally acknowledged. Secondly, commissioning arrangements and associated contracts further led to social care needs and services being overlooked and restricted the power of service providers to redress this imbalance. Lastly, short-term

funding arrangements featured as a barrier to good practice impacting on the continuity of service provision and familiarity with professionals that matters so much to families.

4.3.1 Implications for policy and practice

Although we engaged only with a very small sample of service providers, taken together with the findings of the consultation, our analysis gives a strong indication of the difference between policy and guidance on the one hand, and practice on the ground on the other.

The difficulties faced by this sample of services that are attempting to deliver innovatively raises important questions about where responsibility for developing services lies in current commissioning arrangements. Furthermore, it suggests a need to go back to the drawing board in relation to commissioning services in order firstly, to enable flexibility and responsiveness to be built in at the service design stage. Secondly, planners and commissioners need to explore creative solutions that would allow the adaptation of temporal aspects of service provision for children with CHCN and their families. Minimally, it identifies the need for further research from a service design and delivery perspective.

Overall conclusions

As explored in the introduction, this knowledge review took place in a rapidly evolving policy context. During the consultation and research review a number of significant policy initiatives and guidance relating to provision for children with CHCN and their families were launched. Others, as stated in the introduction, were published subsequently so we are unable to address them here.

We looked at four sources of government guidance that apply to all children:

- *Every Child Matters*⁶
- *National Service Framework for children, young people and maternity services*²
- *Common Assessment Framework*⁴
- the Common Core of Skills and Knowledge for the Children's Workforce (2005)¹⁶⁴ keyworking and multiagency and integrated services.

We also looked at five sources of government guidance that apply specifically to children with CHCN:

- National Service Framework Standard 8 on *Disabled children and young people and those with complex needs*¹⁶⁰
- *Complex disability – Exemplar*¹¹
- *For the NHS Commissioners commissioning children and young people's palliative care services*⁹
- *Including me*¹⁰

Finally we looked at three sources of recent guidance from non-government bodies:

- *A guide to the development of children's palliative care services*¹⁶¹

- *A Framework for the development of integrated multi-agency care pathways for children with life-threatening and life-limiting conditions*¹⁶²
- *Direct experience*¹⁶³

Much of this emphasised the need for improved coordination and multiagency working. As a body of guidance it is strong on child and family-centred care, on social inclusion in a general sense and on flexible, responsive services built around family needs. There is also much guidance on meeting children's health needs in a more integrated and coordinated way, often through keyworking. Thus, there was a high level of compatibility with the priorities identified through this knowledge review. However, the knowledge base relating to the social care needs of children with CHCN raises some challenges to current policy and guidance and suggests that certain issues remain overlooked.

In this concluding chapter, we summarise key findings from the knowledge review, drawing together the messages for practice improvement by elucidating the implications for policy, practice and research.

5.1 Impact of research and consultation-based evidence

5.1.1 What matters most?

The findings of the research review are consistent with those of the consultation in terms of what matters most to children and young people with CHCN and their families. In particular both verify that children with CHCN have the same 'ordinary' wishes and needs as other children, that is, to live at home with their families, go to school, spend time with their friends and participate in leisure and community activities with family and peers. Yet getting 'ordinary' things remains extraordinarily difficult. Barriers derive initially from the CHCN themselves but also from the service system and its responses (this issue is addressed further below [[**where?**]]).

Relationships with family and friends were extremely important to all children and young people consulted. These were closely linked to issues of individuality and identity, that is, 'being who you are'. Research findings indicated that relationships were strongly linked to emotional wellbeing. The priority given to these issues by children and young

people is not matched in current practice or guidance and this needs to be addressed.

The urgency of practicalities for children with CHCN and their families was also evident in research and the consultation. These included accessing facilities, getting the right equipment and securing the necessary finances. Many families report increased financial hardship with the majority of mothers giving up paid work while the need for home adaptations, house moves and equipment, among others, create additional costs.

The issue of both organisational competence and clinical competence is a further concern for children with CHCN and their families. Staff recruited to carry out aspects of care requiring specialist skills can lack the necessary training or qualification needed to provide that specialised intervention. Organisations providing care in this environment may not recognise the need, or lack the resources, to train staff in order to offer the level and range of skill needed.

5.1.2 Reconceptualising 'social care' needs and allocation of agency responsibility

The research review and consultation clearly demonstrate that categorising the needs of children with CHCN and their families according to service provision is deeply problematic. 'Social care' needs are very difficult to disentangle for this group of children and young people. Their healthcare needs are so much a part of their everyday lives that dividing their needs into different categories is untenable. Moreover, the wider needs of children and families are likely to be inextricably linked, including emotional, educational, financial as well as health and social care needs. Concomitantly, professional roles and boundaries are often and necessarily blurred, that is, 'social care' needs are not necessarily met by social care agencies and 'healthcare' needs are not necessarily met by health services.

This issue speaks to the very foundations of service provision and practice. Much research, policy, guidance and practice is based on the assumption of separable needs. The model of 'divided thinking' is so entrenched that it is difficult to step back and see the needs and experiences of children with CHCN and their families differently.

The knowledge review has not settled these definitional problems and perhaps it should not be expected to have done so. The knowledge base suggests instead that the 'needs' of children and young people with CHCN and their families are simply not amenable to rigid classification. The review does, however, suggest the potential of understanding 'social care' from an ordinary life or ordinary needs perspective. The use of 'ordinary life' or 'ordinary needs' criteria, to determine needs and attendant services, therefore, requires further exploration.

5.1.3 Putting an end to the struggle

If key definitions are not amenable to rigid classification and professional roles and boundaries are necessarily blurred, negotiation both between families and agencies and between agencies themselves is inevitable. Yet protracted boundary and funding disputes between agencies and delays in the provision of vital services, hospital discharge and school inclusion remain common. Despite evidence of good practice in the consultation, families still often experience services as sources of frustration and despair, rather than support and solace; notions of 'fighting' and 'struggling' are ubiquitous. Families talk about 'taking on the system' and there is an urgent need to replace the adversarial approach that this implies. Disagreement and negotiation need to be built into service planning and provision in such a way as to be attentive to quality of process as well as outcomes.

There are some indications that families are experiencing benefits from coordinated planning and the keyworker approach, in that it reduces the pressure of coordination on families. However, efforts are required to ensure that keyworking does not simply relocate the problem and further marginalise families' participation by relocating the problem one step away from them.

Further consideration needs to be given to the particular competencies that keyworking for children with CHCN and their families might require, due to the complexity of both families' needs and the service system itself. Effective key working for these young people requires engagement with families' emotional needs as well as their practical day-to-day needs. It requires respect for people as full citizens with rights but also as people living extraordinary lives who can be distressed, exhausted, angry, frightened and lonely. This presupposes personal engagement with, and

commitment to, children and families. The best ways to support this in practice require further attention.

Lastly, caution is needed to ensure that the benefits of keyworking do not distract attention from systemic difficulties that keyworking is not able to address. These include the complexity of funding sources and statutory responsibilities, eligibility criteria for services and geographical differences in service provision.

5.1.4 A family-centred approach: flexibility and responsiveness

A ‘family-centred’ approach received strong empirical support from research and consultation. While in principle this approach considers the needs of all family members, including siblings, both as individuals and as a unit, the consultation evidence seems to emphasise the needs of the family unit over and above the needs of individual family members as individuals, while this emphasis is reversed in the research review findings.

This speaks to the inevitable tension between child-centred and family-centred practice, including the potentially conflicting needs of siblings, which remains under-researched. Further documentation and exploration of this issue is needed in order to provide practitioners with examples of good strategic work in action.

In the research and the consultation, flexibility and responsiveness were heavily emphasised in families’ accounts of service provision that would enable them to get on with ordinary life individually and together. This related to a range of issues, including control and direct access to services, where and when health needs should be met, the accommodation of family events, preferences and emergencies and the roles/responsibilities of any one professional. The question of how such flexibility and responsiveness can be built into care plans and provision from the beginning is vital.

The current allocation of services only to specific individuals rather than families creates difficulties, for example, siblings being excluded from childcare arrangements or play or leisure opportunities. This urgently needs to be redressed.

Current service configuration rarely allows for the blurring of professional roles and boundaries that children with CHCN and their families

prefer and a way out of this impasse is required. The question of how such role expansion can be accommodated and supported needs attention.

Inadequate or irrelevant policies, staff training, supervision and support to facilitate the requisite flexibility are also evidenced, creating a lack of clarity about workers' responsibility and confusion about accountability. These issues need to be clearly identified and addressed organisationally as well as individually in each child's plan.

Meeting parental support needs can enable them to cope longer term and consequently promotes child-focused outcomes. Research indicates a variety of opinion on the part of parents as to the pros and cons of different kinds of assistance with and breaks from caring, including home-based services (such as additional nursing, ancillary care and sitting services), those within alternative family settings and institutionally based breaks. In the face of such a diversity of opinions in the evidence, a flexible approach that respects individual parents and children's wishes is required. Much more needs to be known about children's views and preferences about short breaks, and methods for genuinely involving children in decisions about services need to be developed, particularly young children and children with impairments of communication or understanding.

5.1.5 Manner, style and duration of service delivery

For children and families alike there is strong evidence that the way in which professionals provide services is as important as the service itself: the manner, approach, emotional availability and sensitivity, levels of respect and understanding. There was strong research evidence that parents feel emotionally supported by helpful and compassionate relationships. Children and their families greatly valued familiarity with professionals and home care providers. The interpersonal skills implicated in manner and style of delivery need to be formally recognised, supervised and appraised.

Temporal aspects of social care delivery also came across strongly. Findings indicate that families need services that can respond rapidly when they are in crisis but they also need services on which they can rely over longer periods of time. Families valued services that were "robust" and "in it for the long term" and wanted services that could continue even when their child's needs changed, rather than having to keep changing

the team or the service. Combining continuity, familiarity and flexibility is very important to families. This combination is currently hampered by a lack of resources, fragile, temporary funding arrangements, restrictive eligibility criteria and short-term allocation of services and creative solutions are imperative.

5.1.6 Preparing parents to provide specialist care

Parents, willingly or under pressure, become the primary carers for most children with CHCN that requires them to have a level of skills and some very specialised techniques, normally in the province of medical staff. Research indicates that insufficient, inadequate and sometimes contradictory training, information and practical advice is given to parents about daily, specialist care giving tasks and how to respond to emergencies. This training needs to attend to the socio-emotional effects as well as medical procedures involved. Introductory materials available as leaflets, booklets or through the internet need to be substantiated by case-specific verbal explanations and advice, through helplines and keyworkers. Mutual advice/information sharing and local parent support groups are found useful.

5.2 Impact of practice-based findings

5.2.1 Common features of good practice

The practice survey confirmed that examples do exist of services that demonstrate flexibility and responsiveness to the individual needs of children with CHCN and their families, use ordinary life criteria to define needs, work in partnership with families as well as working with wider networks of family, friends, other services and settings. Such examples need to be recognised, disseminated and praised.

Common features of these services included:

- families were perceived as competent experts;
- the child and family were acknowledged as partners in defining need;
- a high value was placed on individual relationships;

- different aspects of a child and family's identity were actively recognised and accommodated;
- autonomy was delegated to frontline staff;
- high levels of flexibility and responsiveness were provided;
- tasks such as 'navigating', 'signposting', 'wayfinding', 'advocating' or 'keyworking' were included within the function of the service;
- volunteers were creatively used within programmes.

It would be useful to share aspects of good practice more widely.

5.2.2 The invisibility of social care work

The most important finding from the practice survey, from the point of view of planners, commissioners and managers, is bound to be the invisibility of the 'social care' services provided across a whole range of professions. Of the eight services identified in the practice survey, only two specifically mentioned social care in the description of their services and then, not as a sole focus. However, when asked, people providing and managing the services all agreed that meeting social care needs was an essential, albeit formally unacknowledged, part of their role.

This disjuncture between the formal and actual nature of services provided is demonstrated by accounts of workers 'breaking the rules' or exceeding the specified remit of their role in order to meet families' needs. We were told about individual staff who, for example, worked additional hours; switched hours around; undertook tasks that were not in their job description; or worked in places where they were not meant to be working.

At the extreme, we learnt about a worker who moved between three different organisations in order to 'follow' a child whose needs were changing.

This suggests the need for managers to find out whether such a disjuncture exists within their own agencies in order to ensure that formal roles and remits are adequate to the tasks at hand, that is, to check that the job specifications that their staff work to designed to be broad enough to meet the needs of children with CHCN and their families and leave scope for staff to respond flexibly.

5.2.3 Power and responsibility in commissioning arrangements

Linked to the finding about the invisibility of social care service provision, many of the services in the practice survey felt that their hands were effectively tied due to current commissioning practices. Many services were navigating complex commissioning arrangements on behalf of individual families, and struggled with contracts focusing on specific needs (usually clinical) when they saw that what families needed was much wider than this. Other services had moved towards rewriting the rules of their own service but were finding these actions blocked by commissioning agencies. There is an urgent need to find ways out of these kinds of impasse.

In broad terms, the findings raise important questions related to commissioning practices. Planners and commissioners urgently need to consider the following:

- How can services be commissioned so as to enable flexibility and responsiveness to be built in at the service design stage?
- Where does responsibility for developing services lie in commissioning arrangements?
- Are there feedback loops in place to allow commissioners to learn from service providers in order to improve practice?

5.2.4 Temporal aspects of service delivery and financial challenges

As with most services, the practice survey also found that these services for children with CHCN and their families were not particularly well resourced. While attempting to provide services upon which families could rely over longer periods of time, these services often had to be cancelled to allow crisis intervention for others. Short-term funding arrangements were found to compound the difficulties they faced in trying to provide the continuity of services and familiarity of staff that matters so much to families. This suggests that planners and commissioners need to explore creative solutions that would allow the adaptation of temporal aspects of service provision for children with CHCN and their families.

5.3 Implications for further research

One of the key findings of this review is the gap in our knowledge base about social care service provision for children with CHCN and their families. While the medical field is continually reflecting current practice and includes progressive work being carried out with children with CHCN and their families, there is much less published research from a social care service design and delivery perspective or about the social care aspects of other professionals' work.

SCIE's practice surveys are designed to redress this. Yet, in this knowledge review, rather than providing models of good practice, the survey surfaced major barriers (as detailed earlier). The methodology adopted by the review team to identify services also restricted the services potentially included. Therefore, the question of whether there are any services that are explicitly set up to enable professionals and paid carers to operate in the flexible and family-centred manner that families want, remains unanswered. Research into such services should be a matter of urgency.

Equally, further research is needed into the process and impact of change and modernisation as it affects services for children with CHCN and their families, particularly joint funding procedures and keyworkers and/or lead professionals.

The impact of short-term funding on service provision for children with CHCN and their families could also usefully be investigated.

As the research review demonstrated, further research is also needed about the views of children with CHCN themselves, particularly younger children and those with the most complex needs. If this holds generally, the research review also identified the specific need for further empirical research regarding:

- children's views of their emotional needs and services to meet those needs
- children's views on short breaks outside the family home.

Research is clearly also required into the needs of minority ethnic families with a child with CHCN and models of service that appropriately and effectively meet the cultural and language needs.

A separate research review of the needs of siblings in their own right is recommended.

5.4 Research and practice: how do they match up?

Due to the difficulties faced in identifying service-level examples of good practice, the question of how research and practice match up cannot be answered with any certainty. As stated above, further research is urgently needed on the social care aspects of service design and delivery for children with CHCN and their families, particularly progressive work being carried out. Without this we cannot ascertain whether or not practice is outstripping research in finding ways to overcome the various challenges to service provision for children with CHCN that have been identified in the knowledge review.

What the knowledge base does seem to indicate is less a mismatch between research and practice than one between policy and guidance on the one hand and practice on the other. Policy and guidance across England, Wales and Northern Ireland, for example, all seem to be strong on child and family-centred care, on social inclusion in a general sense and on flexible, responsive services built around family needs. There is also much emphasis on meeting children and families' needs in a more coordinated fashion, often through keyworking. Crucial practice issues related to implementing and embedding such policy and guidance, therefore, remain.

Conversely, as stated earlier, there seems to be relatively little in the available guidance about some of the other priorities identified in the consultation, in particular about the importance of friends for children, about the nature of relationships between professionals and families, about when and where health needs should be met and about enabling children to have a positive sense of themselves.

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Appendix A

Search terms for each database

The selection of databases to be searched was informed by the Social Care Institute for Excellence (SCIE) guidelines on systematic reviews and by the experience of carrying out searches for previous knowledge reviews. In addition to the databases listed by SCIE, Social Care Online was searched. However, it was decided not to search Dissertation Abstracts because of the difficulty of obtaining copies of the citations identified within a realistic time span.

ASSIA

Searched 30/09/05

- 1 child*
- 2 infan*
- 3 adolescen*
- 4 (young adj adult*)
- 5 (young adj person*)
- 6 (young adj people)
- 7 (early adj years)
- 8 baby
- 9 babies
- 10 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9
- 11 (social adj work*)
- 12 (social adj care)
- 13 normalisation
- 14 (community adj care)
- 15 (community adj living)
- 16 inclusion
- 17 participat*
- 18 (day adj care)
- 19 (key adj worker*)
- 20 keyworker*
- 21 (day adj centre*)
- 22 (day adj center*)

- 23 respite
- 24 (short adj break*)
- 25 (domiciliary adj care)
- 26 (social adj services)
- 27 (family adj support)
- 28 (formal adj care)
- 29 transition*
- 30 (care adj manager*)
- 31 (care adj assistant*)
- 32 (personal adj assistant*)
- 33 advoca*
- 34 (palliative adj care)
- 35 (home adj care)
- 36 (interdisciplinary adj care)
- 37 (multidisciplinary adj care)
- 38 (daily adj li*)
- 39 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22
or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33
or 34 or 35 or 36 or 37 or 38
- 40 (complex within 3 needs)
- 41 (complex within 3 impairment*)
- 42 (complex within 3 disabilit*)
- 43 (multiple within 3 needs)
- 44 (multipl* within 3 impair*)
- 45 (multipl* within 3 disab*)
- 46 (additional within 3 needs)
- 47 (additional within 3 impair*)
- 48 (additional* within 3 disab*)
- 49 (profound within 3 needs)
- 50 (profound* within 3 impair*)
- 51 (profound* within 3 disab*)
- 52 assistive
- 53 (significant within 3 needs)
- 54 (significant* within 3 impair*)
- 55 (significant* within 3 disab*)
- 56 (technology within 4 dependent)
- 57 (chronic within 3 needs)
- 58 (chronic within 3 impairment*)

- 59 (chronic within 3 disabilit*)
 60 (challenging within 3 needs)
 61 (challenging within 3 impairment*)
 62 (challenging within 3 disabilit*)
 63 (severe within 3 needs)
 64 (severe* within 3 impair*)
 65 (severe within 3 disab*)
 66 (substantial within 3 needs)
 67 (substantial within 3 impairment*)
 68 (substantial within 3 disabilit*)
 69 DE=('disabled children' and 'severely')
 70 DE=('multiply disabled preschool children')
 71 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or
 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or
 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70
 72 10 and 39 and 71

British Education Index

Searched 19/08/05

((kw: child* OR kw: infan* OR kw: adolescent* OR kw: young w adult* OR kw: young w person* OR kw: young w people OR kw: baby OR kw: babies)) and ((kw: complex w3 needs OR kw: complex w3 impairment* OR kw: complex disability* OR kw: multiple w3 needs OR kw: multipl* w3 impair* OR kw: multipl* w3 disab* OR kw: profound w3 needs OR kw: profound* w3 impair* OR kw: profound* w3 disab* OR kw: assistive OR kw: significant w3 needs OR kw: significant* w3 impair* OR kw: significant* w3 disab* OR kw: chronic w3 needs OR kw: chronic w3 impairment* OR kw: chronic w3 disabilit* OR kw: technology w4 dependent OR kw: challenging w3 needs OR kw: challenging w3 impairment* OR kw: challenging w3 disabilit* OR kw: severe w3 needs OR kw: severe* w3 impair* OR kw: severe* w3 disab* OR kw: substantial w3 needs OR kw: substantial w3 impairment* OR kw: substantial w3 disabilit* OR de: severe disabilities OR de: severely handicapped children)) and ((kw: social w work* OR kw: social w care OR kw: normalisation OR kw: normalization OR kw: community w care OR kw: community w living OR kw: inclusion OR kw: participat*

OR kw: social w services OR kw: social w support OR kw: formal w care OR kw: daily w li*) and yr: 1985-2005

Care Data

Searched 27/09/05

TI, AB:

((child* / infan* / adolescen* / (young w1 adult*) / (young w1 person*) / (young w1 people) / baby / babies / (kw= Adolescence) / (kw= Children)

and

((social w1 work) / (social w1 care) / (community w1 care) / (community w1 living) / (social w1 services) / (social w1 support) / (interdisciplinary w1 care) / (multidisciplinary w1 care) / (palliative care) / (child w1 protection) / normalization / normalisation / (domiciliary w1 care) / respite / (short w1 break*) / (day w1 care) / keyworker* / (key w1 worker*) / (day w1 centre) / (day w1 center) / (family w1 support) / transition* / (care w1 manager*) / (care w1 assistant*) / (personal w1 assistant*) / advoca* / inclusion / participat* / nursery / leisure / (outreach w1 care) / (home w1 nursing) / (home w1 care) / (formal w1 care) / (daily w1 lif*) / (daily w1 liv*) / (kw= Multidisciplinary Services) / (kw= Care Workers) / (kw= Community Care) / (kw= Day Centres) / (kw= Normalisation) / (kw= Palliative Care) / (kw= Respite Care) / (kw= Social Care) / (kw= Social Work))

and

((complex w3 needs) / (complex w3 impairment*) / (complex w3 disabilit*) / (multiple w3 needs) / (multipl* w3 disab*) / (multipl* w3 impair*) / (profound w3 needs) / (profound* w3 impair*) / (profound* w3 disab*) / (additional w3 needs) / (additional w3 impairment*) / (additional w3 disabilit*) / assistive / (significant w3 needs) / (significant* w3 impair*) / (significant* w3 disab*) / (chronic w3 needs) / (chronic* w3 impair*) / (chronic* w3 disab*) / (technology w4 dependent) / (severe w3 needs) / (severe* w3 impair*) / (severe* w3 disab*) / (intensive w3 needs) /

(substantial w3 needs) / (substantial w3 impairment*) / (substantial w3 disabilit*) / (life-threatening w1 condition) / (ventilator w1 dependent) / (assisted w1 ventilation) / (epilepsy) / (severe w1 asthma) / (uncontrolled w1 diabetes) / (anaphylaxis) / (muscular w1 dystrophy) / (cerebral w1 palsy) / (cystic w1 fibrosis) / (high w1 support w1 needs) / (kw=Chronically Sick Children))

Child Data

Searched 26/09/05

Keyword search and free-text search carried out separately:

Keyword search

(="muscular dystrophy" / ="terminally ill children" / ="anaphylaxis" / ="asthma" / ="diabetes" / ="muscular dystrophy" / ="cystic fibrosis" / ="epilepsy" & ("care management" / ="child protection" / ="community care" / ="social work" / ="inclusion" / ="participation"))

Free-text search

((social work)/(social care)/normalization/normalisation/(community care)/(community living)/(multidisciplinary care)/(interdisciplinary care)/(daily living)) & (complex w3 needs)/(multipl* w2 disab*)/(technology w4 depend*)

CINAHL

Searched 22/04/05

limit set YEAR > 1985

- 1 child\$
- 2 infan\$
- 3 adolescen\$
- 4 young ADJ adult\$
- 5 young ADJ person
- 6 young ADJ people
- 7 early ADJ years
- 8 baby\$

- 9 babie\$
- 10 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9
- 11 social ADJ work\$
- 12 social ADJ care
- 13 normalisation
- 14 normalization
- 15 community ADJ care
- 16 community ADJ living
- 17 domiciliary ADJ care
- 18 respite
- 19 short ADJ break\$
- 20 day ADJ care
- 21 keyworker\$
- 22 key ADJ worker\$
- 23 day ADJ centre\$
- 24 day ADJ center\$
- 25 family ADJ support
- 26 child ADJ protection
- 27 transition\$
- 28 care ADJ manager\$
- 29 care ADJ assistant\$
- 30 personal ADJ assistant\$
- 31 advoca\$
- 32 palliative ADJ care
- 33 home ADJ nursing
- 34 home ADJ care
- 35 interdisciplinary ADJ care
- 36 multidisciplinary ADJ care
- 37 formal ADJ care
- 38 daily ADJ liv\$
- 39 daily ADJ lif\$
- 40 (social-care.DE.)
- 41 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR
20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR
29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR
38 OR 39 OR 40
- 42 complex NEAR3 needs
- 43 complex NEAR3 impairment\$

- 44 complex NEAR3 disabilit\$
- 45 multiple NEAR3 needs
- 46 multipl\$ NEAR3 impair\$
- 47 multipl\$ NEAR3 disab\$
- 48 profound NEAR3 needs
- 49 profound\$ NEAR3 impair\$
- 50 profound\$ NEAR3 disab\$
- 51 additional NEAR3 needs
- 52 additional NEAR3 impairment\$
- 53 additional NEAR3 disabilit\$
- 54 assistive
- 55 significant NEAR3 needs
- 56 significant\$ NEAR3 impair\$
- 57 significant\$ NEAR3 disab\$
- 58 chronic NEAR3 needs
- 59 chronic\$ NEAR3 impair\$
- 60 chronic\$ NEAR3 disab\$
- 61 technology NEAR4 dependent
- 62 severe NEAR3 needs
- 63 severe\$ NEAR3 impair\$
- 64 severe\$ NEAR3 disab\$
- 65 intensive NEAR3 needs
- 66 high ADJ support ADJ needs
- 67 ventilator ADJ dependent
- 68 assisted ADJ ventilation
- 69 substantial NEAR3 needs
- 70 substantial NEAR3 impairment\$
- 71 substantial NEAR3 disabilit\$
- 72 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50
OR 51 OR 52 OR 53 OR 54 OR 55 OR 56 OR 57 OR 58 OR 59
OR 60 OR 61 OR 62 OR 63 OR 64 OR 65 OR 66 OR 67 OR
68 OR 69 OR 70 OR 71
- 73 10 AND 41 AND 72

ERIC/Australian Education Index

Searched 19/08/05

((kw: child* OR kw: infan* OR kw: adolescent* OR kw: young w adult* OR kw: young w person* OR kw: young w people OR kw: baby OR kw: babies)) and ((kw: complex w3 needs OR kw: complex w3 impairment* OR kw: complex disability* OR kw: multiple w3 needs OR kw: multipl* w3 impair* OR kw: multipl* w3 disab* OR kw: profound w3 needs OR kw: profound* w3 impair* OR kw: profound* w3 disab* OR kw: assistive OR kw: significant w3 needs OR kw: significant* w3 impair* OR kw: significant* w3 disab* OR kw: chronic w3 needs OR kw: chronic w3 impairment* OR kw: chronic w3 disabilit* OR kw: technology w4 dependent OR kw: challenging w3 needs OR kw: challenging w3 impairment* OR kw: challenging w3 disabilit* OR kw: severe w3 needs OR kw: severe* w3 impair* OR kw: severe* w3 disab* OR kw: substantial w3 needs OR kw: substantial w3 impairment* OR kw: substantial w3 disabilit*)) and ((kw: social w work* OR kw: social w care OR kw: normalisation OR kw: normalization OR kw: community w care OR kw: community w living OR kw: inclusion OR kw: participat* OR kw: social w services OR kw: social w support OR kw: formal w care OR kw: daily w li*)) and yr: 1985-2005

HMIC (Health Management Information Consortium)

Searched 27/09/05

- 1 child*
- 2 infan*
- 3 adolescen*
- 4 young ADJ adult*
- 5 young ADJ person
- 6 young ADJ people
- 7 early ADJ years
- 8 baby
- 9 babies
- 10 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9
- 11 social ADJ work
- 12 social ADJ care

- 13 normalisation
- 14 community ADJ care
- 15 community ADJ living
- 16 domiciliary ADJ care
- 17 respite
- 18 short ADJ break*
- 19 day ADJ care
- 20 keyworker*
- 21 key ADJ worker*
- 22 day ADJ centre
- 23 day ADJ center
- 24 family ADJ support
- 25 child ADJ protection
- 26 transition*
- 27 care ADJ manager*
- 28 care ADJ assistant*
- 29 personal ADJ assistant*
- 30 advoca*
- 31 palliative ADJ care
- 32 inclusion
- 33 participat*
- 34 social ADJ services
- 35 social ADJ support
- 36 nursery
- 37 leisure
- 38 outreach ADJ care
- 39 home ADJ nursing
- 40 home ADJ care
- 41 interdisciplinary ADJ care
- 42 multidisciplinary ADJ care
- 43 formal ADJ care
- 44 daily ADJ liv*
- 45 daily ADJ lif*
- 46 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR
20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR
29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR
38 OR 39 OR 40 OR 41 OR 42 OR 43 OR 44 OR 45
- 47 complex NEAR3 needs

- 48 complex NEAR3 impairment*
- 49 complex NEAR3 disabilit*
- 50 multiple NEAR3 needs
- 51 multipl* NEAR3 impair*
- 52 multipl* NEAR3 disab*
- 53 profound NEAR3 needs
- 54 profound* NEAR3 impair*
- 55 profound* NEAR3 disab*
- 56 additional NEAR3 needs
- 57 additional NEAR3 impairment*
- 58 additional NEAR3 disabilit*
- 59 assistive
- 60 significant NEAR3 needs
- 61 significant* NEAR3 impair*
- 62 significant* NEAR3 disab*
- 63 chronic NEAR3 needs
- 64 chronic* NEAR3 impair*
- 65 chronic* NEAR3 disab*
- 66 technology NEAR4 dependent
- 67 severe NEAR3 needs
- 68 severe* NEAR3 impair*
- 69 severe* NEAR3 disab*
- 70 intensive NEAR3 needs
- 71 high ADJ support ADJ needs
- 72 life-threatening ADJ condition
- 73 ventilator ADJ dependent
- 74 assisted ADJ ventilation
- 75 substantial NEAR3 needs
- 76 substantial NEAR3 impairment*
- 77 substantial NEAR3 disabilit*
- 78 47 OR 48 OR 49 OR 50 OR 51 OR 52 OR 53 OR 54 OR 55 OR
56 OR 57 OR 58 OR 59 OR 60 OR 61 OR 62 OR 63 OR 64 OR
65 OR 66 OR 67 OR 68 OR 69 OR 70 OR 71 OR 72 OR 73 OR
74 OR 75 OR 76 OR 77
- 79 10 AND 46 AND 78

IBSS

Searched 19/08/05

(child* OR infan* OR adolescen* OR baby OR babie* OR (young person) OR (young people) OR (young adult*)) AND ((social work*) OR (social care) OR normali?ation OR (community care) OR (community living) OR inclusi* OR participat* OR (social services) OR (formal care) OR (daily li*) OR (social support)) AND ((complex needs) OR (complex disabilit*) OR (complex impairment*) OR (multiple needs) OR (multipl* disab*) OR (multipl* impair*) OR (substantial needs) OR (substantial* impair*) OR (substantial* disab*) OR (profound needs) OR (profound* disab*) OR (profound* impair) OR assistive OR (significant needs) OR (significant* impair*) OR (significant* disab*) OR (technology dependent) OR (technology dependent) OR (challenging needs) OR (challenging impairment*) OR (challenging disab*) OR (severe needs) OR (severe* disab*) OR (severe* impair*))

Medline

Searched 19/08/05

- #1 child*
- #2 infan*
- #3 adolescen*
- #4 (young w adult*)
- #5 (young w person*)
- #6 (young w people)
- #7 baby
- #8 babies
- #9 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8
- #10 (complex w3 needs)
- #11 (complex w3 impairment*)
- #12 (complex w3 disabilit*)
- #13 (multiple w3 needs)
- #14 (multiple w3 impairment*)
- #15 (multipl* w3 disab*)
- #16 (profound w3 needs)
- #17 (profound w3 impairment*)

- #18 (profound w3 disab*)
- #19 (technology w4 dependent)
- #20 (additional w3 needs)
- #21 (additional w3 impairment*)
- #22 (additional w3 disabilit*)
- #23 assistive
- #24 (significant w3 needs)
- #25 (significant w3 impairment*)
- #26 (significant w3 disab*)
- #27 (chronic w3 needs)
- #28 (chronic w3 impairment*)
- #29 (chronic w3 disabilit*)
- #30 (challenging w3 needs)
- #31 (challenging w3 impairment*)
- #32 (challenging w3 disabilit*)
- #33 (severe w3 needs)
- #34 (severe w3 impairment*)
- #35 (severe w3 disab*)
- #36 (substantial w3 needs)
- #37 (substantial w3 impairment*)
- #38 (substantial w3 disabilit*)
- #39 #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19
or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28
or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or
#38
- #40 (social w work*)
- #41 (social w care*)
- #42 normalisation
- #43 (community w care)
- #44 (community w living)
- #45 inclusion
- #46 participat*
- #47 (social w services)
- #48 (social w support)
- #49 (formal w care)
- #50 (domiciliary w care)
- #51 respite
- #52 (day w care)

- #53 keyworker
- #54 (day w centre)
- #55 (day w center)
- #56 (family w support)
- #57 (child w protection)
- #58 transition*
- #59 (care w manager*)
- #60 (care w assistant*)
- #61 (personal w assistant*)
- #62 advoca*
- #63 (palliative w care)
- #64 (daily w liv*)
- #65 (daily w lif*)
- #66 #40 or #41 or #42 or #43 or #44 or #45 or #46 or #47 or #48 or
#49 or #50 or #51 or #52 or #53 or #54 or #55 or #56 or #57 or
#58 or #59 or #60 or #61 or #62 or #63 or #64 or #65
- #67 #9 and #39 and #66

Psycinfo

Searched 20/09/05

- #1 (social adj work*)
- #2 (social adj care)
- #3 normali?ation
- #4 (community adj care)
- #5 (community adj living)
- #6 (domiciliary adj care)
- #7 respite
- #8 (day adj care)
- #9 (keyworker*)
- #10 (key adj worker*)
- #11 (day adj centre*)
- #12 (day adj center*)
- #13 (family adj support)
- #14 (child adj protection)
- #15 transition*
- #16 (care adj manager*)
- #17 (care adj assistant*)

- #18 (personal adj assistant*)
- #19 advoca*
- #20 (palliative care)
- #21 inclusion
- #22 participat*
- #23 (social adj services)
- #24 (social adj support)
- #25 nursery
- #26 leisure
- #27 (outreach adj care)
- #28 (home adj nursing)
- #29 (home adj care)
- #30 (interdisciplinary adj care)
- #31 (multidisciplinary adj care)
- #32 (formal adj care)
- #33 (daily adj lif*)
- #34 (empowerment in KC)
- #35 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11
or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or
#21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or
#30 or #31 or #32 or #33 or #34
- #36 child*
- #37 infan*
- #38 adolescen*
- #39 (young adj adult*)
- #40 (young adj person*)
- #41 (young adj people)
- #42 (early adj years)
- #43 baby
- #44 babies
- #45 #36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44
- #46 (multiple disabilities in KC)
- #47 (complex near3 needs)
- #48 (complex near3 impairment*)
- #49 (complex near3 disabilit*)
- #50 (multiple near3 needs)
- #51 (multipl* near3 impair*)
- #52 (multipl* near3 disab*)

- #53 (profound near3 needs)
- #54 (profound* near3 impair*)
- #55 (profound* near3 disab*)
- #56 (additional near3 needs)
- #57 (additional near3 impairment*)
- #58 (additional near3 disabilit*)
- #59 assistive
- #60 (significant near3 needs)
- #61 (significant* near3 impair*)
- #62 (significant* near3 disab*)
- #63 (chronic near3 needs)
- #64 (chronic near3 impairment*)
- #65 (chronic near3 disabilit*)
- #66 (technology near4 dependent)
- #67 (challenging near3 needs)
- #68 (challenging near3 impairment*)
- #69 (challenging near3 disabilit*)
- #70 (severe near3 needs)
- #71 (severe* near3 impair*)
- #72 (severe near3 disab*)
- #73 (intensive near3 needs)
- #74 (high adj support adj needs)
- #75 (lifethreatening adj condition*)
- #76 (ventilator adj dependent)
- #77 (assisted adj ventilation)
- #78 (substantial near3 needs)
- #79 (substantial near3 impairment*)
- #80 (substantial near3 disabilit*)
- #81 #46 or #47 or #48 or #49 or #50 or #51 or #52 or #53 or #54 or
#55 or #56 or #57 or #58 or #59 or #60 or #61 or #62 or #63 or
#64 or #65 or #66 or #67 or #68 or #69 or #70 or #71 or #72 or
#73 or #74 or #75 or #76 or #77 or #78 or #79 or #80
- #82 #35 and #45 and #81

SIGLE

Searched 27/09/05

- #1 social adj work
- #2 social adj care
- #3 normalisation
- #4 normalization
- #5 community adj care
- #6 community adj living
- #7 domiciliary adj care
- #8 respite
- #9 short adj break*
- #10 day adj care
- #11 keyworker*
- #12 key adj worker*
- #13 day adj centre
- #14 day adj center
- #15 family adj support
- #16 child adj protection
- #17 transition*
- #18 care adj manager*
- #19 care adj assistant*
- #20 personal adj assistant*
- #21 advoca*
- #22 palliative adj care
- #23 home adj nursing
- #24 home adj care
- #25 interdisciplinary adj care
- #26 multidisciplinary adj care
- #27 formal adj care
- #28 daily adj liv*
- #29 daily adj lif*
- #30 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11
or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or
#21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29
- #31 child*
- #32 infan*
- #33 adolescen*

- #34 young adj adult*
- #35 young adj person
- #36 young adj people
- #37 early adj years
- #38 baby
- #39 babies
- #40 #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39
- #41 complex near3 needs
- #42 complex near3 impairment*
- #43 complex near3 disabilit*
- #44 multiple near3 needs
- #45 multipl* near3 impair*
- #46 multipl* near3 disab*
- #47 profound near3 needs
- #48 profound* near3 impair*
- #49 profound* near3 disab*
- #50 additional near3 needs
- #51 additional near3 impairment*
- #52 additional near3 disabilit*
- #53 assistive
- #54 significant near3 needs
- #55 significant* near3 impair*
- #56 significant* near3 disab*
- #57 chronic near3 needs
- #58 chronic* near3 impair*
- #59 chronic* near3 disab*
- #60 technology near4 dependent
- #61 severe near3 needs
- #62 severe* near3 impair*
- #63 severe* near3 disab*
- #64 intensive near3 needs
- #65 high adj support adj needs
- #66 life-threatening adj condition*
- #67 ventilator adj dependent
- #68 assisted adj ventilation
- #69 epilepsy
- #70 severe adj asthma
- #71 uncontrolled adj diabetes

- #72 anaphylaxis
- #73 muscular adj dystrophy
- #74 cerebral adj palsy
- #75 cystic adj fibrosis
- #76 substantial near3 needs
- #77 substantial near3 impairment*
- #78 substantial near3 disabilit*
- #79 #41 or #42 or #43 or #44 or #45 or #46 or #47 or #48 or #49 or
#50 or #51 or #52 or #53 or #54 or #55 or #56 or #57 or #58 or
#59 or #60 or #61 or #62 or #63 or #64 or #65 or #66 or #67 or
#68 or #69 or #70 or #71 or #72 or #73 or #74 or #75 or #76 or
#77 or #78
- #80 #30 and #40 and #79

Social Care Online

Searched 27/09/05

Child* and (complex health care needs) and social

Social Services Abstracts

Searched 26/09/05

- 1 social work
- 2 social care
- 3 community care
- 4 community living
- 5 social services
- 6 social support
- 7 interdisciplinary care
- 8 multidisciplinary care
- 9 palliative care
- 10 child protection
- 11 normalisation
- 12 domiciliary within 1 care
- 13 respite
- 14 short within 1 break*
- 15 day within 1 care
- 16 keyworker*

- 17 key within 1 worker*
- 18 day within 1 centre
- 19 day within 1 center
- 20 family within 1 support
- 21 transition*
- 22 care within 1 manager*
- 23 care within 1 assistant*
- 24 personal within 1 assistant*
- 25 advoca*
- 26 inclusion
- 27 participat*
- 28 nursery
- 29 leisure
- 30 outreach within 1 care
- 31 home within 1 nursing
- 32 home within 1 care
- 33 formal within 1 care
- 34 daily within 1 liv*
- 35 daily within 1 lif*
- 36 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or
14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or
25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35
- 37 child*
- 38 infan*
- 39 adolescen*
- 40 young within 1 adult*
- 41 young within 1 person
- 42 young within 1 people
- 43 baby
- 44 babies
- 45 early years
- 46 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45
- 47 complex within 3 needs
- 48 complex within 3 impairment*
- 49 complex within 3 disabilit*
- 50 multiple within 3 needs
- 51 multipl* within 3 impair*
- 52 multipl* within 3 disab*

- 53 profound within 3 needs
- 54 profound* within 3 impair*
- 55 profound* within 3 disab*
- 56 additional within 3 needs
- 57 additional within 3 impairment*
- 58 additional within 3 disabilit*
- 59 assistive
- 60 significant within 3 needs **[[okay?]]**
- 61 significant* within 3 impair*
- 62 significant* within 3 disab*
- 63 chronic within 3 needs
- 64 chronic* within 3 impair*
- 65 chronic* within 3 disab*
- 66 technology within 4 dependent
- 67 severe within 3 needs
- 68 severe* within 3 impair*
- 69 severe* within 3 disab*
- 70 intensive within 3 needs
- 71 substantial within 3 needs
- 72 substantial within 3 impairment*
- 73 substantial within 3 disabilit*
- 74 life-threatening condition
- 75 ventilator dependent
- 76 assisted ventilation
- 77 epilepsy
- 78 severe asthma
- 79 uncontrolled diabetes
- 80 anaphylaxis
- 81 muscular dystrophy
- 82 cerebral palsy
- 83 cystic fibrosis
- 84 high support needs
- 85 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or
58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or
69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or
80 or 81 or 82 or 83 or 84
- 86 36 and 46 and 85

Social Work Abstracts

Searched 26/09/05

- 1 social work
- 2 social care
- 3 community care
- 4 community living
- 5 social services
- 6 social support
- 7 interdisciplinary care
- 8 multidisciplinary care
- 9 palliative care
- 10 child protection
- 11 normalisation
- 12 domiciliary adj care
- 13 respite
- 14 short adj break*
- 15 day adj care
- 16 keyworker*
- 17 key adj worker*
- 18 day adj centre
- 19 day adj center
- 20 family adj support
- 21 transition*
- 22 care adj manager*
- 23 care adj assistant*
- 24 personal adj assistant*
- 25 advoca*
- 26 inclusion
- 27 participat*
- 28 nursery
- 29 leisure
- 30 outreach adj care
- 31 home adj nursing
- 32 home adj care
- 33 formal adj care
- 34 daily adj liv*
- 35 daily adj lif*

- 36 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35
- 37 child*
- 38 infan*
- 39 adolescen*
- 40 young adj adult*
- 41 young adj person
- 42 young adj people
- 43 baby
- 44 babies
- 45 early years
- 46 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45
- 47 complex near3 needs
- 48 complex near3 impairment*
- 49 complex near3 disabilit*
- 50 multiple near3 needs
- 51 multipl* near3 impair*
- 52 multipl* near3 disab*
- 53 profound near3 needs
- 54 profound* near3 impair*
- 55 profound* near3 disab*
- 56 additional near3 needs
- 57 additional near3 impairment*
- 58 additional near3 disabilit*
- 59 assistive
- 60 significant near3 needs
- 61 significant* near3 impair*
- 62 significant* near3 disab*
- 63 chronic near3 needs
- 64 chronic* near3 impair*
- 65 chronic* near3 disab*
- 66 technology near4 dependent
- 67 severe near3 needs
- 68 severe* near3 impair*
- 69 severe* near3 disab*
- 70 intensive near3 needs
- 71 substantial near3 needs

- 72 substantial near3 impairment*
- 73 substantial near3 disabilit*
- 74 life-threatening condition
- 75 ventilator dependent
- 76 assisted ventilation
- 77 epilepsy
- 78 severe asthma
- 79 uncontrolled diabetes
- 80 anaphylaxis
- 81 muscular dystrophy
- 82 cerebral palsy
- 83 cystic fibrosis
- 84 high support needs
- 85 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or
58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or
69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or
80 or 81 or 82 or 83 or 84
- 86 36 and 46 and 85

Appendix B

Numbers of citations on each database

Database name	Total citations retrieved by search strategy	Total citations included after initial screening
ASSIA	222	38
British Education Index	8	0
Care Data	469	35
Child Data	51	9
CINAHL	2,985	58
Australian Education Index	50	0
ERIC	704	19
HMIC	183	18
IBSS	8	2
Medline	1,175	35
Psycinfo	780	25
SIGLE	28	9
Social Care Online	6	6
Social Services Abstracts	232	27
Social Work Abstracts	22	14
Total	6,923	295

Appendix C

Format for collecting information through keywording process

Authors
Title
Year of publication
Linked to other reports (please select one)	Yes/No
Identification of report (select one)	Electronic database Contact Citation Hand search Other Unknown
Status (select one)	Published In press Unpublished Don't know
Location of study (select one)	UK North America Europe Australia/New Zealand Israel Africa Asia Latin America

Who has provided data?
(select one)

Child with CHCN
 Family of child
 Parents/PPR
 Siblings of child
 Other children
 Formal care worker/professional
 Other/More than one
 Who, if other or more than one?

Settings for social care needs/services
(select one)

Home
 Shared (home/education)
 Shared (home/health including
 palliative care)
 Shared (home/short break)
 Shared (home/social services day
 centre)
 Home/transition to adult services
 Other, please specify.....

How are social care needs defined in study?

Child's social care needs, indicate all that apply:

Physical wellbeing	Yes/No
Emotional wellbeing	Yes/No
Educational/work participation	Yes/No
Social participation	Yes/No
Other	Yes/No
Other, please specify	

Family/PPR's social care needs, indicate all that apply:

- | | |
|--|--------|
| Advice/information | Yes/No |
| Short breaks | Yes/No |
| Emotional wellbeing | Yes/No |
| Home support | Yes/No |
| Training/education | Yes/No |
| Other | Yes/No |
| Family/PPR's 'other' social care needs | |

Suitable for in-depth quality appraisal? Yes/No
(select one)

State reasons:
.....
.....

Appendix D

Form for data extraction and quality appraisal

Generic details

Name of reviewer	
Date	
Author(s) of study	
Year of publication	
Title	

Study

<i>Study type/design</i> What type/design of study is it?	
<i>Theories/conceptual models</i> referred to in the report?	
<i>Aims/research questions</i>	
<i>Intervention</i> What, if any, is the intervention? Is there a comparison intervention?	
<i>Outcome measures</i> What outcome measures are used in the study?	

Setting

<i>Area and care setting</i> What is the geographical and care setting for the study?	
<i>Rationale</i> What is the rationale and appropriateness for this choice?	
<i>Detail</i> Is there sufficient detail about the setting?	

Sample

<p><i>Inclusion and exclusion criteria</i> Who was included and who excluded in the study?</p>	
<p>How are <i>complex healthcare needs defined</i> in the study?</p>	
<p><i>Selection/recruitment</i> How was the sample selected/recruited?</p>	
<p><i>Size/characteristics of sample</i> What is the size of the sample and groups comprising the study?</p> <p>Is the child's/family's ethnicity reported? Specify</p> <p>Is the child's gender reported? Specify</p> <p>Is the parent's gender reported where they are the respondent? Specify</p> <p>Is the family's socio-economic status reported? Specify</p> <p>Is the family type reported (eg birth, adoptive, foster, one-parent)? Specify</p>	<p>Yes/no</p> <p>Yes/no</p> <p>Yes/no</p> <p>Yes/no</p> <p>Yes/no</p>
<p><i>Appropriateness</i> Is the sample appropriate in terms of its ability to meet the aims of the study, the depth of data that it enables to be collected, and its breadth?</p>	
<p><i>Ethics</i> Was ethical committee approval obtained? Was informed consent obtained? Does the study address ethical issues adequately?</p>	

<p><i>User/carer-centredness</i> Are there any other indications of responsiveness to the needs of users and carers beyond ethical committee approval (eg carer/user involvement in study, ways of feeding back study data or findings?)</p>	
--	--

Data collection

<p><i>Methods</i> What data collection methods were used?</p>	
<p><i>Role of researcher</i> What is the role of the researcher within the setting?</p>	
<p><i>Fieldwork</i> Is the process of fieldwork adequately described?</p>	
<p><i>Data analysis</i> How are the data analysed? How adequate is the description of the data analysis? Is adequate evidence provided to support the analysis? (eg use of original data, iterative analysis, efforts to establish validity and reliability) Is the study set in context in terms of findings and relevant theory?</p>	
<p><i>Researcher's potential bias</i> Are the researcher's/researchers' own position, assumptions and possible biases outlined? Indicate how they could affect the study in terms of analysis and interpretation of the data</p>	

<p><i>Overall strengths/limitations of the study</i> Please rather whether you think this study is low, medium or high in terms of the weight to be given to evidence in the following parameters:</p>	
<p>a) trustworthy (ie taking account of all quality assessment issues, can the study findings be trusted in answering the study question(s)?</p>	<p>Low, medium or high? Reasons</p>
<p>b) Appropriateness of research design and analysis for addressing the question, or sub-questions, of this specific systematic review.</p>	<p>Low, medium or high? Reasons</p>
<p>c) Relevance of particular focus of the study (including conceptual focus, context, sample and measures) for addressing the question or sub-questions of this specific systematic review.</p>	<p>Low, medium or high? Reasons</p>
<p>d) Taking into account trustworthiness, appropriateness of design and relevance of focus, what is the overall weight of evidence this study provides to answer the question of this specific systematic review?</p>	<p>Low, medium or high? Reasons</p>

<p>Key findings</p> <p>What findings about social care needs are identified within this study of the</p> <p>a) child with complex healthcare needs</p> <p>b) parent of child with complex healthcare needs</p> <p>c) family of child with complex healthcare needs</p> <p>d) sibling child with complex healthcare needs</p>
<p>What findings about the needs of the professional are identified? (if appropriate)</p>
<p>What outcomes for the CCHCN are</p> <p>a) specified?</p> <p>b) implied?</p>

Policy and practice

<p><i>Generalisation</i></p> <p>To what extent are the study findings able to be generalised?</p> <p>Are the conclusions justified?</p>	
<p><i>Implications for policy</i></p> <p>What are the implications for policy?</p>	
<p><i>Implications for practice</i></p> <p>What are the implications for practice?</p>	

Appendix E

Summary of information collected when keywording

Location of the study	Count	%
UK	58	41
North America	68	49
Australia/New Zealand	6	4
Israel	3	2
Europe	6	4

Publication status	Count	%
Published	136	96
Unpublished	4	3
Don't know	1	1

Format of report	Count	%
Article	121	86
Book	3	2
Book chapter	1	1
Dissertation	2	1
epublished	1	1
Report	13	9

Source of citation	Count	%
Electronic database search	117	83
Hand search/from references	24	17

Type of empirical study	Count	%
Replicable evaluation	128	91
Single case design	13	9

Whose needs are focused on?	Count	%
Child	39	28
Family (child+parents/person with parental responsibility (PPR) and/or siblings)	63	45
Parent/PPR	30	21
Formal care worker/professional	9	6

Who has provided data?	Count	%
Child with CHCN	12	9
Family of child	5	4
Parents/PPR	53	38
Other children	1	1
Formal care worker/professional	27	19
Other/more than one	43	30

Child's age group	Count	%
Unspecified	40	28
Specified	101	72
Specified ages ranged from 0-36		

Settings for social care needs/services	Count	%
Home	88	63
Shared (home/education)	10	7
Shared (home/health including palliative care)	18	13
Shared (home/short break)	10	7
Home/transition to adult services	13	9
Other	2	1

Studies by number of bodily functions specified	Count	%
Unspecified	46	32
1 only	28	20
2	25	18
3	16	11
4+	26	19
Total	141	

Bodily functions focused on in studies	Count	Single focus
Breathing	59	13
Eating/drinking	49	2
Mobility	40	3
Toileting	24	0
Other, specified	61	10
Unspecified	51	n/a
45 studies made no specific mention of any particular bodily function		

Social care needs	Count	% of all KW
Child's social care needs – physical wellbeing	109	77
Child's social care needs – emotional wellbeing	43	30
Child's social care needs – educational/work participation	55	39
Child's social care needs – social participation	55	39
Child's social care needs – other	7	4

Family social care needs – advice/information	63	45
Family social care needs – short breaks	58	41
Family social care needs – emotional wellbeing	80	57

Family social care needs – home support	66	47
Family social care needs – training/education	42	30
Family social care needs – other	39	28

Children's 'other' primarily information/training (3), also 2 for advocacy, and 1 each for participation in medical appointments, and continuity of care from child to adult

Family 'other' primarily finance, housing adaptation/equipment, transport and coordination

Appendix F

Summary of studies subject to data extraction and in-depth quality appraisal

Study	Aims of the study	Study design	Findings and implications for policy and practice
Antle (2004) ⁸²	To investigate the correlates of self-worth for 230 young people with either spina bifida or spinal cord injury	Statistical and regression analysis of correlations in data gained from standardised instruments; 46 follow-up interviews; North America	The findings suggest that the 'majority of children with physical disabilities have global self-worth scores similar to those of their non-disabled peers' (p 172). No gender difference in self-worth was identified, but it was found to be important that parents continue to have ongoing input into supporting the child, even into early adulthood. Perceived social support from friends and parental support and social support from friends are likely to lead to higher self-worth. Social workers should aim to play a long-term role in the family life of these young people, and devote attention to supporting the parental relationship rather than emphasising the child's independence to the exclusion of that relationship.

Study	Aims of the study	Study design	Findings and implications for policy and practice
Atkin and Ahmad (2000) ⁶⁷	<ol style="list-style-type: none"> 1. Examine parental perspectives on the nature and appropriateness of service provision 2. Relate these to the views of practitioners and managers 3. Provide an understanding of coordination of services 4. Develop recommendations to improve services 	<p>Qualitative evaluation of service support for children with thalassaemia or sickle cell disease in UK.</p> <p>Semi-structured interviews with 62 parents/guardians. Because of the nature of the medical condition, these are non-white families</p>	<p>Implication that outcomes for children are dependent on their parent's ability to cope. Bad experiences with professionals regarding inappropriate care made coping far more difficult, due to losing trust in workers. Consequent anxiety was not necessarily associated with over-protectiveness. Where there was language difficulties, husbands, children and siblings were often placed in the position of 'gatekeeper' and had to translate difficult medical information for mothers. This was distressing and unhelpful.</p> <p>Coping supported by:</p> <ol style="list-style-type: none"> 1. Managing and achieving mastery over the condition most common. 2. Parent emphasising the normal aspects of the child's experience. 3. Religion, as long as this did not cause stereotyping; policy makers must ensure that racism is not codified in policy. 4. Supportive worker (particularly keyworker) who instilled trust, and provided information, emotional support, and help with finances and benefits; particularly important where there was no wider family. These need to be culturally sensitive, ie in terms of language. <p>The nature of the illnesses meant that at times parents were <i>engulfed</i> by the conditions. However, this was seen to be temporary; coping strategies shifted as necessary service commissioners and health professionals need to identify and sustain parents' coping strategies</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
Barbarin et al (1994) ⁶⁵	To examine prevalence of maladjustment in psychosocial functioning among 327 poor urban children aged 4–17 with sickle cell anaemia (SCA), and investigate its relationship to age, gender, family income, and severity of illness	Exploration of variables within domains of psychosocial functioning, with age, gender, income and illness severity. Data from pre-existing structured interviews from psychosocial assessments by medical or social work staff; log-linear analysis; North America	Social relations, isolation and shyness are of particular concern for these children, at least in the opinions of their parents. Frequency of academic problems higher than in studies of comparable non-ill populations. Severity of pain was positively correlated with frequency of depression or psychological problems. Many parents have unrealistic levels of fear about the child's illness, which could potentially colour their appraisal of the child's capabilities and lead them to limit the child's activities. Family functioning, however, was found to be generally positive, suggesting that these families coped well overall with the strain of chronic illness. Psycho-educational work should be undertaken with families to reduce fears and promote a more realistic assessment of the child's capabilities. Implied positive outcomes if social relations are supported (eg support groups, social confidence training).

Study	Aims of the study	Study design	Findings and implications for policy and practice
Baum (2004) ¹³⁸	To explore the use of Internet Parent Support Groups (IPSGs) from the perspective of primary caregivers of a child with special healthcare needs	Internet survey using 'an exploratory, retrospective self-report design'. A variation of the transactional model of stress, coping and adaptation used as a guide for research questions and outcomes; 114 caregivers, caring for 140 children with special healthcare needs, and using 100 different IPSGs responded; worldwide	<p>IPSG participation was found to be significantly related to the following positive outcomes for carers:</p> <ol style="list-style-type: none"> 1. Improved caregiver-child relationship 2. Positive shift in most carers' perceptions of their situations, particularly in respect of relief and gratitude 3. Laughing and relaxing more 4. 'Empowerment'. <p>Carers also felt with IPSG that they were in control of the amount and type of support they were receiving. It was on their own terms and without the same social niceties that needed to be upheld in face-to-face support. It was 'a link to the outside world' – important as many found it hard to get out because of their caring responsibilities.</p> <p>Advised that caregivers need to be provided with internet access at home to improve their self-help coping strategies. Workers should find out what IPSGs are available and then have them ready to recommend to parents who have access to a computer/internet. However, practitioners should note that there are can be drawbacks in terms of emotional overload, misinformation and people selling products or therapy via the groups.</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
Diehl et al (1991) ³⁰	A state-wide needs assessment as part of the Special Children, Special Care Project in Florida, designed to develop a training programme for people who care for children with CHCN	Not intervention-based; qualitative; focus groups of caretakers of medically complex/technology-dependent children; 9 sessions with 6-10 participants per group, across six sites; data analysed through ethnographic and content analysis; North America based	<p>Children's developmental, emotional and educational needs were often ignored or downplayed by professionals in favour of medical needs. The whole child must be seen and supported. Children were often scared about hospitalisation, and parents were concerned about how to prepare them for this. Equipment needs.</p> <p>The care of the child needed to be shared in the family in order to hold the family structure together. Difficulties were getting time away from caring to go out as a family, and financial stress. Parents need to have their expertise and parenting role acknowledged, and expressed frustration and anger at being dealt with 'disrespectfully' by professionals. Professional must treat parents with respect. Some parents needed to talk about their grief at their child's coming death, but found it difficult to find a listener, or time to do so as the child's needs increased. Support groups immensely helpful in enabling parents to deal with emotional issues.</p> <p>Training was considered essential but was often far too sparse and 21% of the parents received no training at all. Many complained about the lack of information they had been given, about their child's needs or condition, about funding, about using equipment.</p> <p>All the family suffered from lack of public acceptance of the child with CHCN, which caused embarrassment or anger for family members. Some extended family members were afraid of the child, limiting receipt of help.</p> <p>Siblings had to bear with the situation, and parents reported their jealousy, suicidal feelings, and fear of medical procedures as a result of living with a sibling with CHCN.</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
Edwards et al (2004) ¹¹³	To examine outcomes for tracheostomy-dependent, ventilation-using children, and discuss the complexities of home discharge for 39, of whom 6 awaiting discharge	Naturally occurring intervention (discharge home from hospital), and descriptive report; no comparison; basic descriptive statistics; UK	Difficulties recruiting suitably trained staff, funding delays and unsuitable housing were found to be the most significant factors hindering discharge. Families were generally found to be committed and capable regarding their children's care. Greater efforts are needed to ensure adequate staffing, possibly using agency care in the interim. Alternative systems of funding are needed to facilitate discharge. Changes to grant eligibility assessment for housing alterations may help to reduce the difficulties associated with unsuitable housing, given the difficulty of finding alternative accommodation.
Heaton et al (2003) ¹⁹ and Heaton et al (2005) ²⁰ referred to in thematic analysis as Heaton et al (2005) ²⁰	'To examine the temporal organization and time consequences of the care regimes for technology-dependent children and their families' (p 6)	Qualitative study using semi-structured interviews, time-line drawings, and written/photographic drawings with 75 members of 36 families including technology-dependent children and siblings. Data analysis using the 'framework approach'; UK	Technological devices for children with complex healthcare needs improve quality of life, but are also disruptive to family and social life. Greater provision of respite care (trained workers) in the home outside school hours, and breaks away from home for the family, are emphasised as important unmet needs (parents need the opportunity to sleep). Multiagency care planning and a single key worker are also recommended to streamline contact with services. Siblings must also be considered within a holistic view of the family. Better organisation will allow the child more time for educational, play and social activities, which should be 'a priority for their development and wellbeing' (p 19). There should be greater provision of out-of-hours trained workers for respite work, and assistance should be provided to allow families to take breaks away from home. Practitioners need to devote effort to multiagency working. A designated keyworker is recommended. Families must be seen more holistically, so that the needs of siblings are not neglected.

Study	Aims of the study	Study design	Findings and implications for policy and practice
Jackson et al (2003) ¹⁰¹	To assess the psychosocial impact on children and their families of Craniopharyngioma and to evaluate the extent to which existing services had been able to meet the needs of families	Main project is described as 'multi-method' but this reports qualitative data arising from it. Semi-structured, face-to-face interviews with 13 families; Australia	Importance of psychosocial assessment and educative support. Physiological severity and impact on family did not necessarily equate. Individual and family factors beyond the severity of physiological symptoms determine impact on the family so requires assessment. Also, even if a child appears to be coping well, their parents may not be. Diagnosis period particularly stressful, particularly with rare conditions that often required parents to insist on further tests. Stressful from learning about the illness and how to care for the child. Professionals' failure to provide information about condition and services in useful way a significant contributor to stress. Parents thought the effects on them of their child's condition were greater than on their child. Children, however, were reported to be often afraid of treatments (injections and surgery). Impacts on the family changed over time depending on the stage of the illness so needs reassessing. Financial impact often greatest to start, with travelling costs mentioned and hospital-based accommodation for parents. Most families in the sample had remained "close and supportive" throughout the illness – only one couple had separated, and another reported strife in first six months. Siblings were said to be affected in terms of behaviour, school grades, and teasing about their sibling's condition or appearance.

Study	Aims of the study	Study design	Findings and implications for policy and practice
Jardine et al (1999) ¹²¹	To identify the number and location of children, 0-16, requiring long-term ventilation in the UK and to establish their underlying diagnoses and needs	Quantitative questionnaire survey; 49 responses by consultants covering 141 children; basic descriptive statistics; UK	<p>It was found that it is possible to care for children dependent on ventilatory support at home, and that this is happening to an increasing extent. Arrangements for funding were found to be a considerable obstacle to early discharge, and these also affected the extent of formal respite arrangements.</p> <p>Other obstacles mentioned were staff unavailable to support families at home and housing being unsuitable to the child's needs.</p> <p>Funding arrangements should be put in place to minimise delays to discharge and complications regarding respite care.</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
<p>Kirk (1999)²⁷ and Kirk and Glendinning (2000)²⁸, referred to in thematic analysis as Kirk (1999)²⁷</p>	<ol style="list-style-type: none"> To explore the experiences of families caring at home for a technology-dependent child To identify problems and good practice in the purchasing, delivery and coordination of services To assess the appropriateness and adequacy of support services 	<p>Naturalistic study, involving qualitative interviews with families (including 4 children) and 38 professionals; grounded theory used to analyse data, coded on NUD*ST; UK</p>	<p>Families overwhelmingly preferred home to hospital care due to flexibility, familiar environment for child, equipment in one place, reduced risk of infection, trust in carers with in-depth knowledge of child's needs. Children can be cared for at home effectively by parents if multiagency professional support is properly commissioned and provided. However, obtaining services is not straightforward with lengthy disputes between health authorities and social services departments over responsibility for funding short breaks, equipment, medication and home workers with local interpretation/variation in services. Needs advanced planning. Joint funding most effective. Short break services often inappropriate or inadequate because of nature of nursing care needed, eg no night sitting available, family-based care only found in one case. Main support for families was provision of home (and school) care during day or overnight to provide break or to support parents eg where medical needs intensive. Use of non-professional staff acceptable to parents. Arrangements for provision of equipment stressful and unreliable with poor link up between hospital and community services. Services rarely coordinated at operational level. Few families had designated key worker/care manager. Parents often left coordinating services. Created extra pressures. Poorly coordinated discharge planning and beyond so families complained of being visited by too many professionals, undermining ordinary family life and confusing over roles/responsibilities. Communication reactive/problem-focused. Parents over-relied on to pass on information. Parents had to fight for support at time of stress.</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
Kirk and Glendinning (2002) ⁴⁷	To explore the experiences of parents caring for a technology-dependent child and of the health professionals supporting them in the community. Investigated what support parents want, what they actually received and how congruent these were with professionals' perceptions	Not intervention-based. Qualitative exploration of the experiences of parents of 24 children and professionals working with them, using semi-structured interviews; grounded theory used to analyse data, coded on NUD*ST; UK-based	Parents' expertise in care can lead to better outcomes for their children, when acknowledged and encouraged. Where this was not valued this was very stressful for parents. Continuity of support was important as it removed the need for parents to continually prove their expertise. Emotional support consisted of having an accessible person who parents knew that they could turn to, being able to talk to that person to share worries and anxieties, and promotion of confidence and reassurance in their abilities to care. Practical support involved advocacy, to help parents to obtain services and benefits needed, 'hands-on' support, which was helpful when available but because of the complexity of the procedures and technologies was sometimes lacking, and the organisation of services and equipment. Provision of practical equipment and services that would provide parents with a break from caring, was most problematic. Parents had to take on a coordination role to ensure they were obtained in time – an additional burden. Provision of information and advice was often inadequate. Attention should be paid to the lead professional or key worker role in order to provide a single point of coordination, support, listening, and advice for parents. This would provide continuity of service, provision of supplies and improve access to short breaks. Professionals need to be reflective of their own strengths and limitations, and be willing to acknowledge and support expert parents in their caring duties.

Study	Aims of the study	Study design	Findings and implications for policy and practice
Kirk and Glendinning (2004) ⁵²	To explore the experiences of families caring at home for a technology dependent child; and identify perceived problems and good practice in the purchasing, delivery and coordination of services	Qualitative study using semi-structured interviews with 24 parents of children with CHCN and 38 professionals involved with the family. Study refers to the way of living for families, rather than specific interventions; grounded theory used to analyse data, coded on NUD*ST; UK-based	Professionals insufficiently aware that caring for a child with CHCN is not just a practical matter of medical or technological knowledge, but 'has a substantial emotional dimension', and that parents may need support and valuing to carry out their parenting role within their families in order to promote outcomes for children. On discharge, parents assume 'responsibility for highly technical procedures that would formerly have only been undertaken by qualified professionals' (p 212). They felt that this was not recognised explicitly or negotiated as it should have been. Parents often had to assume roles that they felt unprepared for, ie painful processes for their child. Felt there was an unspoken assumption about the clinical duties involved without any negotiation for the emotionally stressful aspects of caring. Parents felt that their lives were dominated by caring duties, and that it was difficult to get a break from them due to lack of appropriately trained people (friends, family or other) to take their place. Need for short break services. Many parents had given up work in order to become full-time carers – a financial strain. Medicalisation of the home and loss of privacy through equipment, support staff and visits by the professional. Family life revolving around the routines of the technology. This was preferable to parents in the study to having the child based in an institution. Siblings were also thought to have missed out on parents' attention and other opportunities.

<p>Study</p> <p>Kirk and Glendinning (2004) ⁵²</p>	<p>Aims of the study</p>	<p>Study design</p>	<p>Findings and implications for policy and practice</p> <p>continued ...</p> <p>Funding disputes between health and local authorities over provision of services and equipment created stress for parents and delayed discharge. Where agreements existed, discharge became much faster. Sufficient time must be given before discharge to enable supplies and services to be in place. Good coordination and communication between professionals enhanced parents' feelings of support, while being offered information instead of having to seek it out, improved their sense of being in control. The lack of a designated keyworker for families was seen as an impediment. Recommended that a keyworker should be appointed for each child with CHCN. Concerns about a lack of professional clarity about roles and responsibilities, interprofessional communication and lack of service coordination.</p>
<p>Study</p> <p>Lobosco et al (1991) ³⁴</p>	<p>Aims of the study</p> <p>Service development focus using the needs assessment/futures planning method reported as a basis for decisions about service coordination in three areas</p>	<p>Study design</p> <p>A survey of needs to inform a futures planning exercise by coalitions of service providers. Thematic analysis of types of barriers to home care for children dependent on medical technology; North America</p>	<p>Findings and implications for policy and practice</p> <p>Children are likely to remain in hospital because of 45 barriers to home care identified, clustered into five groups:</p> <ul style="list-style-type: none"> a) finance b) care coordination/case management c) discharge planning d) family support: support and information e) manpower and training. <p>Coordinated approaches are indicated, at least in respect of discharge process and school inclusion.</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
Margolan et al (2004) ¹⁰³	<ol style="list-style-type: none"> 1. Describe the families' experience of the services they receive, where there is a child requiring long-term ventilation 2. Describe the care packages associated with long-term ventilation 3. Identify both problems and good practice 	Questionnaire survey incorporating qualitative and quantitative data; 15 families; UK	<p>Almost all the children requiring long-term ventilation had other healthcare needs such as assistance with feeding, toileting, mobility, gastrostomies or naso-gastric tubes. Funding for equipment, ongoing care inside the home and at school, and house adaptations was a major issue for all these families and their children. Agencies were unable to agree resource allocation and funding led to the majority of delays to discharge home. Children were often not receiving the education they were entitled to, because of difficulties in agreeing funding for carers between education and health. Joint funding needs to be clearer and the responsibility shouldered and not shoved aside. Keyworkers who can coordinate services and funding for families, as well as provide information and advice, would relieve many stressful situations for families and their children. Parents felt that health professionals had taken them for granted while the child was awaiting discharge, and that training in procedures ignored the emotional side of having to do this to your own child. Nine families received some respite care; the majority found planned respite was inadequate. Because of the complexity of care, extended family and friends were unable to help out unless formally trained. Professionals need to be more aware that families' needs change and require reassessment if families are to stay well.</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
McGrath (2001) ¹⁰⁹	To obtain feedback on the need for a volunteer service for families coping with a child with a life-limiting condition	Not intervention-based. Postal survey to parents – questionnaire with some open-ended questions inviting comments from respondents; 107 responses; no discussion of data analysis; Australia	<p>Over half the families had no support from their close family, and where it was available there were often problems or qualifications associated with the support. Volunteers would be useful in a wide range of helping situations, from the 'heavy practical workload' to 'emotional assistance' for all members of the family. Volunteers could:</p> <ol style="list-style-type: none"> 1. Take child out 'for fun', and introduce new interests to them 2. Help the child with fears of medical procedures 3. Help with exercise and other skills. 4. Support siblings who are feeling pushed out or ignored 5. Give parents physical help with tasks such as physiotherapy, or household chores. <p>However, over half of the respondents said that there could be disadvantages to having a volunteer helping, including privacy of the home or shy children, not getting on or the volunteer imposing their own agenda, and the fear of a volunteer's lack of ability and unreliability. It is vital that volunteers are trained and monitored, and that families will have choices.</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
Neufeld et al (2001) ¹⁴²	<p>Which respite services do primary caregivers of children with chronic medical condition and/or ongoing disability access?</p> <p>What do primary caregivers perceive as barriers to respite?</p>	<p>Descriptive design using questionnaires to families of 59 children; North America</p>	<p>Caregiving needs of sample: 54% intensive; 35% intermediate; 11% moderate level of care. Mainly to do with activities of daily living, medication administration, treatments and therapies and behavioural programmes.</p> <p>Different types of respite care distinguished: (a) <i>in home</i> formal services: 73% 'babysitting'; 55% need from less than once a month to daily/40 hours per week; (b) <i>host family</i> respite: 40% ranging from week or two at a time to every second weekend; (c) <i>group home</i>: 26% ranging from 4-30 days a time; (d) <i>institutional</i> respite care: 26% two days per year to one weekend per month; (e) <i>camp</i>s for older children: 40% 1-2 weeks in summer or day camp for five days to eight weeks.</p> <p>Level of use: 26% rare; 26% occasional; 14% often; 34% frequent.</p> <p>A total of 77% thought the level of break was limited and more should be provided; 13% no complaints. Lack of people/agencies to provide care most frequently mentioned barrier.</p> <p>A total of 71% wanted changes: availability of qualified staff (33%), increased access (20%), increased frequency (18%), and short-term emergency provision (8%).</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
<p>Noyes (1999)²¹, Noyes (1999)²⁹, Noyes (2000)²² and Noyes (2002)²³ cited in thematic analysis as Noyes (1999)²⁹</p>	<ol style="list-style-type: none"> 1. To describe views and experiences of ventilator-dependent children (and their parents) of their health, social care and education 2. To ascertain if their needs were met 3. To describe their aspirations for the future 4. To report on barriers to hospital discharge 5. To disseminate views and experiences 	<p>Qualitative in-depth study using open interviews with 18 children and their parents. A framework of 'patient-centred 'needs' was adapted to guide the interview process (p 4). Data analysed from phenomenological view for key themes, and from Pickin's needs framework to see if needs were being met; UK</p>	<p>Life as a young 'ventilator-dependent' person was characterised by discrimination, poorly organised and inadequate services, violation of human rights, social exclusion and in many cases inadequate and poor quality education. Funding often a huge obstacle to social inclusion, both in provision of medical equipment that allows the child to be independent as well as safe, in the altering of homes and schools to make them accessible, in the provision of appropriate hospital care when necessary (ie so that children do not have to spend prolonged periods of time in ICUs or adult wards), and in the provision of sufficient and appropriate care at home so that child can be at home with their family, and the SCNs of the family can also be met. Where there were delays to hospital discharge children's basic human needs for attachment, security, communication, friendship, continuity and belonging were not met. Better coordination between services is needed, with clearer guidelines on funding to ensure that responsibility is taken for both health and social care needs.</p> <p>The attitudes of professionals were often a key barrier to children and their families with children often medically objectified by professionals. Their views were not taken into consideration, their education curtailed, their needs for friends and a social life not being responded to. With home care, families felt that carers often imposed their views within the home, laying down unnecessarily strict 'laws' that meant children were not able to do things the carer deemed 'too risky'. Loss of privacy, feeling out of control, not getting on with the carer.</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
<p>Olsen and Maslin Prothero (2001)¹⁴³</p>	<p>To evaluate the views of existing service users of a nurse-led, home-based, respite service for the families of children under five years with CHCN. To explore parental experiences over an extended period and to develop an understanding of change within the family over this time</p>	<p>Qualitative evaluation of innovative service. Interviews of 18 families at three stages, receiving service over 18-month period; framework approach for analysis; UK</p>	<p>Receiving respite is important for some families but for many it is one among a variety of factors contributing to family wellbeing. The absence of respite support seen to have little negative impact on those families where the child is getting stronger, achieving some developmental milestones and requiring less hospitalisation. Factors associated with family wellbeing were threefold:</p> <ol style="list-style-type: none"> 1. Child's condition, eg not needing hospital care during period of service 2. Service availability, eg attaining age for special nursery 3. Other factors, eg better house, parental job security, receipt of welfare benefit. <p>Professionals need to recognise that respite is needed for different purposes – some to support siblings directly or indirectly; differences between wanting a break from the child or 'another pair of hands' alongside to help care (especially where child and parent had been apart because of hospitalisation). Especial need for services to be clear about eligibility (and underpinning value judgements) eg use of respite to support parents working. Tension between spreading service widely and responding quickly to immediate need. Some parents wanted to pre-book and plan others to get flexible/immediate support in response to child's fluctuating health needs or life events. There can be a loss of faith in the service if it is not flexible.</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
Pownceby (1997) ⁷⁷	How does cystic fibrosis impact on young people's personal and social lives? How can transition to adult services be improved? How might young people's compliance with treatment be facilitated?	Mixed method – combining open and structured sections, with four psychometric measures that were analysed statistically; 104 young people with cystic fibrosis in UK	<p>Children need to be given more freedom and responsibility as they get older to foster their independence. This appears to improve adherence to treatment. Over half the group had not been involved in discussing, decision making or planning around their transfers from child to adult services. In the post-transition group, half had found out through the grapevine rather than through official notification. A more coordinated approach to health and social care needs to be taken. Better transition processes support mental wellbeing, dispel worries and anxieties. Family relationships in terms of caring, cohesiveness and control impact on the young person's perceptions of themselves re loneliness and optimism. Family interventions are warranted to improve treatment adherence and wellbeing of young person and family. Stigma and discrimination are rated worst for young people, being less fit than peers coming second.</p> <p>Many young people will put their social needs above their treatment regime, and a balance can only be achieved by working in partnership with them.</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
Ray (2002) ⁹⁹	<p>Study is aimed at validating author's conceptual model, PACC (parenting and childhood chronicity), describing the work required to raise a child with a chronic health condition. Aim was to show also that much of the work of parents is not recognised because it moves beyond the medical model of life-sustaining practice</p>	<p>Qualitative, interpretive study. Sample of 30 families with 34 children. Semi-structured interviews with 43 parents regarding the PACC model; North America</p>	<p>Caring needs cannot easily be subdivided as changes in one domain often affect the others, therefore services should consider a wider picture. Caring is a 24-hour job. Parents had to be constantly on guard for changes to symptoms or problems with equipment. Many accepted that they would have caring responsibility for the rest of the child's life, including social monitoring and providing help with skills and development. The 'invisible' parts of caring (monitoring, balancing chores and time, the administration/advocacy/coordination tasks) need to be acknowledged and taken into account. The more expert parents became in providing these caregiving responsibilities, the more invisible and taken for granted their efforts become until they faltered in their ability to keep up with the workload. Great frustration expressed about the systems in place, seen as a constant struggle, eg lack of information, and coordination. Having one consistent person to whom they could turn to help them with the systems and support was considered important but not often available. All parents had to take an advocacy role for their child to coordinate and improve care. In-home respite help invaluable in order to achieve some rest and also in terms of personal support. In order to cope, most parents take the attitude that they just have to get on with things. Parents have to make clinical decisions about their child's care in the light of the larger family and their needs. Having the extended family and friends involved was invaluable in terms of physical and emotional support. Parents had to make special efforts to do activities with siblings, who they felt perceived themselves as pushed aside by the needs of the child with CHCN. But this was seldom achieved as a family. This study backs up all calls for coordination of services, information sharing and provision of key workers for families with a child with CHCN.</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
Rehm (2002) ⁴⁹	<p>To describe promotion of safety and health in school of children aged 5-18 who are medically fragile/technology dependent (mf/td).</p> <p>To explore perceptions of social and emotional consequences of school participation for the children, their schoolmates, and families</p>	<p>Qualitative: exploratory, interpretive study based on symbolic interaction as the methodological framework.</p> <p>Semi-structured interviews with 11 parents, 8 educators, 9 nurse managers, 5 school nurses plus informal observations, in 4 schools.</p> <p>Data analysed using a constant comparative method; North America</p>	<p>Some children were kept out of school by parents during winter months in order to avoid the chance of infection during the cold season, or when a contagious illness was in the school. Although two of the parents in the study had asked for work to be provided at home, all the children missed the social interaction that school provides.</p> <p>Parents had to learn to be persistent, to continue to monitor children's wellbeing and service provision, and to put up with reputations for being difficult. Because of the specialisation needed to look after the children, parents often found themselves to be more knowledgeable than the professionals and had to train them. Some parents resented the extra help that they were expected to provide.</p> <p>Finding a person who was willing to look out for their child's interests and advocate on their behalf was helpful to the parents. Otherwise, they turned to outside advocacy agencies. The provision of a keyworker for parents would help to alleviate some of the advocacy work that parents do on behalf of their child.</p> <p>Educators have an ambiguous role as both educator and care provider. Schools took an individual approach to the provision by teachers of medical care, and within schools, some teachers and nurses drew their own lines of responsibility.</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
Robinson et al (2001) ¹⁴⁴	To highlight (a) the difficulties families experience in obtaining adequate and appropriate short breaks for their children and (b) the lack of social work monitoring of short break placements	Qualitative design using semi-structured interviews gaining parental experiences and professionals' views on short breaks. This research combines the results from two separate studies effectively treating them as one for the purpose of the findings; UK	<p>The boundaries between health and social care are too unclear in situations where a child has CHCN, leading to confusion about who is responsible for the care. Guidance is needed from the Department of Health on what constitutes social, as opposed to health, care and where the respective agencies' responsibilities start and finish. Parents need breaks in order to cope. General lack of support for families with parents carrying high levels of responsibility in the absence of sustained support. Services are not uniformly available, and children are placed in inappropriate settings due to lack of choice otherwise. This raises additional concerns about both child safety and possible psychological damage to children through a lack of consistent care, and carers. Many stressed the safe care in hospices that they believed ensured the child was comfortable and happy. Parents had real concerns about the quality of the care that could be provided by people who were not qualified nurses. There needs to be a more consistent line from local authorities on who can undertake these very complex healthcare tasks.</p> <p>Better guidelines to monitor short break accommodation needed. Eight steps to better practice are recommended, to ascertain how many families within a local authority have a child with CHCN, what their needs are through consultation with the client families, and better funding, information and coordination of services. It is suggested that keyworker systems are put in place to support families.</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
<p>Smith et al (2003) 114</p>	<p>To identify how many children attend Nottingham schools with a tracheostomy and to determine the support they receive</p>	<p>Simple descriptive naturalistic study collecting quantitative and qualitative data. Sample of 11 children aged 2-16 with mean of 9.7 years. Questionnaires completed by parents and child's carer at school; UK</p>	<p>Children can be readily included in school if there are properly trained carers in place. In 4 out of 11 cases return to school was delayed by up to eight months due to lack of suitable carers. One child missed six days schooling subsequently as carer absent. Children had between 1 and 14 carers including nursery nurses, care assistants and school nurses. One child performed the care himself. Four families were dissatisfied with aspects of child's experience: issues of quality of carer, attitude of staff and funding. Unspecified problems experienced in finding suitable carers for the journey to school. Six out of 11 children were excluded from school trips because of lack of carer. Eight out of 11 required no emergency change of tracheostomy at school and few missed school through ill health.</p> <p>No child had the recommended Health Care Plan (DH 1996). Many parents were involved in the training of school carers and the majority were satisfied with care received by their children. Trained carers need to be in place early.</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
Sullivan-Bolyai et al (2003) ⁷⁶	'To provide a detailed description of mothers' actual management behaviours and the meanings mothers attributed to them ... [to] help to design more precise nursing interventions that may assist mothers in the day-to-day management' (p 23)	Naturalistic study with qualitative design based on concept of 'constant vigilance', which incorporated cluster of management behaviours. Interviews with 28 mothers; grounded analysis used to analyse data, coded on NUD*ST; North America	<p>Mothers described having to use hyper-vigilant caregiving behaviour to accomplish day-to-day management, ie (a) ongoing monitoring of illness-related care; (b) identifying appropriate and safe resources that could meet child's needs; (c) juggling illness-related care with developmental needs of child.</p> <p>Central theme was burden of 'constant vigilance'. Three aspects of this:</p> <ol style="list-style-type: none"> 1) Day-to-day concerns 2) Day-to-day management 3) Supportive resources. <p>These were stressful and exhausting. Discharge planning should take account of parental worries and provide follow-up to decrease burden of daily care/health problems. Fathers to be more involved. Importance of nurse working in partnership with family to provide information, guidance, reassurance re management of condition especially in early months after diagnosis. Reassurance/validation of feelings of loss of confidence after severe episodes. Parental empowerment is facilitated by drawing on inner strength.</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
Thorne et al (1997) ¹⁵²	How do parents/ carers of children with gastrostomy devices perceive the experience of caring for these children?	Interpretive descriptive study in conjunction with larger longitudinal study. Semi-structured interviews with 46 parents and professional carers. Constant comparative analysis to create categories of coping; North America	<p>Nine categories of coping grouped into three broad themes:</p> <ol style="list-style-type: none"> 1. Everyday gastrostomy maintenance 2. Dealing with people (handling stigma, advocating for the child, training carers, maintaining vigilance) 3. Maintaining normalcy (as normal a personal and family life in face of relentlessness of care. <p>Full range of supportive services needed including respite care for a few hours or longer.</p> <p>'Values and expectations of home care support workers must align more with normal family life and the emotional health of caregivers than with the rules, policies and procedures that make sense in institutions' (p 52).</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
<p>Townsley et al (2004)²⁴ and Abbott et al (2005)²⁵ referred to in thematic analysis as Townsley et al (2004)²⁴</p>	<p>Explore the experience of multiagency working for</p> <ul style="list-style-type: none"> - disabled children with CHCN - their families - the professionals who support them 	<p>a) Exploratory phase to determine extent of multiagency working for disabled children with CHCN in UK</p> <p>b) Visits to 26 services</p> <p>c) Case study of 6 services (3 England/1 Wales/1 Scotland/1 Northern Ireland)</p>	<p>In contrast to previous research families were receiving support that enabled them to adequately manage their children's CHCN at home. Most families seemed to be doing their own coordination – a source of pressure, families feel 'on call' 24 hours a day and can get extremely stressed. More than half said multiagency working had improved family quality of life but coordination only effective if there were adequate services to be coordinated. But even in two out of three sites not specifically aiming to teach parents skills/supply equipment. Majority of families had made/were making adaptations but very few families had received a coordinated response and some had organised and paid for adaptations themselves. Three out of four families received less than national average income. All families experienced major difficulties in finding/organising opportunities for themselves and their children to enjoy a break or leisure activity. Need a whole-family approach to social wellbeing, not seen as a set of individuals with separate and non-convergent needs. Many families felt isolated. Families relied on short breaks but there was a lack of suitable and available services.</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
<p>Townsley et al (2004)²⁴ and Abbott et al (2005)²⁵ referred to in thematic analysis as Townsley et al (2004)²⁴</p>			<p>continued ...</p> <p>Almost one out of three said they had no emotional supportive, whatsoever from any source. Some parents had a supportive, open relationship with their keyworker, suggesting that they could be contacted at any time between meetings to discuss problems/issues. Little emotional support offered to children themselves. Many had dislikes related to medical/physical issues especially physical discomfort but faced a lack of emotional support and few if any outlets or opportunities to describe and express pain, discomfort and distress; only one child said he was very unhappy. All children of school age were going to school or nursery on a regular basis. There was no evidence of access problems and children appeared to be well-supported at school. Relationships with family, friends and carers important to children. Little evidence that children were consulted, informed or given choices about who helped with their care. Children want professionals to communicate with them directly and to be treated with respect and dignity. Only some of the keyworkers made a positive effort to get to know the child. General lack of contact with keyworker and experience of being 'talked to'. Social contacts and leisure pursuits important to developing independence but required considerable support to do.</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
<p>Townsley et al (2004)²⁴ and Abbott et al (2005)²⁵ referred to in thematic analysis as Townsley et al (2004)²⁴</p>			<p>continued ...</p> <p>Professionals positive about multiagency working. Significant improvements in interprofessional communication. Two out of three created new role of keyworker as a central point of family contact and coordinator of professionals and support services. Access to and sharing of information easier. But some fears about duplication of meetings. Social workers felt medical and healthcare issues dominated and social model of disability threatened by this. Certain health professionals (eg GPs and teachers) more difficult to engage with. Multiagency service structures thought to be better and more effective for coordinating support and services for families and contact with professionals. This said to enhance relationships with families, to have clearer insights into issues for families, appeared a more coherent team to families. Overwhelming belief that all this made positive difference to families' quality of life, especially by enabling healthcare needs to be met in home/community setting. Some concerns about insufficient resources to match raised family expectations</p>

Study	Aims of the study	Study design	Findings and implications for policy and practice
<p>Wilson et al (1998) ⁴²</p>	<p>What is the experience of mothers providing home care for their ventilator-dependent child?</p>	<p>Naturalistic study, qualitative design developing the concept of 'absolute involvement' as the basic social process around which all other core variables are integrated. Telephone interviews with 16 mothers; grounded analysis; North America</p>	<p>Proposal that 'absolute involvement' of the mother is the core variable/central phenomenon at work to facilitate day-to-day family life and to provide for the child's care. Confident caring results in good child experience. Incorporates three categories:</p> <ol style="list-style-type: none"> Attributes of mothering (resources and constraints) Meeting the demands (mother's ability to meet caregiving demands by using 'process skills and strategies') Appraising impact. Fourfold categorisation: confident, looking to improve, reclusive, distrustful. Suggestion that reclusive parenting ie constant effort to manage day-to-day care was a detriment to family relationships. <p>Successful appraisal occurred when mothers met self-determined standard of care and day-to-day demands.</p> <p>Need to:</p> <ol style="list-style-type: none"> Consider 'life expectancy' of a family caregiving unit and what follows this Consider funding Support mothers, who have demonstrated their commitment so they can achieve the dual roles of mother and caregiver rather than fighting for resources/rights for child. Base support on the 'family caregiving system'. Understand function of mother's expectations and promote relationship by initiating ongoing discussion about the 'rules' of engaging in caregiving and 'alleviating confrontation' (p 231). Facilitate mothers' learning of skills/strategies and linkages with professionals to get feedback on these and avoid isolation. Need 'primary nurse or a telephone help hotline'.

Appendix G

Judgements on trustworthiness, appropriateness, relevance and overall weight of studies subject to data extraction and in-depth quality appraisal

Study reference	A: Trustworthy	B: Appropriate	C: Relevance	D: Overall weight
20	Low-medium	Medium	Medium	Medium
29	High	High	High	High
24	Medium	High	High	Medium
27	Medium	Medium	High	Medium
30	Low	Medium	High/medium	Medium/low
34	Low	Low	Medium	Low
42	Medium	Medium	High	Medium
47	Medium	High	Medium	Medium
49	Low	Medium	Medium/Low	Medium/Low
52	Medium	High	Medium	Medium
65	Low	Low	Medium	Low
67	High	High/medium	Medium	Medium
76	High	High	High	Medium
77	High	Medium	High	High
82	Medium	Medium	Low	Low
99	High	High	High/medium	High
101	Low	Low	Medium	Low
103	Low	Low	Medium	Low
109	Low	Medium	High	Medium
113	Medium	Low/Medium	Low	Low
114	Medium	Low	Low	Low
121	High-Medium	Medium	Low	Medium
138	Medium	Low	Medium	Medium
142	Medium	Medium	Medium	Medium
143	Medium	Medium	Medium	Medium
144	Low	Low	Medium	Low
152	Low	Low	Medium	Low

Definitions of judgements used for in-depth quality appraisal, adapted from the EPPI-Centre categories

Category	Judgement of weight of evidence
A	Taking account of all quality assessment issues, can the study findings be trusted in answering the study question(s)?
B	Appropriateness of research design and analysis for addressing the question, or subquestions, of this specific systematic review
C	Relevance of particular focus of the study (including conceptual focus, context, sample and measures) for addressing the question or subquestions of this specific systematic review
D	Taking into account trustworthiness, appropriateness of design and relevance of focus, what is the overall weight of evidence this study provides to answer the question of this specific systematic review?

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'Necessary stuff':

The social care needs of children with complex health care needs and their families

This knowledge review sets out to identify what is known about the social care needs of children with complex health care needs (CHCN) and their families, and about the services designed to meet those needs.

The review is made up of three distinct parts:

- a consultation with children with CHCN and their families
- a review of relevant research
- a survey to identify examples of good practice in service provision.

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