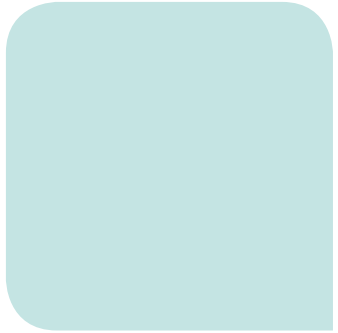
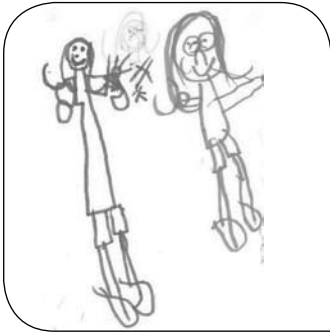


'Necessary stuff': the social care needs of children with complex health care needs and their families



"me and my two helpers"

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This knowledge review set 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 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 health care' 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 health care 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, usually 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.

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The full knowledge review is available on our website.

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This publication is available in an alternative format upon request.

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