Community Children's Nursing in England

Research Team and Co-authors

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Acknowledgements

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Index

Introduction

Community Children's Nursing represents a diverse and dynamic approach to providing care to children within their own homes and support to their families. The services provided encompass a range of different activities including everything from continuing care to children and families with complex health care needs, to those children who need high levels of technological care and those who require a single visit to remove sutures.

The Community Children's Nurse's role encompasses education, training, emotional support, and expert clinical care requiring high order cognitive skills in relation to decision making, problem solving and solution finding. The diversity is, to some degree, a strength as it has allowed teams, models and systems to develop according to local needs, skills, resources and policies. However, this local development has sometimes resulted in an ad hoc development of services resulting in very dissimilar provision in different geographical parts of the same region. Community Children's Nursing requires integration and joint working across health, social care, education and many other agencies.

As part of current government consultation on community services for children and their families and linking to initiatives such as 'Healthy Lives, Brighter Futures' (DH, 2009), 'Transforming Community Services' (DH 2009), 'Aiming High' (2007) and 'Better Care, Better Lives' (DH 2008) this review was commissioned.

From March 2009 to early April 2009 views were sought from children, young people, their families, community children's nurses, other health care professionals working with children's community health care services as well as other key stakeholders. The focus of the consultation was to identify:

- What is working well in community children's nursing in England;
- How well it is meeting the needs of children and families who require support in the community and what could be improved;
- What the vision is for future community children's services and where the community children's nurse will fit within these services; and
- What the caseload of the future is likely to encompass.

This report presents the findings and key themes derived from the consultation.

Overview of key literature

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 they are being nursed" (House of Commons Select Committee 1997). The need identified in 1997 still exists today.

The Darzi Report '*High Quality Care for All*' (DH 2008) set a clear overall vision: to make quality the organizing principle for the NHS. The report defines quality as spanning three areas which collectively will make a quality service: patient safety; patient experience; and the effectiveness of care. 'Better Care, Better Lives' (DH 2008) was the first national strategy dedicated to the development of children's palliative care and improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions.

More recently, 'Healthy lives, brighter futures' (DH 2009) has recognized the central role that Community Children's Nurses play in the lives of children with disabilities and those with complex health needs. Within the strategy there are clear expectations that commissioners will develop these services to provide 'all-round' care packages including end-of-life care in the location preferred by the family that covers 24 hours a day, seven days a week. A commitment to work with health staff to develop a 'community children's service', with nursing as a central component, is explicit within the strategy. There are similarly clear directives in terms of safeguarding children which resonate with the recommendations of the Laming Report (2009) which acknowledges the lack of high-quality specialist training on child protection across services. It focuses on the strengthening of Continued Professional Development (CPD) around safeguarding issues, the need for professionals to be equipped to identify and respond to the health and ill health needs of children and families and the need to be aware of their safeguarding children responsibilities when they are concerned about a child's welfare and safety.

A variety of stakeholders now have a key involvement and investment in Community Children's Nursing including primary care trusts, acute trusts and charity/voluntary sector posts. Community Children's Nursing is now an 'umbrella' term for a wide range of roles including 'traditional' community children's

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nursing, acute care, ambulatory/urgent care, disability nursing, special school nursing, complex needs, palliative care, diabetes care, acquired brain injured children, technology/ventilation dependent, paediatric oncology outreach nursing (POON), continuing care and advanced practice (Sidey and Widdas 2005, Whiting 2008).

Despite the increase in the number of teams providing care, there are still children who do not have access to a community children's nurse. In addition the complexity of community children's nursing practice has been acknowledged (Kirk 1994, Kirk 1999, Carter 2000, Noyes 2002, Elston and Thornes2002, Kirk and Glendinning 2004, Sidey and Widdas 2005, Noyes and Lewis 2005, Sloper and Beresford 2006, RCN 2009 a,b,c,d). Also, the need to effectively manage workload has been identified (Parker et al 2002, Samwell 2005, Pontin and Lewis 2008).

Workload planning through the use of a workload model has been proposed as one strategy to enhance service provision (Pontin and Lewis 2008, Lewis and Pontin 2008). The need to build the capacity of the children's workforce has also been clearly identified (Taylor *et al*. 2008).

The nursing of children is thus being refocused, from hospital care to home care, by provision of community children's nursing (CCN) services (Cramp *et al*. 2003, DH 2003, DH 2004, DH 2006a,b). The Darzi report maps regional activity across the CCN service but there is little doubt that the change for commissioners, staff and stakeholders will be transformational (RCN 2009c,d).

In order to secure modern, high quality community services there also needs to be organizational structures that enable teams of CCN services to provide care. This requires working together with other multi-agency professionals to plan and deliver on workforce development, ensuring the right skills and training are in place and that there is a clear process for joint commissioning for services (Coad 2008). In short, CCN teams and the individuals within them need to be subsequently *fit for current purpose*. But, services also need to be sustainable and flexible so that they are capable of evolving to meet an increasingly challenging environment of rising patient expectations, an increased number of children requiring community care, more demanding Trust services and practice-based commissioners (wanting higher service quality, more effective targeting of resources to need, and better value) (DfES 2003, DH 2006, DH 2008,

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the needs of children and families are changing as they become increasingly active participants in their own care

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…services need to be sustainable and flexible so that they are capable of evolving to meet an increasingly challenging environment

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Directorate of Commissioning and System Management /Social Enterprise Unit and Social Enterprise Coalition 2008; DH 2009)

However, there is currently no clear, national 'blueprint' for this change process. Decisions are being taken and led locally by Primary Care Trust (PCT) Boards (Directorate of Commissioning and System Management/Social Enterprise Unit and Social Enterprise Coalition 2008) but it is in everyone's interest that change is managed coherently, to high standards, reflecting common guiding principles and criteria (Coad 2008).

At the same time, the needs of children and families are changing as they become increasingly active participants in their own care. With this comes a need to ensure that all health services are planned and delivered with users' views in mind. Community children's nurses will be key to ensuring this culture change is successfully delivered. But for any change to take place there needs to be a process of engagement with all stakeholders if the levers are to be understood and for this process of change to be effective (Carter 1998, Randall 2008, Coad and Shaw 2008). This is congruent with the commitment in the UK to involve stakeholders (including children and young people) in matters that concern them (DFES 2004, DH 2004). To achieve this goal innovative ways of understanding their experiences and views have been undertaken in order to elicit their views (Coad and Houston 2008). Whilst consulting with staff, families and children does raise particular challenges a number of initiatives established dialogue and elicited the views of all stakeholders including children and young people (Coad et al 2009). However, any success is heavily dependent upon the development of strategies, which both engage and facilitate meaningful input from this group.

Methods and Methodology

Appreciative Inquiry (AI) was chosen as the most appropriate philosophy to underpin the consultation. Fundamental to this approach is the desire to discover 'what works well' in organisations/systems and 'why it works well' (see for example, Cooperrider and Whitney 1999, Liebling *et al.* 2001, Gergen *et al.* 2004, Keefe and Pesut 2004, Carter *et al.* 2006, Carter 2006). AI has been used effectively within a variety of complex, organisational structures including within health and social care settings (for example, see Young et al., 2006; Carter *et al.* 2007). AI lends itself well to the pragmatic, praxis based approach which was felt to have good fit with a consultation on the practice and practices of community children's nurses (CCNs) and community children's nursing services (CCNS). It provided an excellent approach to eliciting the voices of children, their families, professionals and other stakeholders within mixed participatory workshops.

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AI lent itself well to the pragmatic, praxis based approach which fitted with the consultative approach taken

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Methods

Aims of the project

The aims of the project were to elicit the ideas, opinions, views, perspectives and experiences about the following core areas:

■ What is working well in community children's nursing in England;

■ How well it is meeting the needs of children and families who require support in the community and what could be improved;

■ What the vision is for future community children's services and where the community children's nurse will fit within these services; and

■ What the caseload of the future is likely to encompass.

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Our methods were chosen to encourage participants to interact, share and generate ideas with minimal direction from the research team

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In order to elicit as many perspectives as possible within the time available we utilized three core methods. We selected these methods so as to enable children and young people to contribute to the study on an equal footing with adult participants. 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' rather than

to require structured responses. Our methods were developed to ensure that children and families were able to attend the events or contribute remotely.

We used five main approaches:

- Thirteen arts-based, participatory appreciative workshops held in five locations in England;

- An online discussion group (with the option of participants using email or letters/art work if they preferred);

- Interviews (either face-to-face or by telephone) for participants who were unable to attend the appreciative workshops and/or who did not have access to the internet/email;

- Dialogue and discussions through an expert advisory group composed of leading practitioners and researchers within community children's nursing to help provide additional contextual grounding and understanding of the findings;

- Involvement of a core advisory group, consisting of children, young people and a parent who provided an additional and ongoing perspective on the nature of the study and the findings.

This range of approaches was deemed necessary in order to encompass the breadth of our participant base. We also wished to acknowledge that many parents of children requiring community nursing support face practical challenges in relation to attending workshops. We aimed for participation to be as easy and as un-intrusive as possible.

Arts-based participatory appreciative workshops

Workshops were held in Preston, Bristol, Coventry, Cambridge and London. The workshops ran from 09.30-18.30 with participants being invited to attend one of three sessions (morning, afternoon, late afternoon). These sessions 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. A parent-

advisor attended two workshops (Preston and London) and contributed to the groups and led some activities.

There were three key activities broadly linking to the three main questions (what works well, what could be improved, and what should the future be).

Activity 1: Clouds & Ladders (What works well)

'Clouds' (cloud shaped paper) were distributed to all the participants who were asked to write down one thing per cloud that, from their perspective, they thought works well about community children's nursing services. Participants had access to as many 'clouds' as they wanted and were encouraged to write down as many examples as they could think of. They were able to confer although this was often undertaken without too much discussion. Once it was clear that there were no more 'clouds' being created, the ideas were shared and critically engaged with and explored within the group. This allowed context, details and explanation to be sought about what exactly was working well, why it was working well, what factors had contributed to it working well.
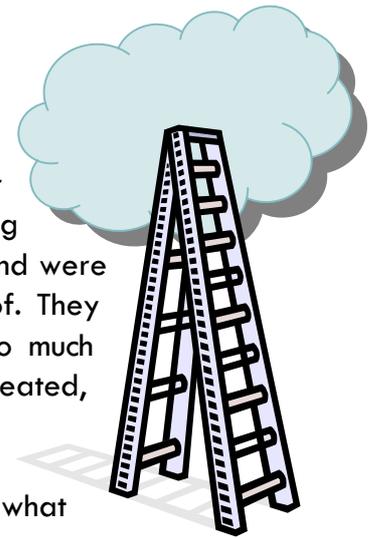
Having completed these discussions the participants were encouraged to place the 'clouds' onto a ladder which triggered categorization and prioritization of the ideas and concepts. The ensuing dialogue that occurred whilst the participants were making decisions about where to position 'clouds' were also noted by the researchers. This aspect of the activity encouraged participants to further question and explore their ideas. This focused reflection also helped to ground analysis in the reality and context of the participants.

Activity 2: Postcards and Padlocks (What needs to be improved)

'Padlocks' (shaped paper) and 'Postcards' (shaped paper) were distributed to all the participants. Participants were asked to make a note of each block/barrier they felt was stopping community children's nursing services from working well. On the postcards, participants addressed their concern(s) to whomever they felt was the most appropriate person to respond and take action. They also identified what they felt would help solve the problem. Participants had access to as many 'padlocks' and 'postcards' as they wanted. In a similar way to activity 1, participants were then given the opportunity to

share their ideas and expand on the frustrations and concerns they experienced as well as solutions they were proposing.

The 'padlocks' and 'postcards' were then posted into clear pockets that allowed participants from across the workshop event to review them.

Activity 3: Mapping the Future

The final activity of each workshop session focused on ideas for the future of community children's nursing/care and support of children and their families within the community. Participants wrote down their ideas for what future services would look like in 5 years and 10 years time. These ideas were shared, discussed and then plotted onto a 'map of the future' which allowed the participants to plot the ideas and concepts in order of priority. Again, this meant that the initial analysis and interpretation of the data were managed by the participants.

Ethics Review

The proposal including all supporting documentation including the letters of invitation, information sheets, consent and assent forms were submitted for ethics review to the Faculty of Health and Social Care, Ethics Committee at the University of Central Lancashire. Approval was given subsequent to review that involved lay representation.

Recruitment of Participants

Participants were invited through the use of:

- Networks;
- Mailing lists (such as paediatric-nursing-forum, PIMH Network, UK Health and Learning Disability Network, CAMHS Network);
- Contact with leading community children's nurses;
- RCN CCN Directory;
- RCN CYP Field of Practice Forums and Communities;

- CYP Conferences;
- Charities such as Special Kids in the UK, WellChild, Jessie May Trust, Lifetime;
- Community Engagement Workers;
- PALS leads in acute settings;
- Direct contacts in tertiary children's hospitals; and
- Direct contacts in secondary and acute care.

Intense activity in terms of focused contacts in the geographical area surrounding each workshop occurred in the run up to each workshop. Snowballing occurred through encouraging study information to be forwarded on to other contacts. Contact was made primarily by email but also through telephoning specific services and key contacts. Many published contact details were often out of date and it took a degree of persistence to identify CCN Services in some areas.

Potential participants who were unable to attend the workshop but who were interested in participating in the consultation were offered the options of either contributing by the online discussion or by (telephone) interview.

The aim was to reach as many services and stakeholders across the whole of England within the time available and to give them the opportunity to participate.

Findings

Participants and Demographics

We directly contacted just under 500 people; others were contacted indirectly through other networks. Table 1 shows the tracked contacts the actual number of people who participated. The tracked contacts represent an underestimation of the total number of people who received and considered the information.

Table 1: Direct contacts made and breakdown of participants					
Workshop/ Other	Total direct contacts made	Professional participants	Parent/Family participants	Child & Young Participants	Total participants
Preston	73	8	5	0 (2)#	13
Bristol	49	6	0	0	6
Coventry	102	18	3	4 (1)#	26
Cambridge	31	10	0	0	10
London	129	9	2	1	12
Others°	109				
Online/Email*	72	50	4	(1)	13
Interview*	10	4	1	1	6
	575	105	15	6	
Total participants across whole study					86

* all emails sent offered participants option of workshop/online/interview – this figure reflects number of specific online/interview contacts followed through

Others° indicates contacts made to people not based local to the workshops

(2)# reflects children who attended who were < 3yrs age

Our final sample was composed of the following participants:

- Our families, young people and children group included mothers (n=5), fathers (n=2), grandmother (n=1), young people (11-18 years of age; n=2), children (n=5)

- Our professional group included (all grades/bands) CCNs, paediatricians, commissioners, integrated care managers, clinical leads for community services, team leaders for CCN Services, student nurses, managers of respite units, learning disability nurses, special needs school nurses, health visitors, social workers, practice educators, university lecturers

The compressed timeline created challenges to recruitment. Overall we recruited fewer participants that we had hoped and have reflected on the reasons for this:

- Children, Young People and Families: the study ran during school/college term time and this may have influenced the number of children, young people and families who attended. We ran one event on a Saturday to give children and families the opportunity to participate without missing work/school but this event coincided with good weather and this may have put families off attending on a day they felt was 'family time'.

- Professionals: participation in the workshops meant time away from practice and although the study design aimed to minimise disruption to practice, getting time away from work to travel to/from and attend the workshops was problematic for some people, especially those in small teams.

- Participation in the online discussion group: although there was a good deal of enthusiastic interest in joining the online discussion group (blog) and 54 consent forms were returned, very few participants actually blogged. It is difficult to be clear about why this was so; perhaps the process of registration which created a couple of days delay between deciding to participate and being able to participate meant that the original motivation was reduced. Other people may have found the process of registering off putting.

There was an under-representation of participants from minority ethnic groups within the study. This may partly reflect the overall under-representation of professionals from minority ethnic groups delivering care and support to children and their families. The reason for the under-representation of child and family participants from minority ethnic groups is less clear although the approaches used (workshops, online discussion and interviews) may have had less appeal for this population.

Overview of the findings

The findings represent an amalgamation of the total data set and they are presented within three major themes and their respective sub-themes. These themes reflect the three key questions that drove the study. Excerpts and quotations from the participants are used in an appropriately anonymised form to illustrate specific points. Photographic images taken during the workshops and art work relating to the study are used to illustrate techniques and particular points.

Section 1: What works well?

- **A user-centred service**
- **Attributes of Community Children's Nurses**
- **Current delivery of community children's nursing services**

Section 2: What could work better/what isn't working well?

- **Under pressure and lacking options**
- **Diversity, deficits/discrepancies and a lack of definition**
- **Marooned and marginalised**
- **Commission, omission, funding and resources**

Section 3: Visions and aspirations for the future

- **Core points that could create an exemplary service**

Section 1: What works well?

In the following section the core themes of a user-centred service, the attributes of community children's nurses, and a modern community children's nursing service are presented and discussed.

Sub Theme 1a: A user-centred service

What worked well and what made a good service was one that could allow a child to reach their full potential. All the parents and CCN's felt that every child and young person had the right to expect care to be provided at home and that hospital admission should be prevented or reduced to the minimum. The children we interviewed also wanted to be cared for at home, both for acute and complex care giving, in that this was viewed as 'normal at home'. This is supported by one mother who explained that CCNs:

> **"give holistic care so my child can be more comfortable and happy in his own home"**

This was also reiterated by one of the commissioners who attended the workshops:

> **'In areas where there is good CCN provision children can spend more time at home – spending time at home and not in hospital is <u>very</u> important to children'**

In all types of examples whether this was part of an acute; complex or palliative, end of life care package our findings showed that CCN's helped the families cope as the child was in familiar surroundings with the people who knew them and was safely and competently cared for in their needs. Repeatedly, children and families spoke about how they really valued this service and the CCN's that supported them. Children's community nurses were thus felt to be in ideal position to work in collaboration with the child and family and facilitate the identification of individual needs and holistic care to meet them. They were felt to be well placed to support children and their families. Even if this was stressful

and difficult, they felt that this was less pressure for them, was the right place for the child to be and ultimately reduced their time in hospital.

Aspects that children, families and non-nursing participants valued were that community children's nurses needed to be friendly and approachable. Repeatedly, the researchers were told that essential skills included good communication and listening. Since they often acted as the single port of call they were ideally placed to listen and share a family's joys and concerns. These interactions occurred in the family's home, in nurse-led clinics and in other settings such as the child's school.

All participants emphasised the need for a non-judgemental attitude particularly when providing care in the child's home; nurses needed to remember their status as a guest in the family home. Community nurses spoke passionately about how being based in the community facilitated closer relationships with children and families and allowed them to be a more visible and integral part of community health care. They also noted that even if their relationship with a family was challenging they felt able to rise to the challenge. Equally, the families spoke about having good access to a children's community nurse fostered closer relationships; accessibility was clearly important. One mother whose child had complex needs had not experienced comprehensive community children's nursing services until she moved to the area where one of the workshops took place. She simply explained that now "I have a community children's nurse". Having access to a CCN was so important to her child and to her (as a mother) and to her family as, for the first time, the service was helping her family to "become more normal".

The families all spoke about the good relationships with and the trust they place in the community children's nurses. Non-nursing participants commented similarly, noting that they considered community children's nurses to be very approachable due to their familiarity with individual children and families. As one mother explained:

> From our experience of community nursing it's been very good really. They appear to be interested in the condition and will seek answers and further knowledge if they need it - they don't fob us off if they don't know

She is very informative, friendly and answered my questions

She cleans my belly button. She cleans my trachy

She is someone you can talk to

[She is] giving me confidence

[She is] knowledgeable

[She] is nice – looking after me

It's nice that we get respite

It's good that we have everything for [child's name] like equipment!

It's good that our nurses are more like friends – we can talk to them.

The families felt that the community children's nurses put the children and families first and gave them the opportunity to be involved in decisions and to have choices about their child's care. Examples of choices cited by the parents included choice about where their child could receive care (e.g., home, hospice or hospital [or all three]), choice about early discharge, choice at an early stage in planning their child's care package, and choice about supplies and equipment. They valued the partnerships that existed between them and the CCNs and felt these worked well because community children's nurses worked flexibly and were ideally positioned to be able to liaise with them and with the multitude of professionals involved in providing care and support. This liaison also crossed the boundaries between the various settings and situations such as acute care, complex care packages and during end of life care. One CCN talked about the centrality of partnership and relationships:

> **Partnership is evident through the discussion/dialogue/negotiation and a mutual valuing. We can contextualise the total relationship – we can see what other things are happening in their lives…... We work honestly and openly so they [families] feel that they can say what's on their mind. You only have that discourse based on the longevity of the dialogue and the professional relationship – this more difficult to have it as a short relationship'……..**

One issue of area in which there was disparity was the ease of difficulty families experienced in contacting CCNs. In some areas, CCNs were easily contactable day and night. However, in other areas this was more problematic and related to local service provision that could be limited to 9am-5pm, Monday to Friday (see section 2 for more details). However, families really valued easy access to CCNs.

All the CCNs liked not having to wear a formal uniform; some wore their own clothes and other teams had casual tops with a specific (team) logo. The families liked this and did not want nurses wearing obvious uniforms coming to their homes. Two of the children we interviewed did not fully realise that the person visiting them was a nurse. The parents said they felt that this was a good thing as this meant that the nurses were just a normal part of the child's life and were not seen to be associated particularly with illness or hospitals. One boy who was visited by a CCN to remove his sutures told the following story which captures the essence of a user-centred service in which nursing care is fitted in around his usual life:

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CCN's care for the child and family as individuals

They act as a conduit for communication through patient journeys

They provide safe, effective treatments.

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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.

Sub Theme 1b: Attributes of Community Children's Nurses

When asked about what was good about the service the important attributes of CCN's were highlighted. However, it is worth noting that Community Children's Nursing is an 'umbrella' term that is now used to reflect a wide range of roles occurring in different contexts. From our data this diversity included:

- 'Traditional' community children's nursing
- Ambulatory/urgent care
- Disability Nursing
- Special School Nursing (and supporting children with complex needs in 'mainstream' school
- Palliative Care
- Diabetes Care
- Paediatric Oncology Outreach Nursing (POON)
- Continuing Care
- Advanced Practice

Our team cover three areas: CCN (specialist areas and generic); Compass (palliative care); CHCT (children with complex needs needing 24 hour cover).

All the professionals who participated felt that they were highly competent, autonomous, skilled professionals who gave high quality care delivery to individual and collective groups of children and families. Some had advanced nursing skill qualifications and were nurse prescribers.

There was a concurrence in the attributes seen as fundamental and this included having an up-to-date knowledge base and good clinical nursing skills. The CCNs needed to be flexible and respond to constant change in order to improve services for children and families. Training will be drawn out further in the next section but CCN's felt that as individuals they had a desire to keep up to date with new challenges and training opportunities.

The CCNs also described the teaching element of their role as being something that worked well.

Their teaching and training ranged across three main groups: parents and children; other CCNs, nurses and health professionals; and training non health professionals and support assistants. Some CCN's described how they had implemented innovative training in schools for teachers and support assistants. Others referred to more competency based training given to multi-agency and family support workers such as the:

> **Regular updating of team members, training and assessing (of family support workers) [that] ensures good appropriate care for the individual child.**
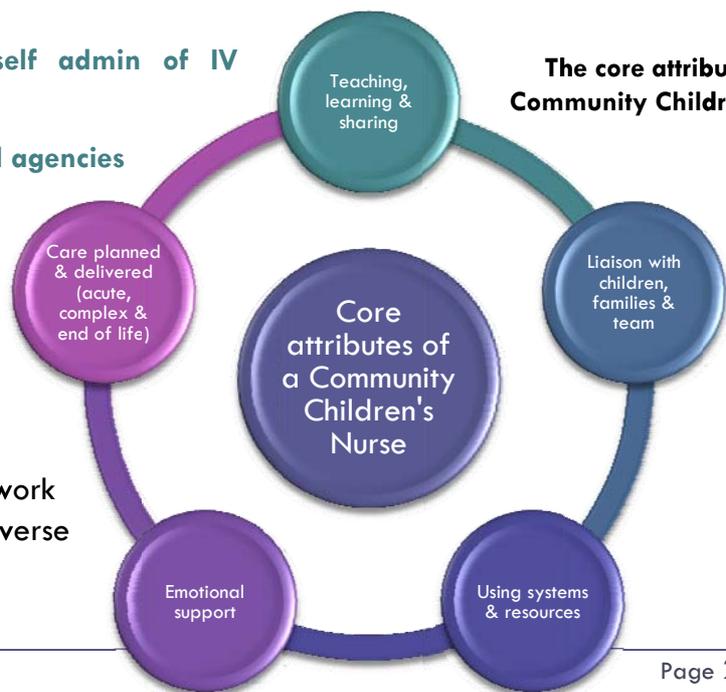
Some CCNs taught on specialist modules of student nurse training and offered placements for learning opportunities. All the CCN participants also stated that training parents and children was also viewed as part of their role and a vital component of empowering families.

We teach parents/children in education centres and thus empower families

Currently improving training for self admin of IV treatment to ensure safe practice

Competency based training across all agencies

Regular updating of team members, training and assessing (of family support workers) – ensures good appropriate care for the individual child.

CCN nurses roles are by nature of the work complex to describe. CCN's are a diverse

The core attributes of a Community Children's Nurse

Teaching, learning & sharing

Liaison with children, families & team

Care planned & delivered (acute, complex & end of life)

Core attributes of a Community Children's Nurse

Emotional support

Using systems & resources

workforce currently working within a variety of models. Many of these models have evolved locally and they reflect local needs and drivers.

Care was generally provided in one of four broad categories of service:

- a generalist service (where all the team members were able to provide care to all children on their caseload);

- a generalist service with some nurses who had a specialist interest in a particular aspect of care (such as diabetes or wound care) and where the nurses with a special interest might work more closely with the children in their 'special interest group';

- a specialist service with nurses whose caseload comprised solely of children with a specific diagnosis and who had little engagement with the other children on the general caseload); or

- a combination of all three.

Community children's nursing teams were also able to provide specialist clinic work like immunisations, emergency care and triage, support for early discharge and assessment at home care and support for children and young people in the community with long term conditions, as well as those with palliative care needs. Community children's nurses also undertook a vast number of roles such as physical care, emotional support, respite care and support in relation to specific requirements such as equipment or feeding. Many emphasised that they were "often a key worker for children with complex needs" as they were good at signposting solutions.

Being the child's advocate was central to their care and this included being aware of the child's holistic health and care needs. Keeping the children safe and promoting their well being was fundamental (even when necessary CRB checks delayed packages of care being implemented). It was clearly seen as important to ensure that:

> **children are protected and safeguarded by Community Services, that reporting is seen as everybody's responsibility and that everybody is accountable for this.**

Sub Theme 1c: A modern community children's nursing service

There were many facets to what constituted worked well in a modern community children's nursing service. These included:

- Team work
- Care packages
- Improving communication between the hospital and community
- New ways of working including partnership working with multi-disciplinary and joint working with multi-agency partners such as social care, education, voluntary services
- Using systems and resources to their best

Team work

> **It is a very nurse led service to meet the changing needs of the children and their families**

'Teamwork' emerged consistently across responses as an integral, and enjoyable, part of effective community nursing and essential for caring for the children and families. Sharing knowledge with colleagues, and was the most commonly cited positive feature of community nursing.

> **We have a good service manager who has been with us for years.**

> **Core team members are experienced, aiming to develop the team and able to move forward**

> **The team as individuals are very flexible and will not hesitate to go the extra mile.**

Those who shared space together and/or space in the acute trust felt that this was ideal as they could have regular dialogue with CCN colleagues or consultants or nurses on the children's ward. Many CCN's referred to having strong nurse consultant leaders in community nursing and where such posts were located all cited the individual by name and spoke about how they led CCN locally but also nationally. Further, all CCN's discussed how their senior nurse managers were supportive and that many had developed creative ways of working to facilitate team work. For example:

> **We have team meetings every week where we share case load issues and challenges**

> **We have clinical supervision of team members usually approximately monthly held in a variety of venues**

Care Packages

It was clear from the data that the provision of medical care at home relieves stress and discomfort for both the child and their family. This was especially so in end of life care or when it avoided long term hospital stay However, it also had resonance for those children with acute care needs. Flexibility was necessary so as to manage the 'rules' to ensure that different providers of community care (e.g. children's hospice and outreach team) needs were met.   There were a number of excellent examples some of which are listed here:

Planning and delivery of such care packages was a common role that the community children's nurses performed and generally they felt that there was a high standard of service given to the child and families. One CCN described how:

> **CCN's here are actively working towards developing new pathways to improve procedures and they have been instrumental in improving care for the children.**

Generally the examples described were drawn from complex care and end of life care but some examples from acute care packages were described.

The the packages of care for end of life (EoL) care and palliative care were frequently cited as intense and care, in these situations, was needed '24/7' and based around the family's needs. Despite limited resources (in some cases) community children's nurses felt that they accommodated child and family preferences and had implemented a number of local initiatives to support families. These included changing hours to suit the service offered despite limited resources and establishing a 24 hour on-call service for all children on caseload via the telephone.

> **We have comprehensive palliative care packages... it's about nursing the child at home with consultant support as back up. And we have a psychologist, play specialist and nurses who are able to prescribe medicines if required**

Table 2: Key examples of core interventions for CCN's		
Acute Care	**Complex Care**	**End of Life/Palliative Care**
Any child with an identified nursing need	Any child with an identified nursing need	Any child with an identified nursing need
Safeguarding to protect from harm	Safeguarding to protect from harm	Safeguarding to protect from harm
Specific team, group and liaison work and teaching role. Joined up working.	Specific team, group and liaison work and teaching role. Joined up working.	Specific team, group and liaison work and teaching role. Joined up working.
Short-term acute illnesses- to prevent the initial referral or admission to hospital/early discharge home	Long term e.g. Diabetes, Cystic Fibrosis, Epilepsy, Asthma; Oncology, Dermatology, brain injured & wide diversity of genetic related conditions	Continuing care/respite care/ partnership working with hospice care
Acute/Emergency assessment	Assessment of baseline and ongoing needs e.g. equipment	Assessment of baseline and ongoing needs e.g. equipment
Removal of sutures	Disability & learning disabilities/Special school nursing	Palliative & 24 hour end of life care/symptom management
Specifically focused drop-in, nurse led clinics especially for children's acute needs	Ventilated/technology dependent	Ventilated/technology dependent
Administration of medication/Injection/ Nurse Prescribers* [Administer medicines under a patient group direction]	Administration of medication/IV's Chemotherapy/Nurse Prescribers [Administer medicines under a patient group direction]	Administration of medication/IV's/ Nurse Prescribers [Administer medicines under a patient group direction]
Post-operative dressings	Offering emotional support	Offering emotional support
Taking blood samples	Premature babies/ low birth weight babies/oxygen dependent	Oxygen monitoring and night saturations
Managing constipation/continence	Sleep studies/oxygen monitoring and sleep studies	Children with special needs (enterally/gastrostomy fed)
Sleep studies /oxygen monitoring and sleep studies	Children with special needs (enterally/gastrostomy fed)	

Improving communication between the hospital and community

Communication between hospital and community staff was noted to be problematic and will be discussed in the next section but there were examples of it working well, as one participant explained:

> We're linked into hospital – we're well known in hospital – it's great for liaison.

Other families also described how supportive the hospital had been and that care had been effectively shared and focused on that the families wanted. As one mother explained:

> Our child used the hospital anytime .. an open door really ….we only had to ring up … it was all based on what we wanted and what we could cope with

Collaborative working was cited in what works well in terms of school nursing, paediatric and community consultants, ward staff, special schools and health visitors. Community children's nurses also felt that they had the potential to reduce and prevent hospital admissions, as well as attendances at outpatient clinics. Participants included CCN's who were based in a 24 hour paediatric A&E department. These CCN's could provide a link between acute and community services, enabling two way communication and sharing of information. They reported a reduction of hospital admissions as a direct benefit. Liaison across acute and community services by a dedicated post was reported in one setting. In another region CCN's were linked to the acute trust and were part of an acute assessment unit so that children could be quickly assessed and then followed up later with a home visit that day and in the following 24 hours. This facilitated smooth care for children and families. Such models were felt to needs led and more responsive.

Such working required creativity, for example one initiative was a facility for families with children who were described as "more complex patients" to have "open admission". It is also meant that some participants had increasingly sought support from the funded

charities/voluntary sector. Two participants were in charity funded posts; one of these posts was specifically focused around discharge liaison and was funded by WellChild. Since the post had commenced (one year) there had been clear improvements (such as better communication) to the discharge process across the region.

New ways of working

The CCN's felt they were in a key position for implementing new ways of working and being instrumental to the Team around the Child delivery. They felt that they were able to play a critical role in assessment of the care packages such as assessing ongoing needs and convening case reviews and, in turn, this meant acquiring new skills and competencies. Other new ways of working included:

- Development and delivery of the acute care service

- Support for CCN's with specialist interests and skills

- End of Life Care

- Support for innovative posts across the acute trust and community such as discharge planning, transition (across children's to adult services and across acute and community care)

- Reducing hospital admissions or preventing re-admissions especially in complex conditions and neonates

- Working closer with School Health Advisors. Sharing caseload details to try to avoid duplicate working.

- Working closely with the Head and teachers in a school to integrate a child with special needs into mainstream.

One aspect that was endorsed in all the data was the need for multi-disciplinary working and learning within primary, secondary and terminal care and multi-agency partnerships across health, education and social care. An important positive message about what had worked well was that there had been a commitment from senior management to engage staff in the process. Participants were well informed and spoke positively about local partners needing to ensure that the planning and performance assessment of CCN service delivery should be *jointly* planned and delivered. CCN's discussed how they had developed or

We are developing and delivering care pathways to aid a swift responsive service

. Fostering multi-disciplinary and multi-agency working was pivotal to effective service delivery

were part of multi-disciplinary and/or multi-agency working groups and felt that they were in important positions in the problem solving process. Fostering multi-disciplinary and multi-agency working was pivotal to effective service delivery, which in turn was felt to be associated with being able to give more holistic care to children and families.

Others spoke of new projects and clinics that had been implemented responding to local need. One example was a joint clinic with a paediatrician running a clinic in a special needs school supported by the CCN. This allowed review of the pupils plus allow teaching staff to raise health-related concerns. There were several citations around planning new nurse-led clinics around immunisations; diabetes, asthma; eczema and epilepsy. There was much positive discussion about such service provisions by all the participants as they felt that this was added value to the total team packages of care being provided to children and families.

Using systems and resources to their best

Participants felt that responsive systems and resources needed to be in place to deliver a modern, community children's service. What worked well was the inter-team working and sharing of resources through the competency assessment framework. Here CCN's, managers and commissioners agreed that shared records with the multi professionals must be a more efficient and responsive service. Measurement of case load and care was also felt to be essential in understanding the CCN role and auditing the service. Some CCN's used existing databases to monitor such information whilst others had implemented their own.

Other improved information technology system included bleep systems, improved use of information technology and in one are an early alert system which gave 'advance notice' to and from the community team using an email alert system. Currently this was being for patient planned hospital admissions but it had helped CCN teams to have the ability to prepare for the individual child and family so it was to be

widened further into electronic alert systems for all known complex care children. The aim here using such technology is to streamline patient journey and improve communication. Another CCN team spoke about how they and other national teams are using new technologies sleep studies could be performed at home to avoid children coming to ward for. To date this had been used with ENT such as sleep apnoeas, pre-adenoidectomy and those with chronic lung disease. The CCN instruct the family on the monitor and once collated data could be downloaded and analysed. This is succinctly summarised in the final extract:

> **We need to have willingness to develop our services and resources – we do do this – we do respond – we are creative – we will go that extra mile ....so that we can support children and parents or carers at home and this way we maintain the child or children's independence**

Section 2: What could work better?

There was a concurrence in the views expressed by all participants about those things that were not working well within service delivery regardless of whether they were presenting a family or professional perspective.

There was a depth of emotional response in this part of the workshop that reflected the difficulties, frustrations, bemusement and despair that parents could experience when community care was not working well and they felt marginalised or abandoned by a system that did not or could not care for their child. Similar feelings were expressed by professional participants who were unable to deliver the care they wanted to and which they felt the children and families deserved. There was a universality about these responses which were evident in each of the workshops and also evident within the online discussions/emails, and interviews.

The four sub-themes presented in this section are: under pressure and lacking options; diversity, deficits/discrepancies and a lack of definition; marooned and marginalized; and Commission, omission, funding and resources.

Sub Theme 1: Under pressure and lacking options

As can be seen from the findings on what was working well, comprehensive community care allowed children and families to sustain a lifestyle based within their homes that supported what parents described as a "normal family life". However, there were stories told about the "massive expectations" that were placed on parents and how some parents were being "put under pressure". One mother explained how she had not had enough "nursing care at home" and that without this care:

> **"children and families" could not "live full lives without being pushed to their coping limits".**

Parents under pressure

Another family described how difficult it was for people to really appreciate "living the life with a child with complex medical needs" particularly as "doctors don't get it". In situations where parents did have a package of care in place this did not always provide the continuing care and support they and their child needed. Some families and professionals described the situation of care and support "falling over" if trained carers were sick and could not cover a span of duty. When sickness cover could not be found, parents had to take over completely. This inevitably added to their physical and emotional stress. This lack of cover in the community meant that for some families there was no choice but for their child to be admitted onto the "ward for overnight care". However, this breakdown in services could be further compounded:

> "if the ward's busy or if it has D&V and therefore it's not appropriate for the child to be admitted, then 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. The implication is that if family doesn't do it, then child can't go home

However, even when the situation was not quite so desperate, parents sometimes felt pressured and "socially limited" when carers they and their child did not know or who did not give care to the level they expected were rostered to provide care. One family were realistic when they explained that:

> "no-one can do it as well as you can but you have to let go and give it over to someone else" [but] "you can't go out" when you do not have confidence in staff.

Some families and professionals described the situation of care and support "falling over" if trained carers were sick and could not cover a span of duty. When sickness cover could not be found, parents had to take over completely.

Sub Theme 2: Diversity, deficits/discrepancies and a lack of definition

There was wide diversity across and between community children's nursing services with some areas having comprehensive services delivered by a large and flexible team containing a wide skill mix and sets of expertise whilst other services only focused on one particular element of care (e.g, complex needs or acute) or were limited in some other way such as "by postcode lottery".

Working patterns

There was intense frustration expressed by the constraints and restrictions imposed by care that could often only be delivered five days a week and between 'standard' working hours (09.00-17.00/ 08.30-16.30). 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. This model was critiqued as a mode of delivery for acute care such as suture removal as well as for ongoing care of children with more complex health care needs or for children requiring end of life care. Limitations to the service reduced the opportunity to engage in a meaningful way with the whole family. Standard service hours coincided with school hours for children (meaning that sometimes children had to miss time at school to see the nurse) and working hours for families. As one CCN working in a 9-5, Monday to Friday service described:

> **"This means we can't access fathers or access/contribute to after school clubs"**

The need to extend hours to cover weekends and evenings and potentially provide on-call or 24 hour cover was seen to be paramount. The 'standard' hours led to "restrictive working" as the CCN could not always visit "when medications are due/when support needed" and it meant that there was disruption to the "parents/child lifestyle".

Parents who needed support after 5pm could not access local, expert and informed nursing care but had to either manage on their own or turn to services such as their GP who they felt could provide less expert and informed advice or to A&E services. CCNs knew that

"trouble" typically flared and help was needed at "5pm on a Friday" and when "access to services is limited". Beyond these obvious implications, there were hidden consequences for staff which were summed up by one CCN who 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". Another CCN explained that services should not be reliant on good will cover as "for a week it's ok but we shouldn't do it. I know that's hard but we have to be able to provide 24 hour care, with a robust system in place, <u>not</u> on good will".

Whilst families were "grateful" for this support, some also felt "uncomfortable" as drawing on good will felt like imposing on the teams.

Caseload Capacity

The notion of 'good will' appeared to be the glue that held some services together for some of their families as many CCNs were stretched because they had "far more work than hours in the day". There was clear and considered evidence presented that some teams were working beyond their capacity. It is worth noting that the word team was frequently used although it use did not reflect a clear image. Some teams could be genuinely described as community children's nursing teams as they were well established, had in excess of 25 staff working collaboratively and under strong leadership. However, there were other 'teams' consisting of 1.5 or 2 whole time equivalents job sharing or virtual teams in which there was only one CCN working in a degree of isolation in which staff sometime felt like "Billy-No-Mates". Interestingly, staff in both large and small teams described feeling under pressure – albeit these pressures appeared less pronounced in the larger teams.

There were reports of having "an overwhelming caseload and not enough hours to care for children effectively" and the "lack of manpower resources mean the service is limited and we can't develop it as much as we would like". These pressures sometimes reflected an increase in the numbers of families on the caseload, a shift in the level of care required and/or changes in the commitments

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There were reports of having "an overwhelming caseload and not enough hours to care for children effectively"

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of team members as exemplified by one CCN who explained that she could evidence an "increase in workload of 25% in 2 years with no more staff and our manager doing much less clinical work due to managerial/PCT commitments". In some cases workload analysis and costings demonstrated a specific need for more staff, for example "4 extra CCN staff per year .... this would provide enough staff to carry out workload effectively".

Inequity and gaps in services

The lack of equitable and universal services for children requiring nursing care and support was a clear source of frustration and concern. There was a genuine sense that "some [families] have everything, some have nothing" and that a "set pathway so all families are entitled to the same" would be fairer and more equitable. The current context of care meant that there was not a universal minimum standard of care for children and not every child had access to CCN care.

The work undertaken by the teams primarily reflected the initial rationale for their development and service development beyond this 'prime directive' required CCNs to lobby to extend not only the hours they worked but also the scope of their practice. Teams which were managed from the acute sector often had a focus on acute care with their primary economic objective being to reduce length of stay in hospital through earlier discharge. Teams which had been set up to meet the needs of children with complex health care needs often saw the benefit in being able to extend to encompass children with acute and shorter term needs.

In areas where there was no dedicated service, the two areas of service delivery that created the greatest challenges were respite care (short break care) and end of life care which were often seen as being "piecemeal and inadequate". As one participant explained:

> **End of life care is limited it means the choice is limited because we don't have comprehensive services. There are different referral criteria to different teams.**

Both end of life care and respite care created an enormous challenge for many of the CCN Services to respond to. These
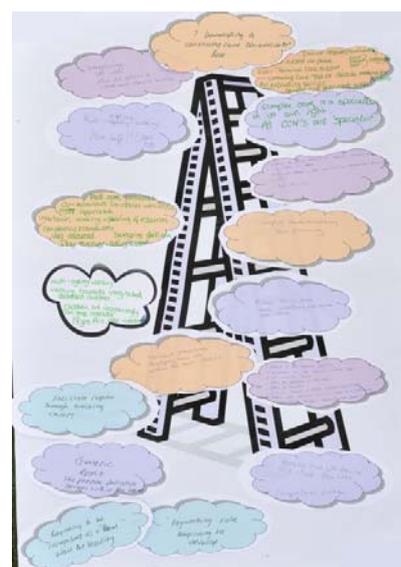
were also the areas where families found the pressures and emotional turmoil that arose as a result of having to 'fight' and shout for services particularly difficult and draining.

Clearly funding limited the capacity of teams to respond to a family's choice for their child's end of life care to be provided within their own home. But equally there were problems in having appropriately trained and experienced nurses to provide the care. The stop-gap in such cases was yet again "good will". Whilst it might be perceived to be laudable for CCNs to be going the "extra mile" for families in a particular crisis situation, such as a child requiring end of life care in their home. One of the CCNs ironically explained that within her locality:

> **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.**

Not all teams could find 'money from somewhere' and whilst it was within the gift of individual CCNs and teams to shift limited resources to provide good end of life care for one child and their family it often resulted in some of the more generic aspects of the caseload (such as "routine, non urgent telephone contacts") were put on hold.

Communicating: discharge, speaking the lingo and talking techy

Three key elements of communication were expressed as concerns. One problem was focused on reciprocal communication, primarily about discharge, between community children's teams and acute/hospital setting. Another concern related to the differences in discourse and language between agencies which should have been experiencing seamless collaboration. The final core issue related to databases and either their absence or the challenges of them working effectively in supporting multi-agency and cross boundary care.

Discharge home from hospital was a source of some contention and although early discharge

was the aspiration for all CCNs it caused problems if they had insufficient time to adequately prepare the family and the community to meet the child's needs safely and effectively.

As pointed out by one CCN the consequences of not involving "community children's nurses in discharge planning" meant that:

> **families can feel isolated and frightened if discharge planning is not done well.**

Lack of communication meant that care packages were not able to be put in place, staff were not fully trained and the delays that could occur if commissioning the care package held up meant that sometime parents who "wanted hope that they could take their child home" kept having these hopes dashed.

Professional liaison across health, education, social care, housing, benefits, management, commissioning, acute and community sometimes created challenges to getting the best for children and families. Professionals were described as:

> **speaking different languages and using different tools.**

This was most evident in terms of defining and agreeing what constituted a health or social care need. One participant described the "quagmire" that divides "nursing and social care needs" although the philosophical and semantic issues could be overcome through the medium of a "joint budget".

Whilst some databases undoubtedly had "some excellent elements" they also were limited by the fact that the system is "not likely to be shared between social care and health..... doesn't work across hospital and community". Other CCNS felt like the database acted in a "Big Brother capacity to monitor work" but did not help them expedite their role.

Sub Theme 3: Marooned and marginalised

One of the strongest messages that came from the CCNs in the workshops was a degree of despondency and bemusement expressed about their apparent lack of identity as valued professionals within the community, the invisibility and

misunderstanding that abounded in relation to their service and concerns about education opportunities. Whilst the issues that underpin these messages might look selfish and self-centred, the motivations were nothing of the sort. CCNs wanted greater clarity about their role, better understanding of their services and improved opportunities for postgraduate study so that they could develop stronger more innovative services for children and their families.

These feelings came through, to a greater or lesser degree in all of the workshops regardless of whether or not community children's nursing was a major or more minor presence in the area. One CCN expressed the frustration expressed by many contributors to the workshops when she said:

> "We are an important service but at the bottom of the pecking order. We are valued by a lot of families but not valued much by other professionals/ If you stopped 20 in the street and asked them what we did, most people wouldn't know"

This lack of insight about the role extended to professionals and other agencies who might have been expected to know about the role of CCN and the services offered in their own area. However, often comments were made such as their being a "lack of knowledge by GPs and hospital paediatricians that CCN service exists". There was clearly a need to distance themselves from the image that "CCN's go and 'drink tea' [as it] is an easy job" and to raise the "profile with families and professionals". The concern here is not that the CCNs wanted to blow their own trumpets but that if "people don't understand what CCNs do [because the] team is often invisible [there are] probably a lot of children we could look after that don't know about us".

The CCNs proposed a rationale for this invisibility as being related to having:

> "no real shared understanding /identity" and not being part of "one single body with one single role..... with no real "corporate image that can be adjusted locally".

This lack of corporate identity was strongly felt by many of the CCNs but did not appear to be important to other participants in the study. The families came to know the role of the CCN through the CCNs they interacted with. Other participants had a sense of the role of CCNs but were unable to be very precise unless they had close experience of working with a team in which case they knew what their team did and assumed that this was what all CCNs did.

The lack of educational opportunities for professionals who held such key roles and who often worked autonomously with children with such a diverse range of needs and requirements for care was a major area of concern. Education was seen to be a central component of workforce development and creating a community children's workforce who could appropriately meet the needs of children and their families now and in the future. The need to "prioritise the skills for community nursing and healthcare" was clearly stated as it was recognised that it "takes a long time to prepare skilled professionals". One participant felt sufficiently strongly to suggest that community children's nursing was being "suppressed" and that nurses needed clear opportunities for "career development" such as becoming "consultant nurses/practitioners". The nature and type of courses will be discussed in section 3. This strong desire for educational opportunities was linked with the need for stronger, more visionary leadership which was felt to be lacking despite the work of "some exceptional individuals".

Sub Theme 4: Commission, omission, funding and resources

Resourcing in terms of capacity, capability and skill mix of services, equipment for children and families, financial constraints and challenges of block budgets, managing budgets and the need to fight the system and shout loudly were core to many of the issues which restrained the services.

Commissioning

Commissioning was seen as problematic by many of the participants including the commissioners who took part in the study. CCNs and parents often expressed concern that commissioners were to blame for lack of funding to services often as a perceived sense that they had "absolutely no background in children's services and has no idea of what is needed", were often "inconsistent" about the

decisions they made in relation to packages of care and failed to see the "priority of children's services". However, the commissioners presented a different perspective clearly wanting to the do the best by the children and their families and feeling frustrated that plans they had made were "on hold" and that obstruction lay higher up the system, for example at Board level. As one commissioner explained:

> **if the acute side overspends then the PCT and Department of Health top slices the budget so we can't develop the services that we want commission.**

Block funding was seen to be problematic and solutions included pathway or practice based commissioning.

One of the factors that was felt to hinder robust commissioning of services to meet the health care needs of children and young people was that the CCNs felt that they had "no nationally recognised, relevant 'must do or must provide' services for children and young people". This meant that their service could be overlooked and that the:

> **"introduction of realistic targets should help ensure children and young people have service equity with adults and have services in place to ensure they have the help and support they need to achieve the 'every child matters' outcomes" was an important concept.**

Equipment

Equipment was a major source of worry and contention for participants resulting primarily from apparently inadequate budgets or poor systems of ordering and/or delivery. There was a strong sense of their being inequity in provision of equipment which as subject to a postcode lottery. Equipment was a fairly widespread worry ranging from not having enough "disposables" such as syringes or "air cylinders" to substantial delays in the delivery of equipment such as walking frames and wheelchairs. Worries about equipment added to the challenges that parents faced and inevitably led to "having to battle and battle" to get heard. As one parent explained

> **We need to have a good service but we're often only recommended what the therapists have experience of using, what is on their prescribing list. But a child with spina bifida has very different needs from a child with cerebral palsy. So if therapists haven't got experience of children with specific conditions and knowledge of a child's specific needs for a walking frame, for example, then this can be a real problem.**

Other participants described scenarios where having liaised with parents and ascertained their wishes about a particular piece of equipment these choices were overridden by someone who had never met the child and knew nothing about them as:

> **Sometimes the signatories don't understand and will block the purchase of a bed that a child needs because they think that they have a better idea of what the child needs. And they don't!**

Whilst some services used prepared home intravenous antibiotics (IVABs) some services required parents to:

> **"prepare them from scratch" and whilst the nurses were "very used to giving IVs so sometimes we don't realise the burden, risks etc for parents".**

Section 3: Visions for the future

- **More CCNs** to deliver a child and family oriented service that is **accessible, equitable, comprehensive, sustainable and flexible** for all children with a nursing need regardless of the nature of the need (.e.g., short/long term, acute/ chronic, complex/technologically dependent, respite, end of life care) that is available 24/7. A greater **capacity for the workforce** to adopt a more balanced proactive approach to care in addition to the reactive response. Universal minimum standards to ensure equity across services.

- More **responsive and flexible respite** services that have more universal criteria and which acknowledge the importance that good respite plays in the lives of children and their families.

- Genuine choice about **end of life care** that acknowledges that whilst home may be the preferred place of care for some families other families' circumstances may dictate that the preferred place is within the hospice or hospital. Skilled, trained care and symptom management available 24/7 to meet the needs of children and their families during this period of the child's life with support also available for the team providing the care. A key vision is that no child or young person should have to die in a place that is not their preferred place for death.

- CCNs having access to **nationally recognised appropriate postgraduate education opportunities to advance practice** which are seen as a priority and which are backfilled. These postgraduate degree courses should be characterised by:

  - joint learning with other agencies and community professionals

  - integration of aspects of health and social care

  - acquisition of clinical skills such as prescribing, assessment/diagnosis, cannulation to help advance practice

- development of skills and competence around areas such as leadership, budgeting and development of nurse led clinics

- placements which facilitate learning through gaining experience across a breadth of services.

- Mentorship by experienced CCNs within the Higher Education Institutions.

■ A **comprehensive, encompassing multi-disciplinary and multi-agency** service that is fully **integrated, co-located** and which has clear responsibility for meeting the needs of the child and their family (through agreed national minimum service standards) and which is not disrupted by geographical boundaries.

■ A service that is centred on **parental choice** and **decision making** and which takes full account of what is important to the children and their families and which aims to promote independence

■ A service that is characterised by **genuine partnerships** and professional relationships with families in which parents are able to put being **parents first** and carers second and in which their skill, expertise, knowledge and role in providing nursing care and helping to maintain their child's care in the community is recognised through economic support/financial reimbursement.

■ **Care packages** which, as appropriate, are lifelong and which meet the needs of the child and their family and which are delivered by competent, trained carers.

■ **Commissioning and budgeting** which robustly resource the service and meet the needs of children and their families and which can be intelligently managed at local level.

■ Greater opportunities for CCNs to **work within and across different acute and community settings** such as Paediatric Assessment Units, Accident and Emergency Units and GP surgeries as a means of reducing admission to and promoting earlier discharge from hospital and maintaining the well being of children and their families through more nurse prescribing and nurse-led clinics.

■ **Equipment** which is provided in a timely and efficient manner which meets the health care needs of the child and family and which also

acknowledges that aesthetic, personal and family considerations are as important as a professional perspective.

■ **Technology** that supports the service including databases which can 'talk' across agencies and settings to facilitate sharing of data as well as developments such as telemedicine which could enhance care and support and help overcome (as appropriate) some of the geographical distances between services and families.

■ Better **transitions** between hospital and home and home and hospital and between children's and adult services.

■ **Fewer hospital admissions** for children and more care provision at **home.**

■ Acknowledgement of the need to **build a workforce** for the future that is characterised by sustainability and acknowledgement that future leaders need to be developed from the current workforce
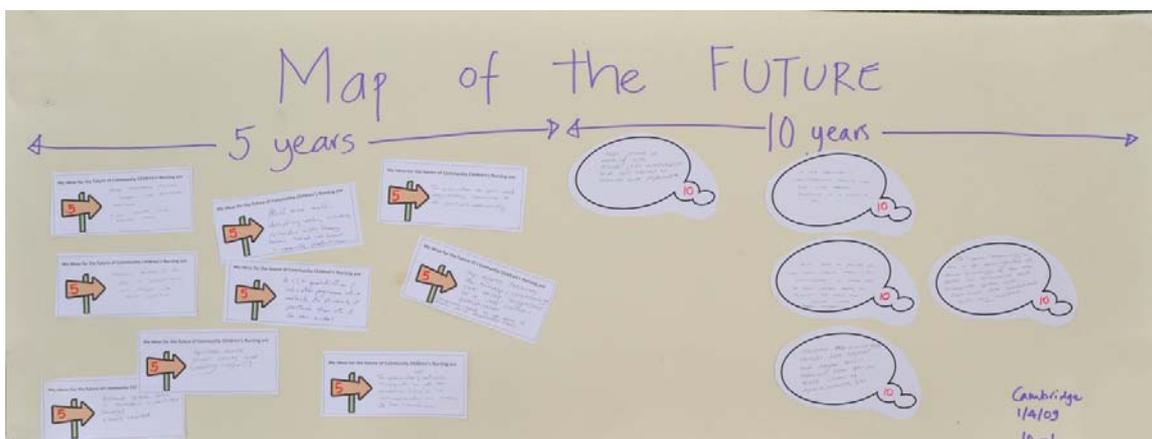
Conclusions

Services that meet the health care (and other) needs of children and their families are currently high on the public health agenda as is evident in the recently published strategies and reports aimed at improving the health, wellbeing and safeguarding of all children and young people. The contribution of Community Children's Nurses is clearly pivotal to meeting these needs. It is clear within these documents that pressure points remain around some services within the dedicated children's heath workforce, one of which is community children's nursing services.

The use of an appreciative, participatory approach enabled participants to share good practice, challenges and concerns which parents, families and professional face on a daily basis.

There was a clear endorsement by the participants that the CCN role is valued by those people who appreciate the complexity and challenge of the role. CCNs and services to children and their families thrived most vigorously where the teams were sufficiently large to be flexible and able to respond quickly to the changing demands of the caseload. 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. For the most part, families felt well supported, hospitals reported a reduction in admissions and CCN's felt that they were delivering a good service.

Services and individuals struggled when local financial arrangements were tenuous and the service was not apparently valued at a strategic level. The lack of educational opportunities for CCNs compounded a feeling of educational and professional marginalisation and a lack of 'corporate identity'.

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. 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.

Recommendations

- Access for all children and young to community children's nursing services and a continuing shift in services from hospital to home.

- Relevant targets to help guide the development and funding of the service.

- Government policies and guidelines should be mandatory to reduce the chance of them being ignored.

- National commitment to provide respite for all children with medical needs.

- End of Life/ Palliative care respite offered in non hospital community based facilities.

- CCNs to have access to nationally recognised appropriate postgraduate education opportunities.

- Acknowledgement of strong desire for CCNs to have a strong corporate identity

- CCN Services written into national commissioning targets and the National Service Framework to ensure all Strategic Health Authorities provide services.

- CCN Services to develop to be increasingly user led as well as user centred.

- Improvement in systems of documenting care so that information can be shared across agencies and settings.

- Research to explore the affects of children and their families receiving care in community settings.

Priorities for Future Work

Priorities should be established and further work undertaken to understand and resolve the issues faced by these services. This work should include:

- Examination of children's, siblings' and families' experiences of community children's nursing care and their perspectives on:

    - what it is that a CCN (CCN Service) does to reduce the need for hospital admission and promote families' confidence to care for their children; and

    - what it is a CCN (CCN Service) does to help families to sustain and maintain 'normal' family life and help children to live as full a live as possible;

- Workforce planning to determine how best to provide proactive universal services for children and young people with acute, complex and other health care needs including the skill mix needed to deliver effective services;

- Scoping at local, regional and national level to determine the size of the population that could benefit from community children's nursing input; and

- Education, training and approaches to ensure the effective development of professionals and their roles to accommodate new ways of multi-disciplinary working within the NHS and in wider teams.

Appendix 1: Expert Advisory Group Members

Name	Role	Location
Christine Anderson	Parent – Advisor	Lancashire
Elodie Coxhead	Children and Young People's Advisor	Coventry & Warwickshire NHS Trust Youth Council / University of Sussex
Nicki Fitzmaurice	Paediatric MacMillan Nurse	Birmingham Children's Hospital NHS Trust
Sue Hatton	Workforce Development Specialist for Women and Children	West Midlands Strategic Heath Authority
User AH	Children and Young People's Advisor	Coventry & Warwickshire NHS Trust Youth Council/Finham Park School, Coventry
User BH	Children and Young People's Advisor	Coventry & Warwickshire NHS Trust Youth Council/Cardiff University
Alex Jones	Children and Young People's Advisor	Stratford upon Avon High School
Linda Partridge	Director of Programmes	WellChild
Duncan Randall	Lecturer	University of Birmingham School of Health and Population Studies
Jessica Riddell	Children and Young People's Advisor	Princethorpe School, Rugby
Mark Whiting	Consultant Nurse Children with Complex Needs	West Hertfordshire Primary Care Trust
David Widdas	Consultant Nurse Care of Complex Needs	Coventry and Warwickshire Primary Care Trusts

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