# Home-based care for special healthcare needs: community children's nursing services

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**Home-based care for children with special health care needs: what works**

**well in Community Children's Nursing Services?**

# Abstract

*Background:* Community Children's Nursing Services (CCNS) provide nursing and supportive care, ranging from relatively simple to highly technological interventions, to children and young people (0-18 years) within the family home.

*Objectives:* The objectives were to elicit the perspectives on and experiences about CCNS in England in relation to 'what was working well', 'what could be improved' and 'the vision for services'.

*Method:* Using a qualitative approach, underpinned by an Appreciative Inquiry philosophy, researchers worked closely with advisory groups (children, young people, parents and professionals) to design and implement the study. Arts-based participatory appreciative workshops were held in nine regional locations in England; shared activities were undertaken to elicit participants' experiences. Participants unable to attend the workshops were able to contribute via semi-structured interview (face-to-face or by telephone) or by a dedicated blog or email.

*Results:* Thematic analysis was used. 214 people participated: families (n=82); children (n=27), professionals / stakeholders (n=105). 'Working well' was evidenced by effective communication, robust leadership, actively enabling the child's care to be sustained at home, and partnership working based on mutual trust. Problems relating to ineffective commissioning, under-provision of services and hours of service availability, feelings of marginalisation, lack of equipment/resources and poor communication between services and settings were areas of concern. The vision for CCNS was for a flexible, equitable and accessible service that supported children's / families needs and choices and which enabled parents to be 'parents first' rather than professional carers.

*Discussion:* Care at home reduces the disruption to children's and families' lives and can empower them to make decisions and control routines and practices. CCNS within larger teams with strong interdisciplinary and transdisciplinary practices seem to offer the best benefits for children /

families. Findings from this study have influenced government policy and practice. Further research is needed to determine efficacy of particular models and practices.

# Introduction

Across developed countries, children with complex / special health care needs represent a diverse and growing population who present a "complex challenge" (McClune, 2009) to health care systems and to the health care professionals charged with providing high quality care. Definitions of this heterogenous group of children vary between different countries and these definitions are subject to change but include children with special health care needs, children with complex medical needs, children with complex health care needs; children with technological medical needs; children with life-limiting and life-threatening illness, including those requiring palliative and end-of-life care. There are numerous other nomenclatures. Also some definitions of this group of children are more specific than others, McPherson et al.'s (1998) broad definition, as stated on the American Academy of Pediatrics (AAP) website (http://www.medicalhomeinfo.org/how/care_delivery/cyshcn.aspx), provides an overview of the "characteristic held in common by children with a wide range of diagnoses":

> "those who have or are at increased risk for a chronic physical, development,
> behavioral, or emotional condition and who also require health and related services
> of a type or amount beyond that required by children generally"

In many countries such as Canada (Peter et al., 2007); Italy (Racca et al., 2011); England (Department of Health, 2011); USA (Wood et al., 2009) there is an increasing recognition of the shift from hospital-based to home-based care. Whilst the home-based care systems operating in different countries for children with special health care needs are diversely funded, managed and delivered, they are underpinned by broadly similar ideologies. For example, the concept of the Medical Home (Medical Home Initiatives for Children With Special Needs Project Advisory Committee, 2002; Council on Children With Disabilities, 2005) in the USA and Community Children's Nursing Services in the UK (Department of Health, 2011) are underpinned by concepts of family-centred care, partnership working, accessible, continuous and coordinated care. These

systems face similar challenges in their desire to promote effective partnership (Looman, O'Conner-Von, Ferski, & Hildenbrand, 2009), care-coordination (Wood et al., 2009; Cady, Finkelstein, & Kelly, 2009).

However, the shift to home based care is not without challenges for professionals and families alike. Most evidence has been generated around the needs of children with complex health care needs with little attention paid to the needs of families whose children require only short term (sometimes single episode) care.  In a study by Anderson, Riesch, Pridham, Lutz, & Becker, (2010) the promotion parent-child relationships is shown to be of importance and they also helped to mitigate some of the "pervasive and profoundly negative experiences" (Tong, Lowe, Sainsbury, & Craig, 2010 p555) that accompany the "dual role of parenting and medical caregiving" (Tong et al., 2010p552). Home based care often results in strain on the family, especially families who have a child with complex health care needs. Looman et al (2009) note the high financial burden carried by parents of children with complex health care needs and Kuster and Merkle (2004) note how the various physical, emotional and financial strains can impact of parents' emotional and physical health.  Blumberg and Carle (2009) also note that parents spending >/ 11 hours a week  providing or coordinating care had lower levels of well-being than families who were better supported.

Within the UK, Community Children's Nursing Services (CCNS) provide nursing and other care to children and young people (0-18 years) within their own homes and provide support to their families. Services encompass different nursing activities ranging from a single visit to the provision of continuing care to children with complex and / or highly technological health care needs (Department of Health, 2011). In 1997 the House of Commons Select Committee identified that "All children requiring nursing should have access to a community children's nursing service, staffed by qualified children's nurses supplemented by those in training, in whatever setting in the community that they are being nursed" (House of Commons Select Committee, 1997 p552). The need identified in 1997 still exists today as many children and their families still

do not have equitable access to CCNS(Department of Health, 2011). Indeed, services are characterised by diversity (Pontin & Lewis, 2009) in terms of service models, caseloads, size and skill mix of teams and funding streams. Families in some geographical areas are relatively well provided for whereas families only a few miles away may no access to a CCNS as such services tend to have developed in response to local demands, needs and drivers (Whiting, 2004; Maunder, 2007). The expectation now is that children who would have previously been cared for in specialist tertiary settings will be cared for at home (Kirk & Glendinning, 2004; Carter, 2000; Wang & Barnard, 2008; Myers, 2005; Lewis & Pontin, 2008; Royal College of Nursing, 2009). Despite the shift to home-based care there is relatively little research which demonstrates clear cost effectiveness (Parker et al., 2002; Cooper, Wheeler, Woolfenden, Boss, & Piper, 2006; Bagust, Haycox, Sartain, Maxwell, & Todd, 2002) with most results demonstrating that financial costs are broadly similar (although borne from different budgets) but that the satisfaction of children and families is higher when cared for at home (Parker et al., 2006).

The role of the CCN is a complex and challenging one requiring a depth and breadth of clinical experience coupled with an ability to work autonomously and make substantial and crucial decisions with the families (Myers, 2005; Carter, 2000). The complexity of CCNs workload and how they manage this is not well understood, (Parker et al., 2006; Pontin & Lewis, 2009)  neither is the impact of multi-agency working on the lives of children and their families (Watson, Townsley, & Abbott, 2002). Workload planning through the use of a workload model has been proposed as one strategy to enhance service provision (Lewis & Pontin, 2008; Pontin & Lewis, 2008). The need to build the capacity of the children's workforce, in particular in relation to community children's nursing, has also been clearly identified (Taylor, Sharland, & Whiting, 2008).

This study was commissioned as part of a UK government consultation on community services for children and their families to determine what was working well, for whom within CCNS and how best practices could be enhanced.

# Methodology and Methods

## Methodology.

An Appreciative Inquiry (AI) philosophy underpinned this qualitative study. Fundamental to AI is the desire to discover 'what works well' in organizations and systems and 'why it works well' (Cooperrider & Whitney, 1999; Liebling, Elliott, & Arnold, 2001). AI which has similarities to action research, lends itself well to a pragmatic and praxis based approach and, as such, it fits well with the study of health and social care settings (Carter, 2006). Unlike many research studies which start by identifying a research problem and then framing the perfect research question to solve the problem, AI adopts a different stance. AI facilitates research to be grounded in contemporary practice whilst encouraging the researchers and participants to take a future-oriented, collaborative and solution-oriented approach. This shift from a traditional, researcher-as-expert and problem-oriented, approach to one which is appreciative (solution-oriented and focused on what was working well) and generative (sharing best practice and new ideas for future working amongst and between the participants and researchers) is potentially a much more enabling and empowering approach to take to research. For these reasons an approach built on AI principles was deemed to be an entirely appropriate approach for fostering participatory engagement with children, families, professionals and stakeholders. The researchers hoped to generate more than data through their study, they hoped to stimulate alliances, dialogue and sharing of ideas.

Thus the team used an appreciative approach to the whole study including the constant reassurance that the expertise of all the participants was integral to the study, the way that research questions were framed, the way the workshops were run, the nature of the activities that were developed and the way that the analysis was undertaken.

Fundamental to AI is the focus on appreciative and generative working which we felt would foster participatory engagement with the children, families, professionals and other stakeholders.

### Aims.

The aims of the study were to elicit the perspectives on and experiences about CCNS in England in relation to the following three core questions:

1. What is working well in CCNS in England?

2. What could be improved to better meet the needs of children and families who require support in the community and what could be improved? and

3. What is the vision for CCNS?

### Methods.

The methods were chosen so as to enable equitable engagement with and between children, young people and adult participants. Whilst we felt that workshops would create an opportunity for a supportive sharing and exchange of ideas that families might enjoy, we acknowledged that some parents might find the logistics of attending a workshop challenging due to competing demands on their time. Therefore we developed methods and strategies to ensure that children and their families were able to contribute to the study without having to leave their homes (Coad, 2007). Our methods were chosen to encourage participants to interact, share and generate ideas with minimal direction from the research team. Our aim was always to facilitate the interactions and to 'follow the data'.

In order to ensure that the research remained consistently grounded, the research team also worked with two advisory groups: primarily through emails, texts and telephone calls at key points during the study (preparation, data analysis and report writing). One group consisted of children, young people and a parent and the second group was composed of leading practitioners

and researchers within the field of community children's nursing. The research team consisted of academic researchers and a parent researcher who contributed to all aspects of the study.

The study was undertaken in two linked phases (March-April 2009 and August-December 2009): these phases reflected the way that the study was commissioned by the Government. Across the two phases we undertook workshops, interviews (face-to-face and telephone) and e-contributions (blog and email). The three core questions created the framework for all methods of data collection.

### *Arts-based participatory appreciative workshops.*

Workshops were held in nine regional locations across England during Phases 1 and 2. Participants were invited to attend one of three 'flexible' sessions (morning, afternoon, late afternoon), which aimed to facilitate attendance by professionals and families during/after the working/school day. Each workshop was facilitated by one of the lead researchers and field notes were taken by a second researcher. ~~There were three main arts-based activities (Table 1) broadly linking to the three research questions.~~ The pragmatics of ensuring that children and young people with complex health care needs could attend the workshops meant that we booked accessible venues which had adequate facilities for plugging in supportive technology (e.g., suction machines, enteral feeding pumps) and that the venues were aware that oxygen cylinders and other equipment would be on the premises. Where a child required ongoing 'nursing' care, this was provided either by their parent(s) or by the health care workers who accompanied the child.

There were three main arts-based activities (Table 1) broadly linking to the three research questions. Each of these activities was developed by the research team (and steering group) to facilitate the generation of appreciative data in a friendly and supportive environment. To an extent the activities created a trigger to thinking, giving the individual participants a chance to reflect upon their experiences and then to share those experiences and ideas with fellow

participants in mixed groups where children, families  and professionals worked alongside each other. Whilst parts of each activity were fairly static  (sat at the table thinking about ideas and writing them down), there was also movement around the tables when people engaged in physically sorting, categorizing and ranking ideas. Also in Activities 1 and 3, people stood up and moved about as they placed the 'clouds' and 'direction signs' on charts. The lead researchers have found that movement in workshops is helpful, particularly when children are involved as it helps to break the session up and free up even more ideas.

Each group had at least two researchers engaged in facilitation.   Principles from nominal group technique were used, whereby the participants worked individually before democratically sharing ideas via a 'round-robin' with members of their group. This round-robin sharing meant that everyone regardless of whether they were a parent, a senior nurse, a child or a doctor took turns to speak knowing that their contribution would be listened to, documented and responded to. The activities described in Table 1 show the activities were broad enough to engage and stimulate children and adults to reflect on their experiences and share their ideas. So, for example in Activity 1, participants were asked to write down an example of something that had 'worked well' in relation to CCNS. The researchers rephrased the question to accommodate the cognitive abilities of the children and to reflect their particular experience. The children were encouraged to either write down their answers or to share the answer with a facilitator who would write it down for them. Some of the children chose to engage through drawing picture responses (e.g., a happy face, or a picture of playing at home with their cat).

Ideally the study would have been set up to facilitate the remote engagement of the children who were unable for whatever reason to attend the workshops. However, the team decided that remote methods (email, telephone interviews) were not an ideal means of engaging with children in this specific study.  However, it was available and had been ethically approved and we chose to use it on a case by case basis. The two young people who did participate by email and telephone were carefully supported throughout and had specifically requested that they participate remotely.

The workshops had been created to be a safe and supportive environment for children, young people (and adults), with extra staff available to talk, play and engage with any child who looked bored, concerned or in anyway distressed.

*Insert Table 1 about here please*

### E-contributions through blogging and emails.

In Phase 1 we offered potential participants the opportunity to blog via a study specific password-protected blog site. However, the level of protection deemed necessary to ensure the appropriate protection for study data meant that accessing the site was unwieldy and therefore a dedicated email address was set up in Phase 2 to facilitate the submission of e-contributions and the blog site was decommissioned. A guide was developed for those participants who wished to communicate through emails (see next section for further information).

### Interviews

Semi-structured interviews were undertaken with those participants who were unable to attend the workshops or who felt more comfortable sharing their perspectives more privately than in a workshop. One-to-one telephone interviews (Phases 1 and 2) and face-to-face interviews (primarily in the family home during Phase 2) were undertaken. The interviews also provided opportunity for participation for those participants who did not have easy access to the internet.

A guide was developed to help structure the telephone interviews and email communications. In essence the guide was structured around the three main study questions: what was working well; what could be improved; and what was the vision for the future. Prompts were available to the interviewer/emailer to elicit additional information. The questions and prompts were all framed in appreciative language to help facilitate the generation and sharing of appreciative responses, for example, 'How do **you** know things are working well?', 'Please give me a specific example of a positive experience with the CCNS caring for your child', 'If you had

a magic wand, what would you change about the CCNS?', and 'What achievement have you felt most proud of in your work as a member of a CCNS?'

The interviews were undertaken by a member of the core research team (primarily BC, JC, LB, TG, AM). The interviews were arranged to occur as a mutually agreeable time (and place when they were face-to-face) and lasted between 20-90 minutes.

### Ethics review.

The proposal, including all supporting documentation, was submitted for and gained full ethics review through the relevant ethics committees at the University of Central Lancashire, Preston and University of the West of England, Bristol.

### Recruitment of participants.

Two core populations of participants were eligible for inclusion in the study: (a) service users - children, young people and their families; and (b) providers - professionals and stakeholders.

The target population for service users consisted of children and young people (and their families) who had or were receiving nursing care from a CCNS in England and who were willing to participate in the study. The study aimed to engage with families whose experience ranged from single episodes of acute care (e.g., removal of sutures post-discharge from hospital) through to children requiring ongoing and complex health care support (e.g., palliative care, long term ventilation, complex medication regimes). Families needed to be able to converse in basic English, support was available to families where literacy was a challenge and to those who had learning difficulties.

Our target population of providers consisted of people whose role brought them into either direct or indirect contact with the work of the CCNS, this basically included: (a) professionals (e.g., nurses working in CCNSs, schools, hospices; paediatricians, commissioners, social

workers, teachers); and (b) other stakeholders (e.g., people working in child/family-related charities).

The researchers directly contacted around 650 people inviting them by email, letter or telephone to participate in the study. Our primary contacts for snowballing were the team leaders for the CCNS, professionals leads for children's services , academic leads for children's nursing education, leads for school nursing services, directors of relevant children's charities and through our expert member steering group. Snowballing occurred through our primary contacts either forwarding our invitation email to colleagues, staff and people they thought would be interested or replying to our email with a list of names and email addresses/telephone numbers they suggested should be contacted. Due to previous work, the lead researchers had an established presence and sound links within the field of community children's nursing. The researchers had no direct contact with potential families until the study had been introduced to them by one of our primary contacts. The primary contacts who linked to the families were either the professionals who worked with them or via contacts the researchers had with the leads in parent-led, user groups who contacted their members about the study.

Potential participants were invited through snowballing via a wide range of methods including professional networks, contact with community children's nurses; the Royal College of Nursing; charities such as Special Kids in the UK, WellChild, Jessie May Trust, Lifetime, PALS leads in acute settings; and direct contacts.

## Data Analysis

The data from both phases were analysed using thematic analysis in line with the approach suggested by Attride-Stirling (2001). However, the three and guided by the core questions (what was working well, what could be improved, what was the vision for the future) were used as default global themes with the data being analysed and themes developed within these global themes (see Table 2). All data (interviews, blogs, emails, workshop discussions, arts based

materials, field notes and notes from the advisory group meetings) from each of the nine areas where the workshop were held were collated and analysed by the research team members who initially identified preliminary codes and areas of interest and importance. These tentative codes were discussed until consensus was achieved and these consensus codes then guided subsequent analysis. These codes were then collapsed into main themes and sub-themes. The themes and sub themes generated by analysis of Phase 1 data were used to guide analysis in Phase 2.  Although key features were noted by the research team for each geographical area, the data are not comparatively reported. Neither were the data specifically compared within families or between children/young people and adults as the aim of the study focused more on appreciatively developing a consensus of understanding. However, children did not always agree with their parents or with each other or with other adults' perspectives. They brought their own individual understandings to the groups. For example, an adolescent girl saw no problem in the male CCN continuing to provide intimate care and did not want the nurse who she trusted and knew well replaced by a female nurse with whom she did not have an established and reciprocal trusting relationship.

*Insert Table 2 about here please*

## Findings

In total 214 people participated across the two phases. Of this total, 82 families (primarily parents / carers and some grandparents), 27 children and 105 professionals and other stakeholders contributed (Table 23).  Although most participants had expressed a preference for attending the workshop as they felt this would be the most engaging way of participating as it would give them the benefit of face-to-face contact and opportunities to network with other families and professionals, this was not always possible. Attendance at tThe workshops were the preferred option for most participants although attendance at these was sometimes affected by external circumstances such as the distance to the venue, the weather, the swine flu epidemic and also

changes in the child's health meaning that a planned attendance was not possible. Thus, some participants who had planned to attend a workshop had no option but to participate by telephone interview or email. Engagement with the families was fairly evenly spread between the different modes: workshops (n=26); e-contributions (n=20) and interview (n=36). Fewer professionals engaged in interviews (n=4) but the remaining professionals were evenly divided between attending workshops (n=51) and e-contributions (n=50).

The findings are presented within three sections: what works well?; what could work better?; and visions and aspirations for the future.

*Insert Table 2 3 about here please*

## What is workings well?

### *Effective communication.*

The best services, regardless of the service delivery model (Table 34) were those which were underpinned by highly effective and collaborative communication between the CCNs, families, health and other care sectors. This resulted in the CCNs being able to act as an informed and trusted link between the family and the range of agencies from whom they gained support (e.g., pharmacies, general practitioners, acute and tertiary health care, the child's school and social care agencies). They acted as a "central intelligence" through their knowledge of how other services and agencies worked, what their priorities were and how best to liaise with them. Services which worked well had an established presence and where CCNs were "known" within different settings (e.g., attending discharge planning meetings within the acute care setting or having a caseload within the local paediatric A&E department). This was often supported by using information technology systems to improve working practices (e.g., gaining "advance notice" for discharge home or for planned hospital admissions for elective surgery.

### *Leadership.*

Robust nursing leadership of CCN teams ( e.g., by a community children's nurse lead or consultant nurse) was strongly evident in services which were described as 'working well' and this helped team members to negotiate the uncertainty and challenge that occurred as a result of working across traditional professional divides. Leadership ensured a strong sense of team cohesion, engagement with the "bigger picture of what was happening regionally and nationally" and enabled team members to be creative in their practice. Strong and engaged nursing leadership meant that issues and knowledge were shared, challenges addressed. Clinical supervision created a secure and supportive environment in which to work. CCNs, especially those who had undertaken post-registration children's community nursing education, were able to drive forward change, respond quickly and effectively to the dynamic needs of children and families in their care. Best practice arose from teams with an appropriate skill mix in which there were sufficient experienced, qualified CCNs to work expertly, autonomously and directly with the children as well as provide guidance to less qualified staff. Families valued both the "level of skills" and "knowledge" of the qualified children's nurses as well as their pragmatic, family-oriented "common sense" approach to decision making which often made "something big and daunting into something manageable".

### *Enabling families to be at home.*

Services which were deemed to 'work well' were those which were centred on the needs of the children and their families and which enabled care, wherever possible, to be provided at home. This often reduced the need for hospital admissions as one parent who had conscientiously maintained a diary of her daughter's admissions to hospital noted:

*"In 2007/8 she had 14 hospital admissions lasting 1 day to 5 days. Since the CCN came during 2009 she has had only two"*

Some families benefitted from a CCNS that had an active presence in the acute setting, (e.g., where staff from the CCNS worked shifts in the Accident and Emergency Unit they were able to reduce the number of admissions to hospital by providing prompt support and follow-up to children who did not need admission but did require nursing support). As one professional explained: "We're well known in the hospital – it's great for liaison".

Families who had previously struggled to manage without the support of a CCNS experienced substantive and positive changes as it opened up opportunities to "make choices as a family". Home was the place where the children and their families were "happiest" and this sense of happiness involved feeling relaxed, "more comfortable", and being part of familiar and expected routines which were part of "normal life". Apart from crises, and occasionally even during crises, home was the simply the "best place" for the sick child and their family to be, as one mother described:

> "I think the best thing is that you don't have to worry about taking her to hospital or
> the GP surgery, where she could catch more infections. All in all this service keeps
> my child out of hospital and at home with me".

Services which were working well, integrated care flexibly into families' lives, reducing disruption and helping the children and their families to sustain active decision making. Despite the inevitable intrusion of technology and professional support into their homes, many parents and their children craved for the relative calm that care at home engendered, as one mother explained:

> "He is happier at home, he gets better quicker at home. If he's asleep, I can sleep; if
> he's in hospital then I can't [sleep]".

Children valued how the nurses "fitted into [my] family" , were supportive and fitted care in around the child's activities:

*"Well the nurse came and went and I went back to watching the TV. And I could sleep at home. I couldn't sleep in the hospital. She [the nurse] came two times I think to my house……………She came the second time and took my stitches out ......right here [shows chest] ………..I liked it at home best of all. I could watch TV and play on my gameboy……She gave me a star for being good and having a clean cut where my operation was".*

### *Relationships and working in partnership.*

Services worked well when relationships, based on mutual trust and respect, were developed between the CCNs and the families and where the CCNs were able to work with the families to find solutions to aspects of the child's care that was causing worry. Central to this support was the tailored and context specific education, training and information that the CCNs were able to deliver "in a way I can understand" to the children and their families in their homes. This engendered greater independence, enhanced confidence and competence. The resulting sense of mastery over medications, interventions and technology meant that care at home – both for short and long-term support -could be sustained more easily and that children and families felt more secure in their ability to cope. Services which were underpinned by "mutual valuing" and "partnership working" established strong relationships with families. One of the mothers explained how the intervention of the CCN had helped her to "sort out" the panic she was in over her child's medication regime. She explained:

*She [CCN] sorted out medicines with me. I was getting in right muddle and went to the GP twice and to the Practice Nurse once and I could see the receptionists raising their eyebrows when I said "I don't understand this!" Then the CCN came and helped me…made me a chart and this helped loads…when and what had to be taken and when to collect next batch. Really dead obvious… but not at first to me*

Although by no means an easy aspect of the role, services which worked well were expert in planning and delivering packages of care for the children and their families based on their shared and cumulative experience which meant that they were able to be "actively working towards developing new pathways to improve procedures and they have been instrumental in improving care for the children" (CCN).

## What could work better?

### *Lack of services and the pressure to cope.*

Parents, children and stakeholders were clear about the positive benefits gained from accessing an effective CCNS that had experience and expertise in supporting families "living life with a child with complex medical needs". Commissioning did not always work well and was acknowledged as problematic even by the commissioners who contributed to the study. "Inconsistency" in decision making, a lack of a real appreciation of "what is needed" and a failure to see the "priority of children's services" were all concerns that meant that children's care at home could be compromised by ineffective commissioning. One factor that hindered robust commissioning of services was the perceived lack of a nationally recognised relevant "must do or must provide" (CCN) list of services for children and young people linked to the 'Every Child Matters'(HM Government, 2004) outcomes.

Families in areas of the country, especially rural areas, where there was either no service or service provision was "patchy at best", felt that there were "massive expectations" of them and they were under "massive pressure" to provide care for their children at home without adequate support and guidance. The professionals were well aware of these pressures and, as one professional explained, :

> *"when a service is restricted to 5 days a week, staff are working on good will and [they are] going in on extra days due to [their] commitments to the family"*

One mother who described managing with insufficient "nursing care at home" to support her child with complex needs, explained that even without this 'insufficient' care she and her family could not "live their lives without being pushed to their coping limits". Some families reported feeling "marginalized" and "abandoned". It was clear from the experiences of families and professionals that when formal care packages "fell over" due to staff sickness, parents were expected to "pick up the slack". One mother who contributed by email at three in the morning, explained how she was covering the night-time care of her ventilated child for the third night running as the carers trained to care for her child's particular needs were "off sick with flu" and there was no other cover available. The following two nights this mother sent emails to say that she was still covering her child's night-time care and that she was tired, frightened and angry: similar stories were shared in nearly all of the workshops. Like other families, inadequate cover and support from appropriately trained carers added to the parents' physical and emotional stress. Sometimes this resulted in the decision for a child to be admitted onto the "ward for overnight care" although as one mother explained:

> "if the ward's busy or if it has D&V [diarrhoea and vomiting] and therefore it's not appropriate for the child to be admitted, then the child can't be admitted and has to stay at home".

In these situations the parents are the last line of defence. They simply have to continue to care for their child regardless of how tired, stressed or ill they are themselves. Parents have to assume both the responsibility for being their child's parent as well as a skilled carer and provider of technological support and medication. As one participant explained:

> "It shouldn't be considered reasonable/acceptable for a parent to be expected to do free slave labour 24/7 - not good enough to treat families this way."

These situations of extreme stress were extremely challenging but even when the situation was less "desperate", parents sometimes felt stressed when new carers were rostered to provide care.

The inequity and gaps in CCNS across the country meant that for some families, family life was regularly and unnecessarily disrupted by their child's needs (e.g. for intravenous antibiotics). One family explained the choice was either to "have to have two weeks in hospital or [drive] 100 miles a day". This resulted in constant and additional disruption to the child's school attendance, his relationships with school friends and other financial pressures on the family. Some families spoke of having "lost hope" that things would change for the better whilst others hoped that the future would bring better services.

### *Standard working hours.*

Generally, small teams (those with fewer than three members of staff) were only able to deliver care in 'standard' working hours (around 8 hours a day for five days a week). This model of working had little fit with the needs of children and their families and it compressed access to and the delivery of optimum nursing care. Professional participants explained that tThe 'standard' hours led to "restrictive working" as the CCN could not always visit "when medications are due/when support needed" resulting in disruption to the "parents/child lifestyle" making it more difficult to engage with fathers who were "typically at work". CCNs knew that "trouble" typically flared and help was needed at "5pm on a Friday" and when "access to services is limited". Many CCNs working in small teams often felt isolated and under pressure with some reporting "an overwhelming caseload and not enough hours to care for children effectively" (Professional) although staffing pressures were also evident in the larger teams. Staffing pressures were of particular concern for end-of-life care where the CCNs wanted to provide optimal care to a family. However, this often had to be provided by teams shifting resources from more routine aspects of caseload work to free up staffing hours to provide care to families whose child was dying. However, as one professional explained:

> *"if children want to die at home they have to die Monday to Friday between nine and five. But if the family wants their child to die at home then I [CCN] will pay for it, I find the money from somewhere."*

### *Equipment and resources.*

Equipment was a fairly widespread concern ranging from not having enough "disposables" (e.g., syringes, air cylinders) to substantial delays in the delivery of equipment such as walking frames and wheelchairs and the need for "a set pathway so all families are entitled to the same" (Professional). Worries about equipment added to the challenges that parents faced and inevitably meant they had "to battle and battle" to get heard. Supply services were often insufficiently flexible and unable to respond to the dynamic changes in a child's condition which could mean that children's needs were often "out of sync" with routine ordering practices. Children with complex, long term needs were particularly vulnerable to poor supply chains or to problems arising from a lack of equipment. As one mother explained "if I haven't got the supplies my daughter has to go into hospital". Another family described being told they would "have to 'make do' [without supplies]" but explained that "they [suppliers] just don't understand that we *can't* just make do".

### *Quagmires of communication.*

Communication was cause for concern in some settings. The most substantive communication issue related to discharge home from hospital where the inadequacies in the level of reciprocal communication between all stakeholders resulted in either delayed discharge due to care packages not being in place in good time or in families feeling "isolated and frightened" when they were discharged home. Another issue related to communication and the differences in the discourse and language of different agencies (health, education, social care and the third sector) as some professionals were described as "speaking different languages and using different tools" and the "quagmire" that divides "nursing and social care needs". The third major issue was associated with databases and the absence of effective databases to support information sharing or databases which acted in a "Big Brother capacity to monitor work" (professional) but did not help expedite the role.

**Visions for the future of community children's nursing.**

*Parents supported to be parents not carers.*

Ideally future CCNS would facilitate care at home that would enable parents to be "parents" rather than have their parenting role subsumed by the need to be a 'professional' carer. Such services would be centred on parental and children's choices and decision making which would reflect those things of importance to the families and which promoted independence. As a matter of course, the wellbeing of all family members would be taken into consideration when designing care packages and determining service delivery.

The vision for future CCNS were that they should share best practice and adopt common systems (e.g., documentation, information technology and training materials) with other services and agencies. Additionally they would encompass an integrated approach with a clear responsibility for meeting the needs of children and their families (through agreed national minimum service standards) which was not disrupted by geographical boundaries Five elements – equity, access, flexibility, sustainability and communication – were viewed as cornerstones of an effective service.

Equity and accessibility meant that families would be able to receive high quality services regardless of their geographical location or need. This would be based on robust and insightful commissioning of CCNS which would resource nursing care within children's homes and respite services, as required, and which could be intelligently managed at local level. Whilst important for all children and families, equitable service provision was seen to be particularly important for end-of-life care.

Flexibility in service provision means that families could feel secure in the knowledge that the service had the capacity to respond to the changing needs of their child with an appropriately educated, trained and skilled workforce. This was particularly important in relation to end of life

care where a key vision was that no child should have to die in a place that was not their (family's) preferred place of death.

Sustainability of service provision meant that the CCNS service itself would be seen as a priority element in meeting families' needs and resources (technology, equipment and consumables) would be readily available to help support the optimal care of children. Sustainability would also be evident in the reduction of hospital admissions through enhanced home care and support. Care packages, rather than being seen as being time-limited, should be life-long and be delivered by competent trained carers and managed by qualified community children's nurses. Another aspect of sustainability was the need to invest in the workforce through education, training and increasing capacity as well as investing in the future leaders of the CCN workforce.

## Discussion

The findings of the study clearly add to the global evidence that home-based care is important to children and their families. What makes the findings from this study unique was its participatory and appreciative focus and the fact that the lens of the inquiry was both solution- and future-oriented. The collaborative approach means that the findings arise from a consensus of understanding from children, young people, professionals and other stakeholders. The strength of this consensus has led to Indeed many of the findings from this study have been being incorporated into the most recent government legislation in England on CCNS (Department of Health, 2011). Services which worked well promoted parent-child relationships which have been shown to be of importance in other studies (Anderson, Riesch, Pridham, Lutz, & Becker, 2010) and they also helped to mediate some of the "pervasive and profoundly negative experiences" (Tong, Lowe, Sainsbury, & Craig, 2010 p555) that accompany the "dual role of parenting and medical caregiving" (Tong et al., 2010p552). This study is also unique in that it looked across different types of CCNS service and across a broad range of geographical settings in England

representing different health care economies. Regardless of the type of service, geographical location or the nature of the caseload there was a clear consensus on what worked, where improvements could occur and what people wanted for the future of the service.

What became clear from the findings of this study was how central it was to all parties that bBeing able to provide care at home meant that families' lives became "more normal" and basic activities such as sleeping and meal times were easier to manage. Continuity of care, as in other studies, (Pontin & Lewis, 2009) was valued by both families and CCNs (see also Pontin & Lewis, 2009) and this study emphasized the importance of . This continuity of care delivered and coordinated by expert and knowledgeable practitioners. When these conditions were in place meant that the services worked well and which were working well were able to reduce the disruption to the lives of children's and their families' lives. Similar emphasis about the value of care coordination is seen in research from the USA (Wood et al., 2009; Graham, Fleegler, & Robinson, 2007) and in Canada (Peter et al., 2007). Efficient and effective services provided the professional support that families needed to help them sustain and maintain family life as advocated within the 'medical home' system within the USA.

Being cared for at home meant that children's schooling was far less disrupted and this impacted on children's friendships being more able to be sustained and families were able to spend more time with each other. Parents reported that their jobs were less at risk as they did not have to make complex arrangements to take time off work for hospital visits. Similar findings from Looman et al (2009) also reflect the high financial burden carried by parents of children with complex health care needs. Blumberg and Carle (2009) notes that parents spending >/ 11 hours a week providing or coordinating care had lower levels of well-being than families wwho were better supported. Kuster and Merkle (2004) note how the various physical, emotional and financial strains can impact of parents' emotional and physical health. There was also some evidence from the parents that support from the CCNS mean that children experienced reduced periods of hospitalization as also seen in work by in this study (as found in other studies such as

Wood et al. (2009) ~~that support from professionals reduced periods of hospitalisation~~. The support from the CCNS ~~All of these impacts~~ helped to reduce the stressors that are an inevitable accompaniment to providing care to a child, regardless of whether the child has a short-term or ongoing need for support.

The wealth of evidence collected during this study reflects a positive, ~~and~~ reciprocal but by no means passive regard by CCNs and parents for each other's work, skills, expertise and in-depth knowledge. The ~~: the~~ CCNs very clearly framed their role as professional support and ~~acknowledging~~ acknowledged ~~their role in supporting~~ the parents ~~and carers who provide~~ as the experts in relation to their own children~~continuous and expert care~~. This mutual valuing led to strong partnership working which has been seen in other studies to be fundamentally important to services working well (Runciman & McIntosh, 2003; Peter et al., 2007) and whose findings highlight the centrality of partnership in the community setting to service delivery(McIntosh & Runciman, 2008). These qualities of mutual valuing are intrinsic to values consistent with human-centred nursing (Pontin, 1999; ~~) and reported in other studies of CCNs (~~Pontin & Lewis, 2009). The findings also demonstrate how the community context lends itself to the establishment of reciprocal trusting relationships as advocated by other writers (McKlindon~~Don~~ & Schlucter, 2004). These relationships are based on trust, respect, and a shared understanding of the children's health, developmental and psycho-social-emotional needs and mean that children can receive individualised and tailored support (McKlind~~Don~~ & Schlucter, 2004). McIntosh and Runciman (McIntosh & Runciman, 2008 p725) note that whilst strong partnership working can be "very productive in ensuring seamless, effective, high quality care" [the]..."complex web of relationships and local knowledge are not quickly or easily developed".

Regardless of whether or not children had ongoing and complex health care needs or if they only required short term, relatively minor intervention from a CCN the message was the same: CCNs make a substantive difference to families' ability to provide 'nursing' care to their children (Whiting, 2004). Access to CCNs means that families are assured of expert assessment of their

children's needs and expert (and pragmatic) information, advice, and decision making that reflects the physical, emotional and social capacity to provide care.

Participants in this study almost always preferred home-based care to hospital-based care, particularly when the children required ongoing care. Children and families felt more empowered within their own homes and more able to make decisions and control the routines associated with illness such as medication or other treatment interventions. It was clear from the feedback from the children in the study that when working well these services actively engaged with children and sought their perspectives and avoided the problems that arise from objectifying and pathologising children which have been reported elsewhere in the literature (Case, 2000).

~~The role of the CCN is a complex and challenging one requiring a depth and breadth of clinical experience coupled with an ability to work autonomously and make substantial and crucial decisions with the families (Myers, 2005; Carter, 2000).~~ CCNs and service delivery thrived most vigorously where the teams were sufficiently large to be flexible and able to respond quickly to the changing demands of the caseload. _This finding is important as little previous evidence exists from across a range of different services to suggest that this is so. Previously, services have been established in a somewhat ad hoc manner, responding to local needs but unable to respond adequately to the wider picture._

All stakeholders ~~in both phases~~ highlighted that service delivery was more fragile and highly dependent on individuals and their commitment where CCNs were in rural areas, working alone or in very small or isolated teams, where very small teams face the challenges of developing strong interdisciplinary and transdisciplinary practices. Transdisciplinary working has been proposed to offer the best benefits for children and families (Watson et al., 2002) as the aim is for the different disciplines to work together holistically where the service delivery focus is on the child and their family. Clear strategic support, strong leadership and a well established service meant that the drive and energy of individuals could be harnessed into productive activities such

as developing nurse led clinics rather than 'marketing' the service. Autonomy and freedom to act, whilst supported by sound leadership, gave CCNs in this study the chance to 'push professional boundaries' and become what has been described as being a "hybrid professional" (Atkinson, Doherty, & Kinder, 2005) whose knowledge and personal experience of other services endows them with an understanding of the structures, processes and discourses within these other services and agencies. In our study we described this as a "central intelligence". Similar findings are evident throughout the global literature where coordination is seen as an essential element (Cady et al., 2009; Carter & Thomas, 2011) of reducing delayed and foregone care (Wood et al., 2009).

Services and individuals struggled when local financial arrangements were tenuous and the service was not apparently valued at a strategic level. Clearly the future is one which requires a workforce with greater capacity to deliver care in children's homes and to promote children reaching their full potential. This requires commissioners of services and CCNs to work more closely together with families to ensure that future services are built around the needs of children and their families. Fundamentally this requires the government and commissioners of services to recognise that caring for a child at home is a 24 hour a day commitment and that children's needs often become more acute outside of limited service hours. Where CCNS are only available for eight hours a day (9am-5pm), the remaining sixteen hours are a long time for a family to manage on their own. Lack of cover at weekends and bank holidays leaves parents and families feeling 'professionally' marooned and isolated. Extending service hours and the number of CCNs to provide cover is fundamental to ensuring that families have adequate support to care for their children. In a recent report, commissioned by and submitted to the Department of Health, the most common pattern of service provision is 'office hours' (9am-5pm, Monday to Friday) or 'extended office hours' (some evening working and cover at weekends); these teams aspired to extend their hours of service to provide more comprehensive cover (Carter, Cummings, & Anderson, 2011).

Not every family receiving care from a CCNS had a completely positive story to share. Some families experienced fragmented care or problems with the service they received. All of the services faced the ~~same sorts of~~ challenges similar to those reported elsewhere ~~in the literature (Wood et al., 2009)~~ in relation to multi-agency working (Wood et al., 2009) including those arising from resources, roles and responsibilities, competing priorities, organisational cultures and management issues (Atkinson et al., 2005). For many families, problems with the supplies of vital equipment added to the stress they experienced and this was often a source of considerable conflict and anger. 'Battles' for equipment ranged from ones relating to getting the right mobility aids for their children to getting sufficient syringes to facilitate tube feeding or sufficient nappies to cope with a child's diarrhoea. However, even in such circumstances, the CCNs, like their counterparts in other global settings (Wood et al., 2009) often acted in an advocacy role and helped to find a reasonable solution. Where families reported being failed or frustrated by community services, this often reflected a service that was isolated, under-funded, unsupported and lacking in leadership. The development of a more user-led service would do much to ensure that CCNS genuinely understood what is of importance to children and their families.

This study highlighted that all children and their families deserve access to a service that not only meets their health care needs but which does so in a way which allows the family the space and the support to be a family. It is positive to see that the document 'NHS at Home: Community Children's Nursing Services' (Department of Health, 2011), appears to be supporting the drive to care at home for children to allow them to reach their full potential.

Reference List

Anderson, L. S., Riesch, S. K., Pridham, K. A., Lutz, K. F., & Becker, P. T. (2010). Furthering the

Understanding of Parent-Child Relationships: A Nursing Scholarship Review Series. Part 4:

Parent-Child Relationships at Risk. *Journal for Specialists in Pediatric Nursing, 15,* 111-134.

Atkinson, M., Doherty, P., & Kinder, K. (2005). multi-agency working: models, challenges and key

factors for success. *Journal of Early Childhood Research, 3,* 7.

Attride-Stirling, J. (2001). Thematic networks: an analytic tool for qualitative research. *Qualitative*

*Research, 1,* 385-405.

Bagust, A., Haycox, A., Sartain, S. A., Maxwell, M. J., & Todd, P. (2002). Economic evaluation of an

acute paediatric hospital at home clinical trial. *Archives of Disease in Childhood, 87,* 489-492.

Blumberg, S. J. & Carle, A. C. (2009). The Well-Being of the Health Care Environment for CSHCN

and Their Families: A Latent Variable Approach. *Pediatrics, 124,* S361-S367.

Cady, R., Finkelstein, S., & Kelly, A. (2009). A telehealth nursing intervention reduces

hospitalizations in children with complex health conditions. *Journal of Telemedicine and*

*Telecare, 15,* 317-320.

Carter, B. (2000). Ways of working: CCNs and chronic illness. *J Child Health Care, 4,* 66-72.

Carter, B. & Thomas, M. (2011). Key Working for Families with Young Disabled Children. *Nursing*

*Research and Practice.*.

Carter, B. (2006). 'One expertise among many'-- working appreciatively to make miracles instead of

finding problems: Using appreciative inquiry as a way of reframing research. *Journal of*

*Research in Nursing, 11,* 48-63.

Carter, B., Cummings, J., & Anderson, C. (2011). *Community Children's Nursing Services (CCNS) in England: Scoping services and identifying core training needs in relation to caring for children and young people requiring long term ventilation (LTV).* Report submitted to the Department of Health, London.

Case, S. (2000). Refocusing on the parent: what are the social issues of concern for parents of disabled children? *Disability & Society, 15,* 271-292.

Coad, J. (2007). Using art-based techniques in engaging children and young people in health care consultations and/or research. *Journal of Research in Nursing, 12,* 487-497.

Cooper, C., Wheeler, D. M., Woolfenden, S. R., Boss, T., & Piper, S. (2006). Specialist home-based nursing services for children with acute and chronic illnesses. *Cochrane database of systematic reviews (Online),* CD004383.

Cooperrider, D. L. & Whitney, D. (1999). Appreciative Inquiry: a positive revolution in change. In P.Holman & T. Devane (Eds.), *The Change Handbook: Group Methods for Shaping the Futre* (pp. 245-261). San Francisco: Berrett-Koehler Publishers, Inc.

Council on Children With Disabilities (2005). Care Coordination in the Medical Home: Integrating Health and Related Systems of Care for Children With Special Health Care Needs. *Pediatrics, 116,* 1238-1244.

Department of Health (2011). *NHS at Home: Community Children's Nursing Services* COI, Department of Health.

Graham, R. J., Fleegler, E. W., & Robinson, W. M. (2007). Chronic Ventilator Need in the Community: A 2005 Pediatric Census of Massachusetts. *Pediatrics, 119,* e1280-e1287.

HM Government (2004). *Every Child Matters: Change for Children.* (Rep. No. DfES/1081/2004). Nottingham: DfES Publications.

House of Commons Select Committee (1997). *Health Services for Children and Young People in the Community: Home and School. Third Report.* London: The Stationary Office.

Kirk, S. & Glendinning, C. (2004). Developing services to support parents caring for a technology-dependent child at home. *Child: Care, Health and Development, 30,* 209-218.

Kirk, S., Glendinning, C., & Callery, P. (2005). Parent or nurse? The experience of being the parent of a technology-dependent child. *Journal Of Advanced Nursing, 51,* 456-464.

Kuster, P. A. & Merkle, C. J. (2004). Caregiving stress, immune function, and health: implications for research with parents of medically fragile children. *Issues Compr.Pediatr Nurs, 27,* 257-276.

Lewis, M. & Pontin, D. (2008). Caseload management in community children's nursing. *Paediatric nursing, 20,* 18-22.

Liebling, A., Elliott, C., & Arnold, H. (2001). Transforming the Prison: Romantic Optimism or Appreciative Realism? *Criminology and Criminal Justice, 1,* 161-180.

Looman, W. S., O'Conner-Von, S. K., Ferski, G. J., & Hildenbrand, D. A. (2009). Financial and employment problems in families of children with special health care needs: implications for research and practice. *J Pediatr Health Care, 23,* 117-125.

Maunder, E. Z. (2007). Community children's nursing services in Wales: will the NSF make a difference? *PAEDIATR NURS, 19,* 22-24.

McClune, A. J. (2009). A medical home for children with special health care needs in rural locations. *Online Journal of Rural Nursing and Health Care, 9,* 45-51.

McIntosh, J. & Runciman, P. (2008). Exploring the role of partnership in the home care of children with special health needs: Qualitative findings from two service evaluations. *International Journal of Nursing Studies, 45,* 714-726.

McKlindon, D. D. & Schlucter, J. (2004). Parent and nurse partnership model for teaching therapeutic relationships. *Pediatric Nursing, 30,* 418-420.

McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P. W. et al. (1998). A New Definition of Children With Special Health Care Needs. *Pediatrics, 102,* 137-139.

Medical Home Initiatives for Children With Special Needs Project Advisory Committee (2002). The Medical Home. *Pediatrics, 110,* 184-186.

Myers, J. (2005). Community children's nursing services in the 21st century. *Paediatric nursing, 17,* 31-34.

Parker, G., Bhakta, P., Lovett, C. A., Paisley, S., Olsen, R., Turner, D. et al. (2002). A systematic review of the costs and effectiveness of different models of paediatric home care. *Health Technology Assessment (Winchester, England), 6,* iii-108.

Parker, G., Bhakta, P., Lovett, C., Olsen, R., Paisley, S., & Turner, D. (2006). Paediatric home care: a systematic review of randomized trials on costs and effectiveness. *Journal of Health Services Research & Policy, 11,* 110-119.

Peter, E., Spalding, K., Kenny, N., Conrad, P., McKeever, P., & Macfarlane, A. (2007). Neither seen nor heard: Children and homecare policy in Canada. *Social Science & Medicine, 64,* 1624-1635.

Pontin, D. & Lewis, M. (2008). Managing the caseload: A qualitative action research study exploring how community children's nurses deliver services to children living with life-limiting, life-threatening, and chronic conditions. *Journal for Specialists in Pediatric Nursing, 13,* 26-35.

Pontin, D. & Lewis, M. (2009). Maintaining the continuity of care in community children's nursing caseloads in a service for children with life-limiting, life-threatening or chronic health conditions: a qualitative analysis. *Journal of Clinical Nursing, 18,* 1199-1206.

Pontin, D. (1999). Primary nursing: a mode of care or a philosophy of nursing? *Journal Of Advanced Nursing, 29,* 584-591.

Racca, F., Berta, G., Sequi, M., Bignamini, E., Capello, E., Cutrera, R. et al. (2011). Long-term home ventilation of children in Italy: A national survey. *Pediatric Pulmonology, 46,* 566-572.

Royal College of Nursing (2009). *A Position Statement: A Child's Right to Care at Home* London: Royal College of Nursing.

Runciman, P. & McIntosh, J. (2003). Evaluation of the PATCH nursing service: partnership and training supporting children with complex needs at home. *Primary Health Care Research & Development (Sage Publications, Ltd.), 4,* 307-318.

Taylor, I., Sharland, E., & Whiting, R. (2008). Building capacity for the children's workforce: findings from the knowledge review of the higher education response. *Learning in Health and Social Care, 7,* 184-197.

Tong, A., Lowe, A., Sainsbury, P., & Craig, J. C. (2010). Parental perspectives on caring for a child with chronic kidney disease: an in-depth interview study. *Child: Care, Health and Development, 36,* 549-557.

Wang, K. W. K. & Barnard, A. (2008). Caregivers' Experiences at Home With a Ventilator-Dependent Child. *Qualitative Health Research, 18,* 501-508.

Watson, D., Townsley, R., & Abbott, D. (2002). Exploring multi-agency working in services to disabled children with complex healthcare needs and their families. *Journal of Clinical Nursing, 11,* 367-375.

Whiting, M. (2004). The future of community children's nursing. *Archives of Disease in Childhood, 89,* 987-988.

Wood, D., Winterbauer, N., Sloyer, P., Jobli, E., Hou, T., McCaskill, Q. et al. (2009). A longitudinal study of a pediatric practice-based versus an agency-based model of care coordination for children and youth with special health care needs. *Maternal & Child Health Journal, 13,* 667-676.

Wood, D. L., McCaskill, Q. E., Winterbauer, N., Jobli, E., Hou, T., Wludyka, P. S. et al. (2009). A multi-method assessment of satisfaction with services in the medical home by parents of children and youth with special health care needs (CYSHCN). *Maternal & Child Health Journal, 13,* 5-17.

Wood, D., Winterbauer, N., Sloyer, P., Jobli, E., Hou, T., McCaskill, Q. et al. (2009). A longitudinal study of a pediatric practice-based versus an agency-based model of care coordination for children and youth with special health care needs. *Maternal and Child Health Journal, 13,* 667-676.

Table 1: Activities used within the workshops~~study~~

Table 2: Breakdown of participants across both phases

Table 3: Global and sub-themes

Table ~~3~~4: Categories of service