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Caring for children '24-7'

The experience of WellChild Nurses and the families
for whom they are providing care and support

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WellChild 
the national charity for sick children

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Contents

Executive Summary	4
Background and Literature Review	6
'24-7' Care	9
The WellChild Nurse Programme	12
Research Approach	13
Interviews With WellChild Nurses and Parents	15
Data Analysis	17
.....	
Findings	18
Seeking Advice And Support Throughout The 24 Hour Day	19
Why Call?	20
When To Call?	23
Who To Call?	26
How To Call?	28
The 'Added Value' Of The WellChild Nurse	30
The Multi-Faceted Role Of The WellChild Nurse	30
The Particular Role Of The WellChild Nurse As Key-Worker	31
.....	
Discussion	32
Conclusions	35
Recommendations	36
References	37
Appendix 1 Interview Schedule: WellChild Nurses	38
Appendix 2 Interview Schedule: Parents	39

Executive Summary

Since the appointment of the first WellChild Nurse in 2006 the programme has expanded dramatically and 2016 saw the appointment of the 32nd WellChild Nurse.

Throughout these 10 years the key objective of the programme has been to improve the provision of community nursing care for children with complex health needs with a clear focus upon the coordination and planning for discharge of children from hospital and support of children and families once at home.

This study set out to explore, from the perspective of both WellChild Nurses themselves and families to whom they are providing care, aspects of caring for children at home throughout the 24 hour day.

The first phase of the study consisted of a scoping exercise which was undertaken with 14 WellChild Nurses (11 completed responses – 79%) and 12 parents drawn from two groups of ‘expert’ parents (9 completed responses – 75%). This phase of the study required participants to answer a short set of 6 questions based upon their experience of care through the 24 hour day. Analysis of the response data provided valuable insight into the area of study focus and helped in development of the interview schedule for the main study.

The main study involved the undertaking of semi-structured interviews with 12 WellChild Nurses and 10 parents. Interviews with WellChild Nurses were undertaken in their main work base. Parents were interviewed in their own homes (one interview was undertaken with a parent in hospital as her child was in Paediatric Intensive Care at the

time of the interview – but the mother was very keen to participate in the study) The key question which the study set out to answer and formed the basis for both sets of interviews was:

“Could you possibly share with me your experience of care throughout the 24 hour day?”

With participant permission, each of the interviews were recorded digitally. The recordings were then transcribed and a thematic analysis was undertaken. This revealed a rich insight based upon many years of experience from both the WellChild Nurse and the parental perspectives. Examination of the key study question inevitably lead to a discussion focussed around how parents seek out advice and support ‘out-of-hours’.

Analysis of the interview data from both groups of study participants identified four interrelated questions which informed the actions that parents take in order to gain access to ‘professional advice’:

- What time of day is it?
WHEN TO CALL?
- Why am I looking for support/help/advice?
WHY CALL?
- Who do I think is the right person to give me that support/help/advice?
WHO TO CALL?
- How do I get in touch with that person?
HOW TO CALL?



This analysis revealed how the WellChild Nurses play key roles in supporting parents as they develop strategies to help them address each of these questions. Parents provided strong evidence of the 'added value' provided by the WellChild Nurse, identifying how the nurses take on 'multifaceted roles' which are consistent with those that might be undertaken by a 'lead professional', who is clearly working in 'partnership' with those parents.

■ **The following recommendations are made for consideration by WellChild:**

- 1** WellChild to give consideration to how it might contribute to establishing a robust and sustainable information resource/ database of the incidence of complex health needs in children throughout the UK.
- 2** WellChild to explore further the relevance of the lead-professional/key worker role in respect of how it relates to current provision and future development of the WellChild Nurse programme
- 3** WellChild to consider how it might work with the WellChild Nurses to ensure that the model is sustainable at a local level ensuring that their role in the provision of 'out-of-hours' care is clearly understood by all stakeholders.
- 4** WellChild to continue to work with parents, WellChild Nurses and other stakeholders in order to establish insight into and understanding of the impact upon families of providing 24 hour care to children in the community.
- 5** WellChild to continue to work with all relevant stakeholders in order to ensure that the commissioning of CCN services includes a clear focus upon children with complex health needs in the community including the needs of those children and their families for care and support throughout the 24 hour day.

Background and Literature Review

The development of community based nursing services for children in the United Kingdom can be traced back to the formation of a 'Private Nursing Service' which was introduced in the late 1880s to provide a 'hospital-at-home' service for children being discharged from the Hospital for Children, Great Ormond Street, London. Similar schemes developed from a number of the other children's hospitals within the UK and several of these operated on a 'paid for' basis including, for some children, the provision of 'live-in' nursing care provided to the child 24 hours per day (Lomax, 1996, Whiting, 2005).

These schemes offered bespoke care for children in their own homes up until the introduction of the National Health Service in 1948. However, as the children's hospitals became part of the new NHS, these private nursing schemes were dis-established and community nursing for children was assimilated into the District Nursing services, though this was on a significantly reduced scale and did not include any form of 'live-in' care provision (Hunt and Whiting, 1999).

The first formally constituted Community Children's Nursing (CCN) Services were established in the late 1940s and early 1950s in Rotherham, Birmingham and Paddington and much of the work of these early teams was concerned with the avoidance of hospital admission for children with acute infections. In 1959, the Committee on the Welfare of Children in Hospital recommended:

"Children, particularly very young children, should only be admitted to hospital when the medical treatment they require cannot be given in other ways without real disadvantage... When the nature of the illness and home conditions permit, mothers should be encouraged to nurse a sick child at home under the care of the family doctor and with assistance, where necessary from the home nurse. Too few local authorities as yet provide special nursing services for home care of children and the extension of such schemes should be encouraged."

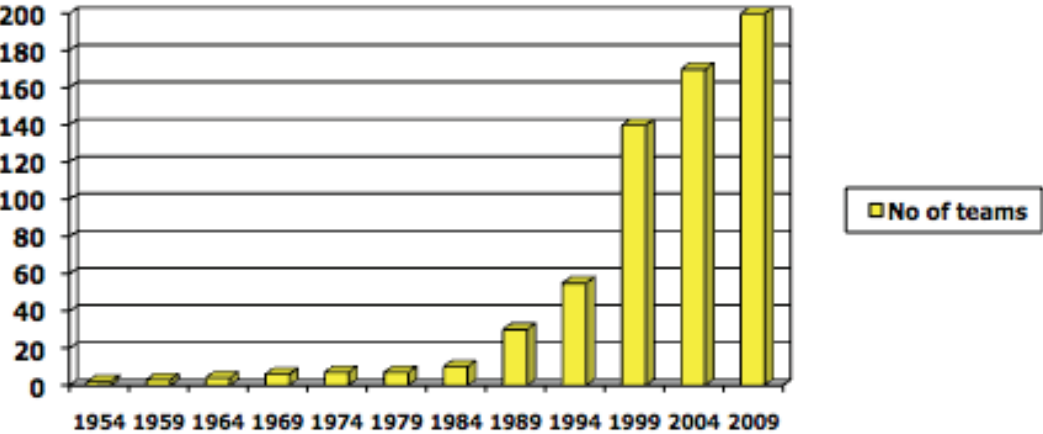
(The Platt Report', Ministry of Health, 1959, paras. 17-18).

During the 1960s and 1970s, a small number of CCN services were introduced in England and Scotland, and this expansion in service provision was accompanied by the development of more specialist roles, including the provision of community nursing support for children with diabetes, cancer and cystic fibrosis.

As CCN service provision expanded significantly during the 1990s and through into the first decade of the 21st Century, there emerged a greater focus on the provision of care to children who were technology dependent (Kirk and Glendinning, 1999; Noyes and Lewis 2005; Wallis et al., 2011) and children requiring palliation and end-of-life care (While and Dyson, 2000; Carter and Petchey, 2007).

Figure 1 offers a graphic illustration of how CCN service provision has expanded dramatically since 1988, at which time there were 24 services in the whole of England employing a total of 45 nurses (Whiting, 1988), to the position reported in 2009 by the Royal College of Nursing in its Directory of Community Children’s Nursing Services which listed 199 CCN teams across the whole of the United Kingdom. In oral evidence provided to the House of Commons Health Select Committee in 1996, the Royal College of Nursing had reported that data on CCN workforce staffing was not routinely collected by the Department of Health, however it was estimated that at that time there were between 500 and 1000 CCNs in total within the UK.

Figure 1: Community Children’s Nursing Service in United Kingdom 1954-2009 (Whiting et al. 2009)



During the early years of the 21st century service provision expanded further with CCN services operating throughout much of the UK. However, many of these CCN teams were very small indeed, in some instances consisting of only one member of staff, or focussing on a single disease entity (such as cancer or diabetes), aspects of technology dependence (for example ventilator care or total parenteral nutrition) or palliative and end-of-life care. Variability in the number of staff employed within local CCN teams and differences in the clinical focus of those services has created significant inconsistency in the hours of availability of nursing support in the community including services which are available:

- 9-5 Monday to Friday
- 9-5 seven days per week
- starting earlier in the morning (usually around 08.00, but possibly as early as 06.00)
- with extended evening working – to 18.00, 20.00 or 22.00
- offering overnight care provision

This inconsistency in provision prompted the Royal College of Nursing (2008, para 2.6) to recommend:

“...for an average sized district with a child population of 50,000 a minimum of 20 WTE community children’s nurses are required to provide a holistic community children’s nursing service.”

It is highly unlikely that the growth in provision has yet achieved the figure recommended by the RCN in 2008. With a current estimated UK child population (0-18 years) of just under 17 million (ONS, 2015), the provision of such a ratio of nurses to children would require there to be around 6,800 CCNs.

In 2011, The Department of Health (England) described CCN Services as providing the “bedrock of the pathways of care” for four groups of children (Figure 2):

■ **Figure 2: “Four groups of children and young people who have been identified as needing CCN services.” (Department of Health, 2011, page 4)**

- Children with acute and short term conditions
- Children with long term conditions
- Children with disabilities and complex conditions, including those requiring continuing care and neonates
- Children with life-limiting and life-threatening illness, including those requiring palliative and end-of-life care

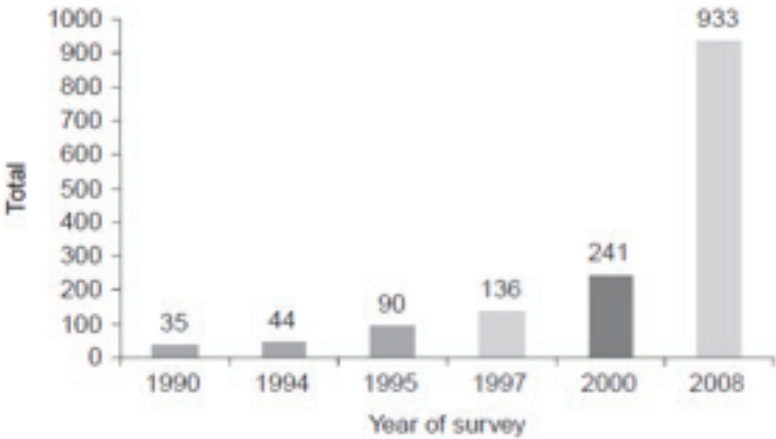
The DoH went on to advise:

“A comprehensive service requires a “critical mass” of staff, which in turn improves the sustainability, accessibility and efficiency of the service. In some areas this could be achieved by bringing together staff from existing disparate services.” (Department of Health, 2011, page 4).

The growth in Community Children’s Nursing provision has been one of the central features of the changing face of child health care in the UK in the past fifty or more years with a clear direction of travel towards a community-based model. This is clearly evidenced by the continuing decline in the mean length of stay for children in hospital and the dramatic reduction in the number of hospital beds for children across the United Kingdom.

A graphic illustration of this is provided in the survey undertaken by Wallis and colleagues in September 2008 which included details of the increasing numbers of children who were receiving home ventilation (Wallis et al, 2011 – Figure 3). Although there is no robust system for routinely collecting data on the overall population of children with complex health needs in the community it is a widely held view that the numbers of such children being cared for by their parents at home continues to increase year-on-year-on-year.

■ **Figure 3: “Review of current (2008) and previous surveys (published and personal communication) of ventilated children in the UK by year of survey” (Wallis et al. 2011)**



'24-7' Care

The notion of providing '24-7' nursing care for children in the community is not new. This approach has been supported by government policy/recommendations dating back to the 1996 NHS Executive report 'Child health in the community' (Table 1). The table also incorporates earlier reference documents which made specific recommendations relating to CCN provision, though not necessarily addressing the particular issue of '24-7' care. Although the most recent reports which are referenced within the table are quite consistent in terms of the recommendation that CCN care should be provided twenty four hours per day, seven days per week, there remains a lack of specificity about the nature of the nursing care provision that might be required. This gives rise to a number of questions:

- Should a '24-7 CCN Service' operate on an on-call basis or is there an expectation that they might be substantively staffed overnight?
- Should the provision to be in the form of 'hands-on care', available to the child at home, or might this be a telephone advice/signposting service?
- To which groups of children do these recommendations relate? End of life care and symptom management/palliation is specifically highlighted as a priority in a number of recommendations. Although this potentially addresses the needs of one of the four groups of children identified within the 2011 DoH report there is very little reference to the other three groups of children: children with acute and short term conditions; children with long term conditions; children with disabilities and complex conditions, including those requiring continuing care.

The lack of reference to '24-7' care is particularly notable by its absence from the Department of Health (England) Framework for Children and Young People's Continuing Care (DoH, 2010, see table 1.)

Table 1: 'Recommendations' relating to the provision of nursing services for children in the community, including '24-7' care

Author/Date	Report Title	Recommendation
Ministry of Health, (1959, paras. 17-18)	The welfare of children in hospital	"When the nature of the illness and home conditions permit, mothers should be encouraged to nurse a sick child at home under the care of the family doctor and with assistance, where necessary from the home nurse. Too few local authorities as yet provide special nursing services for home care of children and the extension of such schemes should be encouraged."
Department of Health and Social Security (1976, page 294, para.17.25(x))	Fit for the future – Report of the committee on child health services	"The responsibility of the child health visitor would be to ...provide with the child health nurse, nursing care for children in their homes or in group practice premises and in health clinics and in this to work closely with the consultant paediatric nurse based on the district general hospital in the case of children discharged from hospital or for whom the latter's advice has been sought."
Royal College of Nursing (1994, page viii)	Wise decisions: developing paediatric home care teams	"Paediatric home care teams are the way forward for a high quality and more cost effective service for children."
Department of Health England (1991, page 4, para. 2.9)	Welfare of children and young people in hospital	"In striking a balance between hospital and community care, account will need to be taken of the extra burden placed on parents by day treatments, the care of chronically sick children at home and patterns of repeated hospital admission. ...Key issues include the contribution of paediatric community nurses in providing support to families at home, in liaison with GPs and hospitals."
Audit Commission (1993, page 53, para. 137)	Children first: a study of hospital services	"There is a need for more teams of RSCNs who can provide secondary care at home."
NHS Executive (1996, page 62, para. 11.10)	Child health in the community	In order "For the full benefits (of a paediatric community nursing service) to be realised, which should include greater consumer satisfaction and, in time a reduction in the requirement for acute beds there should be... sufficient staff to provide a 24 hour service."
Department of Health (1996, page 13)	The patient's charter. Services for children and young people	"You can expect to have appropriate help and support from the community nursing team when nursing your child at home. Preferably there will be a children's community nursing team. If one has not been set up in your area yet, the help will be from the district nursing team. You and your child will be told the name of the children's community nurse who is responsible for your child's care and how to contact him or her or a member of the nursing team at any time of the day."
House of Commons Health Select Committee: (1997)	Health services for children and young people: third report of session 1996-97	Page xix, para. 48 "It is a cause for serious concern that only 50% of health authorities purchase CCN services and that only 10% of the country's children have access to a 24 hour service. We regard it as highly undesirable that there should be such local disparities in the provision of CCN services and are not convinced that there is any logical explanation for this." Page xx, para 50 "All children requiring nursing should have access to a children's community nursing service, staffed by qualified children's nurses... in whatever community they are being nursed This service should be available 24 hours a day, 7 days a week."
Department of Health (1997, page 19)	Government response to the reports of the Health Committee on health services for children and young people, Session 1996-97	"There is a long history of a district nursing service to the elderly, children's community nursing services are fairly recent developments and, as a new service, require research into their effectiveness... All children and their carers should have access to an appropriate service provided by properly trained and experienced staff."
Department of Health England (2004, page 37)	National Service Framework for children, young people and maternity services: children and young people who are ill	"Primary Care Trusts ensure that children or young people who require ongoing care have access to a children's community team regardless of condition or geographical location. This is taken into consideration when writing care plans and planning discharge from hospital. Where appropriate, there may need to be 24 hour access."

Author/Date	Report Title	Recommendation
Department of Health (England), (Craft & Killen, 2007, page 7)	Palliative care services for children and young people in England	"Commissioners should ensure an increased focus on community services to help manage and support children with palliative care needs to stay at home. Every sub-region needs to ensure it develops community teams capable of providing support and advice, including end of life care, 24 hours a day, 7 days a week."
Royal College of Nursing (2008, para. 3.2)	A child's right to care at home	"We are calling for: A clear strategy to address the deficiencies and patchy provision of community children's nursing services in England, Scotland, Wales and Northern Ireland to enable a 24 hour, 7 days a week service."
Department of Health (England) (2008, page 20)	Better care, better lives	"Commissioners will need to consider how this new funding can enable the development of children's community nursing services capable of providing an all-round care package, including end-of-life care, 24 hours a day, seven days a week in the location that the child and family prefer."
Department of Health (England) (2010)	National framework for children and young people's continuing care	The framework document makes no specific mention of children's need for 24-7 or even overnight care, though does highlight the need for clinical interventions during the night – including children requiring re-positioning due to sleep deprivation arising as a result of mobility related issues; breathing difficulties requiring suction; overnight ventilation; medication requirements overnight, including pain management, and overnight seizures.
Department of Health (England), (2011, page 12)	NHS at home: community children's nursing services	"The service provides 24/7 access to advice and support for families and carers and, in end-of-life care, 24-hour visiting as required. The findings (Carter et al, 2009) suggest a service is needed to children at home 8am–10pm with telephone advice out of hours, by people who are knowledgeable about community children's services and the individual child, with the ability to make a home visit if necessary."
Parker et al (2011, page 17)	Evaluating models of care closer to home for children and young people who are ill: main report	"The importance of 24 hour, seven day a week support. For some CCTH (Care Closer To Home) services this can be provided effectively through telephone support systems. For other services that are intended as real alternatives to acute hospital care, our evidence suggests that it is counterproductive, both for children and families and for the health care system, to limit them to 'office hours'."
Children and Young People's Health Outcomes Forum (2012, page 49)	Report of the children and young people's health outcomes forum	"Care for children with acute, complex or palliative care needs should be delivered as close to home as possible – this includes the need for highly skilled teams in hospitals, linked with comprehensive 24 hour 7 days a week community children's nursing teams."
Royal College of Nursing (2014, page 8)	The future for community children's nursing: challenges and opportunities - RCN guidance	"A good CCN service has the following attributes: a comprehensive service with integrated and coordinated locality care that caters for all four groups of CYP; the service is responsive and flexible to local population needs and accessible seven days a week, with 24-hour provision and an on-call service."
Royal College of Paediatrics and Child Health (2015, Recommendation 5, page 13)	Facing the future: together for child health	"Each acute general children's service is supported by a community children's nursing services which operates 24 hours a day, seven days a week for advice and support, which visits as required depending on the needs of the children using the service."

The WellChild Nurse Programme

In 2006, WellChild introduced the first of what has grown to be an established network of 32 WellChild Nurse posts located in England, Scotland and Wales. To date there have been three detailed evaluations of the programme (*Johnson and Coad, 2008; Carter et al. 2010; Coad et al. 2016 in press*). Each of these studies has confirmed that the WellChild Nurse programme:

- Works to improve the provision of community nursing care for children
- Is concerned with the care of children with complex health needs
- Is focussed upon coordination and planning for discharge of children from hospital and support of children and families once at home.

In 2009, in collaboration with the Royal College of Nursing, WellChild introduced the 'Better at Home' campaign, which called for:

- Timely high quality and effective care to be delivered in the home where possible.
- Packages of care which coordinate health, social care and education in a way that meets the individual and ongoing needs of the children and their families.
- The Government's commitment to support greater financial investment in the provision of community children's nurses to work specifically with this group of vulnerable children and bridge the gap between hospital and community services.

In 2014, WellChild launched a 'Manifesto for Change' which sought to ensure better outcomes for all UK children with serious illness or complex care needs based around three key priorities. "We want these children, young people and their families to:

- Receive the highest possible standard of care in hospital.
- Be fully supported in their journey from hospital to home.
- Have access to a full range of quality home care and practical support services at home."

At each site where a WellChild Nurse has been appointed, three years of 'pump-prime' funding is provided to allow for the appointment of a single Registered Children's Nurse. Applicants to the programme (NHS provider organisations) are required to provide a written commitment that they will continue funding at the end of three years.

A number of the established WellChild Nurse posts are 'stand-alone', for example a hospital-based WellChild Nurse who provides an outreach role to support children who require invasive ventilation as they are discharged from hospital to home. Other posts are 'embedded' within an existing community children's nursing team – though the WellChild Nurse role is clearly differentiated from that of other members of the team.

Whilst it is clear that many of the children upon whom the WellChild Nurse programme focusses are likely to require care and support throughout the 24 hour day, the WellChild Nurses have generally been employed to work on a 9-5, Monday to Friday basis¹.

The remainder of this report will seek to explore the notion of 24-7 care as it relates to the WellChild Nurse model as experienced by both the Nurses themselves and the parents of children who are being cared for at home.

¹ It is recognised that this is a very simplistic description of the WellChild Nurse work pattern: this is explored in more detail later in the report.

Research Approach

In consultation with the WellChild Director of Programmes it was agreed that a research study would be undertaken which would draw upon the experience of both WellChild Nurses and families for whom they are providing care and support. It was agreed that the study focus would be upon the need of families for **care and support throughout the 24 hour day**. The research study reported below is a qualitative exploratory study which was based upon data collected through semi-structured face-to-face interviews with both nurses and parents. At the heart of the interviews was the question:

“Could you possibly share with me your experience of care throughout the 24 hour day?”

In order to inform the development of the content of the interview schedule within the main study, a preliminary scoping exercise was undertaken. This consisted of two sets of exploratory questions which were set out in a short questionnaire sent to two groups of ‘experts’:

Expert Group 1 consisted of each of the WellChild Nurses in post on 31st December 2013: 14 nurses in post, 11 responses were received (response rate = 79%).

Expert Group 2 was a Parent Reference Group (PRG) of 12 members made up from:

- a. 6 parents drawn from the Hertfordshire Parent Carer Involvement Board (identified as a result of direct involvement of the lead researcher [MW] with the Board) - five responses were received (response rate = 83%).
- b. 6 parents nominated by WellChild who were identified through their previous involvement with the WellChild Parent Network - four responses were received (response rate = 67%).

The two sets of questions are included in Table 2 overleaf. Examination of the responses to the questions helped to inform the development of the semi-structured interview schedules for the main study. Commentary from this preliminary scoping exercise will be incorporated within the discussion section of the report, below.

As the main study involved interviews with parents, formal ethical approval was sought and awarded through the NHS Research Authority in March 2014 (NRES Committee – London Central, REC Reference 14/LO/0449). Site-specific research approval was granted at 12 NHS sites (9 in England, 2 in Wales and 1 in Scotland). Consent forms, participant information sheets, letters of introduction and interview schedules for parents and WellChild Nurses were all formally approved as part of the research application process.

■ **Table 2: Study scoping questions**

	WellChild Nurse Questions	Parent Questions
Q1	What do you understand to be the meaning of the term "24-7 Community Children's Nursing Care"?	What do you understand to be the meaning of the term "24-7 Care in the community"
Q2	Based upon your experience as a WellChild Nurse, what do you consider to be the key issues for parents/ carers (in relation to 24-7 care) when children with complex health needs are discharged (or are in the process of being discharged) from hospital?	Based upon your experience as a parent what 'out of hours' support have you accessed in order to help you meet your child's health care needs. (** The term 'out-of-hours' might relate to any time other than Monday to Friday 9.00 am to 5.00 pm)
Q3	What are the key issues for nurses (in relation to 24-7 care) when children with complex health needs are discharged (or are in the process of being discharged) from hospital?	Which professional staff have you been able to access 'out of hours' and how have you been able to access them?
Q4	What specific skills, knowledge and experience do WellChild Nurses (or Community Children's Nurses) bring to bear in supporting parents in providing for the 24-7care needs of children?	What specific care/skills/knowledge/ information/ advice have you been able to access out of hours and who has provided this?
Q5	What sources of advice/support are available to parents 'out-of-hours'?	Are you able to identify any gaps in the provision of 'out-of-hours' support? (You might want to think about support in terms of – advice that might be provided over the telephone, face-to-face contact with health professional staff, urgent/emergency 'home' visits etc.)
Q6	In addition to the points raised above, what do you think are the key questions I ought to be asking in a research study with the working title "24-7 Community Children's Nursing Care"?	In addition to the points raised above, are there any other questions I ought to be asking in a research study with the working title "24-7 Care in the community"?

Interviews with WellChild Nurses and Parents

The main study involved two purposive, convenience samples of research participants.

Sample 1 consisted of 12 WellChild Nurses who were identified through direct communication with WellChild as being in post on the 26th February 2014 (date of submission of the Research Ethics Committee and Site Specific study applications). Verbal consent to participate in the study was sought from each of the Nurses either during their attendance at a scheduled WellChild Nurse event in the early summer of 2014 or by telephone. Each of the nurses indicated their willingness to participate in the study and this was re-confirmed during a telephone call to finalise arrangements for the study interview. A letter of introduction, nurse participant information sheet and study consent form were provided for each of the nurses at this stage. Written consent was confirmed/obtained by the lead researcher (MW) immediately prior to undertaking the study interview. Each of the Nurse interviews were undertaken at a hospital or community location selected by the individual nurse. A copy of the Nurse interview schedule is included as Appendix 1.

Sample 2 consisted of 10 parents nominated by the WellChild Nurses. Each Nurse was asked to select a family from their caseload who would be willing to participate in a study 'which was concerned with the provision of out-of-hours (or "24-7") care in the community.' The nurses secured initial verbal consent from a parent in the study family to participate in the interview. At this stage, parents were provided with a letter of introduction, a copy of the parent participant information sheet and two copies of the study consent form. Written consent was obtained by the lead researcher immediately

prior to undertaking the interview. Only 10 parents were actually interviewed. Two parents withdrew from the study on the day that had been scheduled for interview – one parent because the study-subject child was unwell and in paediatric intensive care and a second parent who cancelled as a result of unexpected family illness. Of the ten parent interviews, nine involved one parent (mother in all instances). The final parent interview was undertaken with a mother and daughter who provided long term foster care to two children who were receiving support from the WellChild Nurse. Parent interviews were usually undertaken in the family home, though one interview was undertaken on hospital premises as the study-subject child was an in-patient on the day of the interview. A copy of the parent interview schedule is attached as Appendix 2.

Each interview was recorded using a digital-audio recorder. All participants consented to the use of the digital recording and to the subsequent use within study reports or presentations of anonymised verbatim text from the study transcripts. Study participants were reassured that the audio recordings would be used exclusively by the researcher, that they would not be made available to any third party, and that the original recordings would be destroyed once the research was complete. A number of the parent participants indicated without prompting that they had no desire to remain anonymous, particularly in relation to very positive comments which they wished to make concerning the support which they had received from the WellChild Nurses, however further assurances were offered in relation to the anonymous presentation of study data.

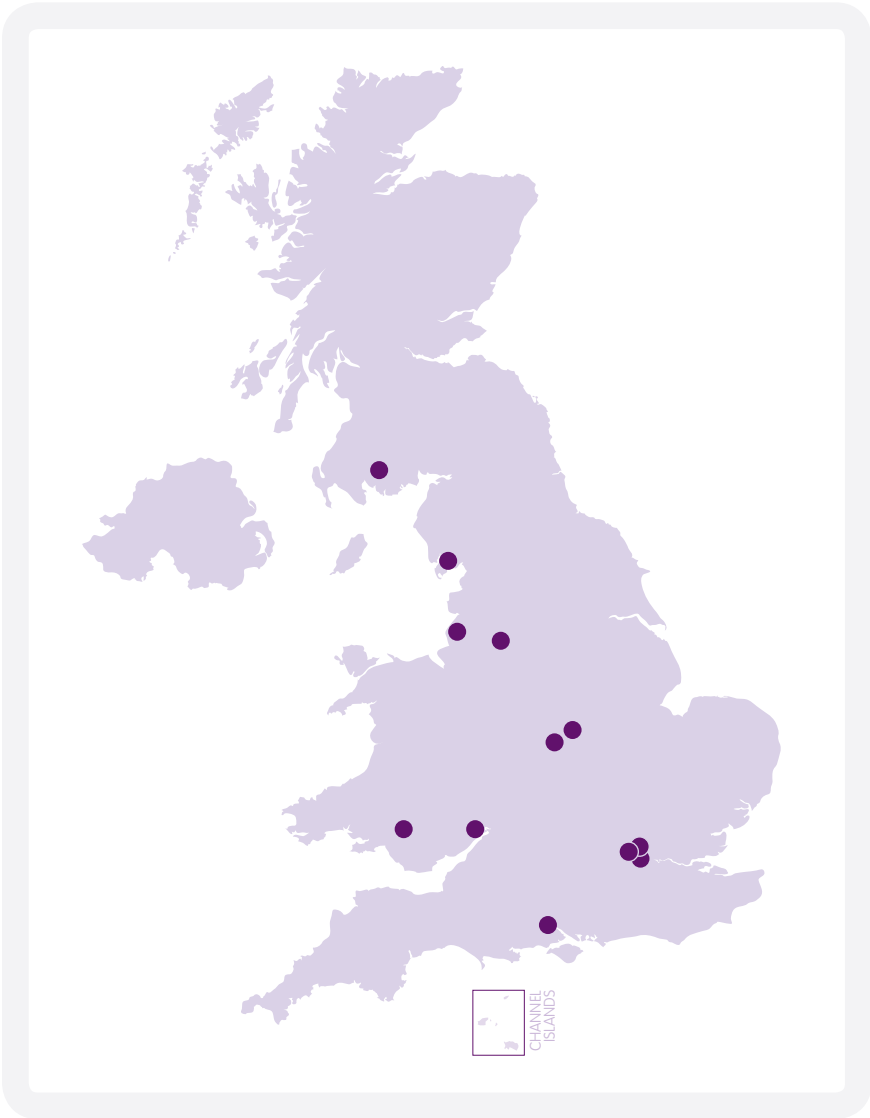
It is important to note at this stage that the parents who were nominated to this study are each providing care throughout the 24 hour day to a child with particular medical complexity and care needs. This gives rise to a very specific perspective in relation to parental experience of '24-7' care.

Where reference to the individual WellChild Nurses and parents is made within this report, the alphanumeric codes N1 to N12 (WellChild Nurses)

and P1 – P12 (parents) are used in order to preserve that anonymity (although only 10 parent interviews were undertaken the numeric element of the codes was retained in order to allow for comparison between the 'pairs' of nurse and parent interviews at each of the study sites).

The twelve interview sites (nine in England, two in Wales and one in Scotland) are illustrated in Figure 4.

■ Figure 2: Location of WellChild Nurses in post at time of study (February 2014)



Data Analysis

Each of the digitally recorded interviews was transcribed to provide a verbatim record of the conversation. The transcribed interviews were then subjected to a thematic comparative analysis using

a step-wise sequential coding approach similar to that described by Glaser and Strauss (1967) and Strauss and Corbin (1998) in order to identify categories and sub-categories from within the data sets (Table 3).

■ Table 3: Qualitative data analysis – data coding approach: based upon Glaser and Strauss, 1967; Strauss and Corbin, 1998.

Coding

Refers to the processes of breaking down the data into discrete parts, linking data, categorising the data, establishing categories and subcategories, making links between the data categories and of identifying one or more overarching categories.

Step 1: “Open” coding

The process of breaking down the data into discrete parts (individual data items), by word, by phrase, by sentence, by paragraph – by listening to and reading the transcript of each interview, extracting from the data set the words and phrases used by the interviewees, and by repeating this process until no further discrete data items emerge (are identified) as a result of further reading – this point is referred to as ‘saturation’.

Step 2: “Axial” coding

The process of linking data, categorising the data, establishing categories and subcategories and making links between the data categories. Clustering of data in this way involves a number of processes:

- examining individual data items
- establishing and defining categories and subcategories
- locating individual data items within categories and subcategories
- constantly comparing data items both within individual data sets (single interviews) and between data sets including comparisons within and between categories and subcategories (This latter point is given particular prominence by Glaser and Strauss, 1967).

Step 3: “Selective” coding

The process of identifying one or more overarching categories, establishing the links between categories and subcategories both within and between the overarching categories – theory building – establishing the relationships between the data as a meaningful whole.

Findings

The systematic analysis revealed a series of recurring and related themes within the data set. The main focus of the study upon 'care throughout the 24 hour day' was examined in terms of the actions that parents might take when seeking advice and support to help them to care for their child.

This element of the data analysis was considered from the view point of both the parents and the WellChild Nurses. In addition the analysis revealed significant parental perspective on the contributions made by the WellChild Nurses to the provision of support throughout the 24 hour day.

Seeking advice and support throughout the 24 hour day

Analysis of the responses from study participants revealed a series of complex decision-making algorithms which focussed around four inter-related questions (Figure 5):

- **Why call?**
- **When to call?**
- **Who to call?**
- **How to call?**

■ **Figure 5: Seeking advice and support throughout the 24 hour day**



■ Why call?

The various reasons why parents might seek advice and support throughout the 24 hour day are illustrated in Figure 5.

The main area of concern for both parents and nurses was upon calls made by parents who were seeking clinical advice and support on how to deal with or trouble-shoot an emerging clinical symptom, such as a rising temperature or a change in the colour or consistency of airway secretions. In addition, participants in both the parent and nurse study samples highlighted issues related to malfunctioning equipment (such as alarms on medical devices or equipment failure).

During a 'normal' working day (see below), parents reported that they would often seek advice from clinical staff before taking any action themselves.

However for calls made out-of-hours, a number of parents described how they might, in the first instance, take steps to manage the situation themselves – only seeking professional advice after the event.

The purpose of the call would be to seek retrospective assurance, from the WellChild Nurse (or other staff whom they recognised as possessing clinical expertise) that their actions were appropriate. Sometimes parents made a call out-of-hours because they wanted the nurse to know what they had done – and the nurse would generally call back in order to receive an update and offer reassurance. The WellChild Nurses provided several examples from their own experience:

For instance I had a mum phone me at the weekend and leave a message, just to tell me the gastrostomy button had come out and she had managed to put it back in herself, because she had never done it before. She had seen it done, but wanted somebody to know, and she just wanted to make sure 'Was that okay?' [N4]

...and the decision is pretty much made, half the time, they just want to run it by me because they just want confirmation that that's a reasonable decision. [N9]

So you know, they will ring you about... we have had some phone calls at, kind of, midnight, one o'clock in the morning from a parent who will say 'they have had diarrhoea for five days now and I don't know what to do' and it might have been an inappropriate time, but really they just want some reassurance that they are doing the right thing and that it can wait until the morning... [N8]

...Last week there was a message from a Mum 'Can I please ring her as soon as I turn my phone on?' Little one is under (Tertiary Hospital) wanting to wean her off O2 and she has started with a cold. Mum had started to reduce it, was unsure because little one had started over a few hours and then had got a real snotty cold. Couldn't get hold of me, she tried to ring the specialist nurse. I rang her straight away in the morning. She had done exactly what I would have told her to do. She just wanted to ring to make sure she had done that. [N10]

Parents seek advice or support that might help to avoid possible hospitalisation for their child, or to sign-post for other sources of support.

Sometimes I think they feel 'Do I ring an ambulance? Do I ring a doctor, No I'll ring the nurse first and see what she thinks.' [N8]

Study participants in both samples highlighted how calls made by parents were seeking the psychological and emotional support that was provided by the WellChild Nurses.

They have had a bad night with their child and they are just really exhausted and they just want somebody to listen. [N10]

Within the first few months, we kind of realised that (WellChild Nurse) was there for everything. [P4]

Yeah, when you first come home you are petrified and having them (WellChild Nurse) on the end of the phone makes a massive difference. [P5]

....and because (WellChild Nurse) was a consistent face to me I felt like I cried on her shoulder quite a bit. [P12]

The need for both practical advice and emotional support is particularly high during the period immediately following a child's discharge from hospital and tends to reduce over time.

When they first come out of hospital, because they are used to that intense support, and they have been hospitalised and clinicalised (sic) completely, I'll generally get lots and lots of phone calls asking me 'Is it okay if this?' and 'Is it okay if that?' [N9]

I think probably in the first two or three months, when they first go home, because they have gone from an acute environment, really where everybody is making decisions for them. [N11]

Sometimes it's the circuits, so it doesn't matter which ventilator it is on, it can be a circuit problem and they are things, ...at the beginning, I didn't, I wasn't sure about, but now I know what to do. [P5]

I think it was very helpful when she came home at the beginning.. she had so many problems and really scared me sometimes a lot....I even thought I couldn't save her life sometimes.... My confidence was really low at the beginning... [P2]

Nurses and parents both described how increasing parental confidence and the development, over time, of knowledge, skills and experience allowed parents to trouble-shoot problems without the need for recourse to professional advice.

And the parents are saying 'oh yeah, they will be fine until tomorrow.' And it is just kind of really saying, well listening to them really because they are the experts. [N8]

Until recently, when I'm more experienced with looking after (child) and I am more used to the signs she shows when she is becoming unwell and things like that, but in the beginning it was all new to me. [P11]

Community nurses were always on call, but there was nothing for them to do, because I put all his NG tubes down and I felt confident with everything, the BIPAP... and he was self-ventilating in the day, was only on BIPAP nocturnally... the only time I needed time out was to go and see my daughter and then my husband would have to step in and I must confess I felt nervous about leaving him with my husband. [P12]

I know him and I know when he needs to come in (to hospital) so I don't need to ring somebody else to ask them what they think, I know that he needs to be seen and I bring him in' [N7 – quoting directly from a conversation with a parent]

Or parents will work through algorithms that they have established over time before seeking that advice.

If she got low saturations or high CO2, if we have tried everything like clear her airway or change her trachy or change the (ventilator) pressures to the top... and still her observations were not very good, I definitely will bring her to the hospital and will let the doctors know what we have done. Yes, most of the time we just treat her by ourselves. [P2]

Just like, his heart rate is up or he had a really unsettled night, 'Could you come (to Wellchild Nurse or CCN) and have a quick look over him' I sort of try and do things to prevent him getting further down the line, sick... if that makes... It was like (child) has this distinctive smell when he is going to become unwell and I rang (Wellchild Nurse) one time, I just said he's got really green secretions, he's got that smell, I think it is Pseudomonas can you bring me a trap and I'll send some secretions off for sampling and then get an antibiotic. [P9]

The WellChild Nurses play a key role in supporting parents by supporting them in developing their confidence and skills. Several of the nurses described this as 'empowering' parents.

I try to empower parents and skill them up [N10]

We try to empower them during our transition (planning for discharge) programme, a little bit about decision making whilst they are in the hospital environment, but it doesn't tend to work (whilst they are still in hospital). [N11]

This notion of empowerment will be considered further within the context of a discussion of the multiple roles which are played out by the WellChild Nurses.

■ When to call?

Analysis of the research interview data revealed significant variability in both parent and nurses experience related to staff and service availability within the 24 hour day, 7 day week. Details of this variability are incorporated in Figure 5.

This experience is consistent with that which was identified by both parents and nurses in the scoping exercise undertaken in advance of the main study (Table 2). As noted earlier in the report, the WellChild Nurses have generally been employed to work on a 9-5, Monday to Friday basis. However the individual nurses described considerable flexibility in their working patterns. This has developed over time, in order to meet the particular need of the children and families within their caseloads.

Variability in the nurses' work patterns also reflected both the differences between the nature of the nursing service within which the individual posts were located and the particular clinical focus of those posts. Nurses who were in stand-alone posts consistently reported that the working pattern, as set out in their job profile, was an 'office hours' week.

Some of the nurses whose posts were based within a larger team included regular evening and occasional weekend working within their work patterns. However, nurses (and parents) described a rather different reality, with working days that were both flexible and of a longer duration than the 'official' 7.5 hour shift.

I am in by 8, probably 8.30 and I don't go home until 6. [N12]

So, out-of-hours, because I work so late, sometimes I'll pop in and see the child asleep and see how they are working and that they are synchronising with the ventilator. [N9]

Another parent had run out of supplies, so I dropped some on my way into work this morning at 8 o'clock – I think she left that message (on mobile telephone answerphone) at about midnight last night... I get busy after 4 o'clock, because I go and see children after school. [N10]

One care package, I was going into the home at 7 o'clock in the morning because I had to learn what care Mum was giving, we were going to teach the care staff to take on that care... and the travelling distance from here to down where they lived was an hour and a half, which was a very early start. [N1]

Parents described how valuable they found the availability and accessibility of the WellChild Nurse as a point of contact at different times of day as well as how the WellChild Nurse had supported them in identifying how they might access other sources of support at times when they were not available:

She has been, I have to say, incredibly flexible with her time with us, and she is, you know, there are times when I have phoned her at five to eight, knowing full well she is off-duty at 8 o'clock and she is absolutely amazing and she will say 'No, I can come and do this.' [P3]

But she always says to me right from the very beginning, if you desperately need me, any time of day, phone. [P4]

You know what, I just ring (WellChild Nurse) anytime, I mean I would never ring her at midnight, I would never ring her at 9 o'clock, but I ring her... [P9]

Nurses and parents at many of the study sites described how parents might make contact 'out-of-hours' confident in the knowledge that the WellChild Nurse would respond to the message in a timely manner, sometimes responding even when they were 'off-duty' or perhaps with a returned message or telephone call first thing the following morning to check on progress or provide advice.

WellChild Nurses also supported parents in identifying pathways to access support and advice throughout the 24 hour day from other professionals including senior clinicians, for instance a respiratory consultant on-call [P2] or direct line telephone number to the hospital High Dependency Unit [P2, P3, P11, P12] or on-call continuing care team [N8, N11].

A number of parents described occasions when they had sought advice to deal with problems as they arose during the night – examples offered by parents included failure of equipment or an unexpected deterioration in their child's condition. It is important, however, to acknowledge that many of the parents in this study have been providing care to their children at home, 24 hours per day over many years. The children are generally clinically stable and a number of the parents have well-established care/support packages in the community. In addition, a number of the parents have been provided with clear protocols and algorithms for dealing with unexpected events and changes in their child's condition.

We kind of give our parents clear pathways of who to contact and where to go when we are not around and we don't get much feedback that that's not working for them. [N5]

Both parents and WellChild Nurses were asked specifically whether they felt that there was a need for additional support through the night. In general, parents felt sufficiently well supported and that this was not a priority. One parent whose child had recently received a course of four-times daily intravenous antibiotics in hospital felt that it would be easier for her to be taught how to administer the antibiotics herself at home than to expect nursing visits during the night.

How is it, having a person arriving at your door at five in the morning... and do those sort of things just for 10 minutes? I know not everybody can do that sort of thing, I feel I'm quite capable of learning to do that one particular thing. I am happy for the nurses to come and do it during the day, to take some of the load off, but then maybe we could do the night time one. [P3]

However, not all of the parents felt that they were adequately supported, as one mother observed: "I have not actually got anyone that I can ring out of hours, at all." [P6]

Although the WellChild Nurses were enthusiastic about the prospect of developing the nursing support services during extended day time hours including over weekends, they were largely unsupportive of the suggestion of overnight, '24-7' provision, offering a range of reasons for this including lack of a clinical need for such a development, shortage of nurses with the necessary skills to deal with acutely unwell children overnight, concerns regarding workforce capacity, and financial resourcing.

I think from the team in the North, who have had the on-call service (now discontinued), it was never accessed very often. [N10]

I don't know, specific to ventilation, how much of an on call, cost-effectively wise, I don't know how much an on-call would be utilised. We certainly haven't really, well, not that I know of, there's not, you don't hear of a lot of issues that haven't been resolved in a timely way. [N5]

I don't think they have the bodies to do it (24 hour visiting service) but I wonder if people would consider it as an over the phone, on-call service? [N7]

I think it is staffing issues to be honest, there just, at present, there wouldn't be the staff to cover that kind of service. [N3]

I think the demand is there (for seven day per week CCN cover), but I think there is a lack of nurses. I think we need more nurses out there in the community, and I know of areas where they have advertised and got very little take up. [N1]

Six of the ten children whose parents participated in the study were either currently receiving or had previously received overnight care as part of an agreed Continuing Care package. One care package was provided entirely by Registered Nurses and the other five by Health Care Support Workers/Carers. Parental views were generally quite positive about the overnight care provision itself, particularly in terms of the relief from having to provide direct overnight care to the child. However, parents raised a number of issues:

Yeah, I mean the care package was, although I felt like I had to fight to get out of hospital with (child), once we had the home care package, on the whole it was a real help to me as a mum... because I could go to sleep, I knew that I could go to sleep and (child) was safe. So yeah, I felt like the overall experience of having a care package although it was invasive in your own home... there is somebody sat right next to her, watching her, so I can either sit, watch TV, relax, have a nice long bath without having to suction her every two minutes. [P11]

I did have nights for quite a while, just one or two nights a week I think it was, but it kind of never really worked for me all that well. I had various problems with it really, probably specifically related to certain carers more than anything... often they would be asleep before I was... or if they were in (child)'s room, in fact she doesn't sleep very well, so once she knew somebody was there, that was it, she was not going to sleep. [P8]

It doesn't feel like your own home. You feel like it is a... you don't feel like a family because you have always got a stranger in your house. You can't relax as much as you normally would do, because you have got somebody else in your house. [P12]

Several of the WellChild Nurses reported the availability of 24 hour care for palliation/symptom management and end-of-life care for children with life-limiting illness. Although a number of children within the study were potentially life-limited, none of the parents made reference to the provision of end of life care/support.

■ Who to call?

Figure 5 includes a summary list of the range of clinical staff (and hospital departments) from whom parents might seek advice and support. This list is very similar to that provided by the Parent Reference Group in the scoping exercise which was undertaken in advance of the main study.

Analysis of the research interviews identified how parents actively try to make contact with somebody who actually knows their child. Parents described how they would try to access a clinician who is able to interpret their request for advice within the context of that member of staff's prior knowledge of the child. Parents observed that this helps to avoid the need to provide a very detailed clinical history.

In addition parents explained that professionals who know the child are less likely to suggest hospital attendance or admission. Participants in both groups also referred to the importance of parents having trust and faith in the specific clinician from whom they might seek advice – again predicated upon a pre-existing relationship.

Parental expectation of the support which they might receive from the family General Practitioner was quite consistent within the study sample, with parents explaining that they would make contact with the GP for minor childhood ailments, but not usually for more complex or 'specialist' issues.

But the GP doesn't know an awful lot about her and they always, they just tell me, like, 'you are best going to the people who know her.' [P4]

I only rarely ring the GP, only if I think he needs antibiotics, they don't really know much about him and they are happy to take my word that he needs antibiotics. [P9]

I find the GPs, not that they panic, but they don't, they don't know what to do. We've been a couple of times and if it is trachy related I am told to ring the hospital. [P5]

Out of hours GP would be (..someone..) who has never seen (child) before and would have to go through the whole rigmarole of explaining her background... and the one time we ran out of Co-Amoxiclav, it was a weekend, I rang the out of hours GP... as soon as he saw she was ventilated he said 'Take her to A&E'. I could have banged my head against the wall (laughing). [P11]

This view was echoed by the WellChild Nurses, particularly in relation to children receiving long-term ventilation at home.

We will invite them (GPs) into the hospital, invite them to discharge planning meetings but they very rarely engage, so if they have not got the experience of an LTV child, if a parent attempts to approach them for anything to do with ventilation, they will just refer them back to the tertiary centre. [N11]

The GPs have very little knowledge of a child on a ventilator or with a tracheostomy or even children who have got some strange metabolic disorder or some genetic disorders, so when the parents go to the GP, the GP usually asks the parents 'What would you do? You know your child, what do you think is wrong with them?' [N12]

I think sometimes if they are unsure, if their child becomes unwell, and quite often, because they don't really link in with their GP as perhaps a child with no health needs would probably do, whereas our children because usually they are having specialist care in the hospital, they quite often would want support either from the hospital or from the community team who are involved with them... we try to involve GPs as much as possible, because, you know, they should be involved in their care, but sometimes some of my parents (of children with long-term ventilation) they lack confidence with their GP. [N2]

This is perhaps unsurprising, particularly bearing in mind the clinical complexity of the children for whom the WellChild Nurses are providing care, it does, however represent a significant area of concern.

There was very little reference from either the WellChild Nurses or parents to the role of other primary care staff, such as health visitors, as a source of advice or support. In addition, there was no specific reference from either parents or WellChild Nurses to the role of community-based paediatricians as a source of advice and support.

Nurses and parents from a number of the study sites identified how parents might access local Community Children's Nursing Teams. This included teams who provided both evening and weekend work in different localities. In addition, nurses and parents described the availability of 24-hour access to on-call support for some children who were in receipt of Continuing Care packages - usually for trouble-shooting care package or staff/off-duty related queries.

Nurses and parents identified the use of a range of rapid access 'passports' or yellow/green/red cards that would allow children to be seen as a priority in both local and tertiary Accident and Emergency or Children's Assessment Units. Parents consistently identified this as a route to access senior clinical staff who already knew their child. Several parents reported that they would call the A&E/CAU for advice out-of-hours, once again offering the view that this allowed them to secure advice from a clinician who is already familiar with their child.

■ How to call?

Analysis of the interviews with both study samples revealed how the use of modern technology – mobile telephones, text messaging and e-mail allowed parents to access advice both during normal working hours and also when the nurses were not on duty. Comments from both parents and nurses were overwhelmingly positive in terms of the value of mobile working technology in allowing them to deal with a range of issues

in a timely manner, however, two of the nurses did comment on the need to establish clear boundaries and appropriate ways of working for out-of-hours calls. Analysis of parental comments indicated that they found the nurses to be responsive and there was very little evidence that the nurses considered calls, answerphone messages, text or emails that were made or sent out-of-hours to be inappropriate or intrusive.

I've phoned her many, many Saturdays and many, many Sundays. I phone her all the time. Simplest of questions, but do you know, like, she's never told me 'Don't phone me I'm on holiday, don't phone me it's the weekend.' I've always been told 'If you need me, phone me, if I can, I'll answer my phone.' [P4]

When dealing with out-of-hours issues that required a more immediate response, parents described the occasional use of emergency ambulance (via '999' calls) and direct land-line calls to Intensive Care/High Dependency Units/Transitional Care Units as well as Accident and Emergency of Children's Assessment Units. A number of parents also described how they used the land-line and mobile telephone numbers to access specific clinicians (including Registrar and Consultant Paediatricians), sometimes in order to request an urgent clinical review.

So if I am talking over the phone to someone, trying to get advice, if it is an emergency situation we need to get here (to the hospital) we need to be seen by the teams, that would be face-to-face. [P12]

The possible use of video-conference calls or photographs, for instance using Skype® or Facetime®, was explored with both parents and WellChild Nurses. Although experience was limited, there was significant enthusiasm from amongst both study groups who offered a range of uses to which this might be put.

From a nursing perspective this included:

- Respiratory assessments “If you can actually see them, that would be much better.” [N8]
- Wounds and dressings assessment: “Being able to take a picture and then perhaps email to the tissue viability nurse.” [N7]
- Communicating with the child: “Being able to ask them ‘are you okay?’” [N9]
- Communicating with the family: “To be able to see the family again, see how stressed they look, seeing the body language can tell you far more than what a voice call can do on the phone.” [N9]
- Saving time: “To see the child without having to go out, because it is half an hour drive there and half an hour back.” [N7]

Parental comments reflected a similar range of positive views on how video technology might be used:

- Clinical assessment: “‘cos if she had a sore stoma or something like that I could video it or take a picture.” [P5]
- Trouble-shooting: “You can talk to somebody on the phone, but if you’ve got somebody on Skype, and you are trying all these different things, to, I don’t know, get their saturations up or can’t pass the nasogastric tube or they are fitting, the Midazolam hasn’t worked and you are still waiting for the ambulance, then if you’ve got somebody on Skype, or something like that, then I would imagine that would be quite good really.” [P8]
- To provide a record of clinical events: “Because obviously if it (seizure activity) happens during the night when the Consultant was not there, at least I can record things.” [P6]

However parents and nurses both sounded notes of caution in relation to the possible use of a video assessment of a child who is acutely unwell at home:

But if you are really worried about something, there’s nothing like face-to-face contact. [P8]

I don’t know that a video, Skype, would make things any different. I suppose the responsibility would fall to me, if (on the basis of a video-assessment) I said ‘No, he looks okay’ or whatever clinical decision I decided, but then if the child deteriorates later on in the day, parents may potentially say ‘but the Nurse said he was alright, he could stay home, she saw him on video.’ [N10]

One additional concern raised about the introduction of mobile technology related to issues of possible connectivity. This was mentioned by two of the WellChild Nurses working in very rural locations, though both commented that this was also a problem with mobile telephone signals.

The added value of the WellChild Nurse

Analysis of the interview data provided insight into two particular aspects of how the WellChild Nurses offer specific support to children with complex health needs and their families.

These seemed to fall within two particular areas:

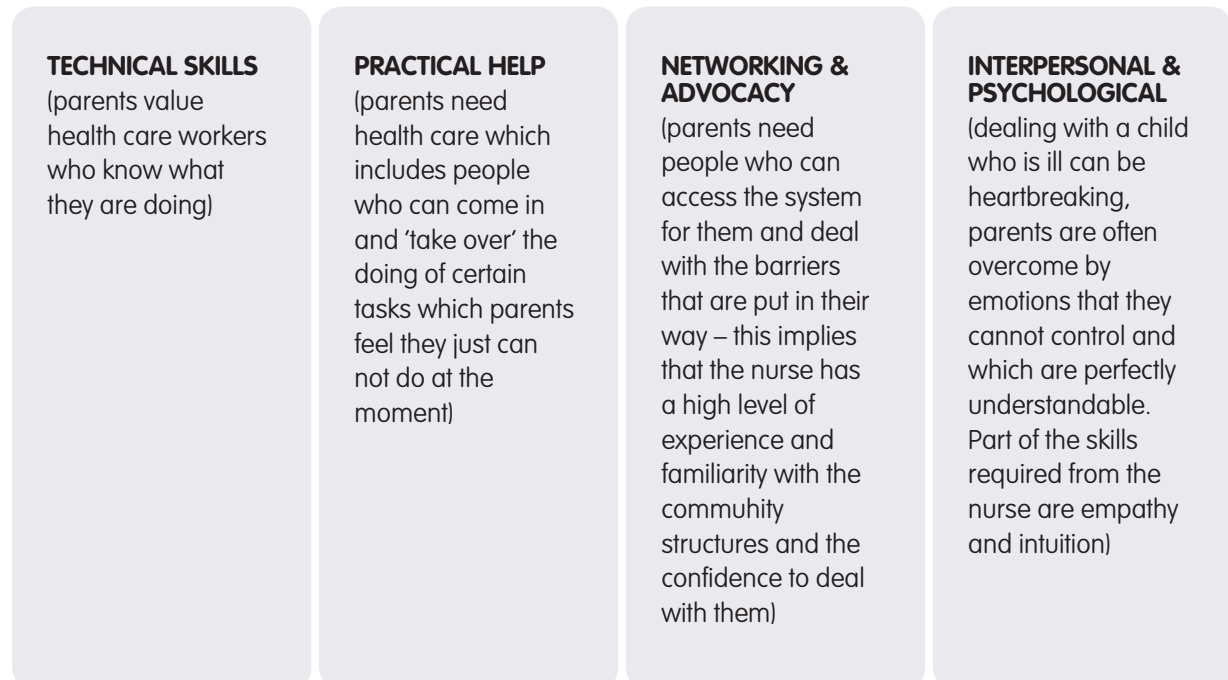
- **The multifaceted roles of the WellChild Nurse**
- **The particular role of the WellChild Nurse as key-worker**

■ The multifaceted roles of the WellChild Nurse

As illustrated in the discussion above, analysis of the interview data from both parents and nurses provided insight into the multitude of roles that were undertaken by the WellChild Nurses. Much of this work mirrors the findings of the study by Cash et al.

(1994) whose focus was upon parent-reported perceptions of the needs of children in the context of the work of Community Children’s Nurses and which revealed four key aspects of that work (Figure 6).

■ Figure 6: The multi-faceted roles of the WellChild Nurse (modelled on Cash et al., 1994)



Analysis of the WellChild Nurses interviews provided many examples of the technical skills element of the nurse’s role. This included non-medical prescribing [N9], passing/re-passing of naso-gastric or gastrostomy tubes [N2, N3, N4] administration of intravenous antibiotics [N3],

expertise in clinical assessment [N3, N7, N8, N11], symptom management and advice [N3, N7, P3] including in the context of end-of-life/palliative care [N6] and ventilator-related skills and knowledge [N2, N5, N9, N11, N12].

Both parent and nurse interviews provided multiple examples of the ways in which the WellChild Nurses offered practical help to children and their families. This included assisting parents in dealing with the practicalities of taking home a child with significant clinical complexity (and all of the equipment that goes with it!) [N2, N5, N11, P2, P11], the provision of algorithm based problems-solving tools and strategies to support parental decision making [N5, N9, P2, P3, P9] and trouble-shooting with equipment and delivery of 'medical' supplies [N1, N3, N4, P3, P1, P9, P11].

A significant area of work for the WellChild Nurses relates to **networking and advocacy** on behalf of children and their families. A number of elements of this role were evident within many of the interviews including: discharge planning [N3, N5, N11, P2, P3, P4, P11], coordination of care [N6, P6, P8], in particular involvement in and coordination of arrangements for the provision of packages of continuing care [N6, N8, N11, N12, P8, P11, P12] as well as a key role in linking between secondary and tertiary care centres [N3, N4, N5, N11, N12, P1, P4] and coordination of planned or unscheduled admissions to hospital [N9, N11, P3].

It was clearly evident from the parental interviews that the WellChild Nurses were considered by many of those parents as offering a significant source of **interpersonal and psychological support**. This included examples of how parents sought out, and the nurses provided, emotional support during particularly difficult situations [P4, P5, P12], as well as descriptions provided by the nurses of how they had offered a reassuring voice over the telephone at times of actual or potential crisis [N4, N8, N10]. In addition, the provision of practical advice and support related to specific problems was described by parents as being of considerable psychological benefit [P3, P4, P11]. This is also illustrated in the discussion by the nurses themselves of their roles in empowering parents [N2, N9, N10, N11] enabling them to take control of their situation. This might involve the provision of practical training in aspects of their child's care (in order to develop parental skills and knowledge) [N4, P3, P4, P9], or in supporting parents to allow them to develop the necessary confidence in their own ability to deal with both the clinical care of their child [P4, P9] and the need to navigate the complex multi-professional relationships that were essential elements of their child's ongoing care arrangements [P4, P11, P12].

■ The particular role of the WellChild Nurse as key-worker

There is, a long history of 'key-working' in relation to the support of children with disabilities and complex health needs and their families (Sloper *et al.*, 2006). In much of the commentary and research relating to key-working parents have identified the responsiveness and availability of the person whom they identify as their family's key-worker as being the feature which they consider to be most valuable. Analysis of the interviews from both parents and WellChild Nurses provided many illustrations of how the nurses playing out this key worker role. Various terms were used by parents to describe this: "first point of contact" [P2], "that

middle-person" [P3], "the person who is there for everything" [P4], "my link-worker" [P6], "the main person, the link-person" [P11], "my point of contact" [P8]. In relation to specific questions about what would make a difference to out-of-hours provision, one parent wondered whether it might be possible for the WellChild Nurse to "move in with us?" [P1]. These comments clearly illustrate the very high regard in which the WellChild Nurses are held by the families within this study. In addition, they highlight how many of the parents in this study view the WellChild Nurse as playing the role of key-worker in their child's care.

Discussion

Caring for children with complex care needs in out-of-hospital settings presents many challenges, both to the parents (and families) of those children and also to the health care professionals who provide care and support to them. This study has focussed upon the role played by a group of nurses, the WellChild Nurses, in providing one specific element of that professional support to a group of children, each of whom requires care throughout the 24 hour day. However, one thing that is abundantly clear from this small study, is that for children with complex health needs who are being cared for in the community, the primary responsibility for providing that care lies with their parents.

Anne Casey (1995) in her exploration of 'partnership nursing' described two related aspects of the caring role which are undertaken by parents and by children's nurses:

- **Family care** - the care which the child or parents usually carry out to meet needs
- **Nursing care** - the extra care which the child may need in relation to a health problem

Casey's study, which was undertaken in hospital settings, highlighted that where nurses and parents work successfully in a 'partnership', negotiation between the nurse and parent allows both parties to take on each of these two aspect of the caring role at different times and in different phases of the child's hospital experience. Taylor (2000) examined how, in the context of community children's nursing provision, the relationship between nurse and parent takes on a different dynamic when care is delivered in the child's (and parent's) own home. In such settings, there is a subtle shift in the 'balance of power' between the parent and nurse. However, the nurse is only a visitor in the child's home and for

those periods through the 24 hour day when the nurse is not present, parents clearly have to take responsibility for delivering both 'family care' and 'nursing care'.

In 2015, WellChild introduced a major campaign – "#notanurse_but" whose purpose is to highlight the challenges faced by parents in taking on the often non-negotiated role of nurse, doctor, physiotherapist, dietician etc. for their child:

"Providing high level medical care to keep these children and young people at home together with their family is a 24/7 job and can include regular complex procedures – from giving physiotherapy to operating a range of highly technical equipment such as nebulisers, suction, feeding tubes, pumps and ventilation." (https://www.wellchild.org.uk/news_item/wellchild-parents-launch-campaign-notanurse_but).

Many of the parents in this study are clearly taking on roles which are significantly beyond those which they might reasonably have expected to take on in parenting their child.

Through the use of semi-structured interviews with twelve WellChild Nurses and ten parents, this small study provided insight into how parents experienced their caring role throughout the 24 hour day and focussed particularly on the question of how parents seek out advice and support 'out-of-hours'. Analysis of the interview data from both groups of study participants identified four interrelated questions which informed the actions that parents take in order to gain access to 'professional advice'. These questions are summarised in Figure 7, opposite (see Figure 5 for more details).



■ **Figure 7: Seeking advice and support throughout the 24 hour day – summary**

The study also revealed how parental decision making in such circumstances is informed by many factors including;

■ **Anticipatory preparation:**

Including in-depth training by WellChild Nurse and other professional staff

This is supported by the provision of care plans, algorithms, trouble-shooting guides etc.

Thinking and planning ahead, including parents making contact with professionals during 'office hours' for instance when their child is exhibiting 'early' clinical symptoms

■ **Experience, knowledge and skills in meeting their child's care needs:**

Often based upon several years of experience caring for their child at home

■ **Knowledge of and skills in navigating 'the system':**

Direct line telephone numbers to access high dependency wards or contact numbers (including mobile telephone numbers) of key staff

Access to dedicated out-of-hours support for some children in receipt of NHS continuing care.

Provision of rapid access 'passports' allowing child to be seen as a priority

■ **Development of confidence and trust:**

In key professionals including senior paediatric medical staff and WellChild Nurses

A positive sense of empowerment which was identified by both parents and nurses as a key factor in parental decision making

Although the parents within this study were all able to identify circumstances in which they might seek clinical advice, support and care out-of-hours, both the WellChild Nurses and the parents themselves reported (largely as a result of the factors set out above), that their actual use of and need for such support and care, particularly through the night time, was somewhat limited.

The WellChild Nurses described patterns of working (including availability to receive and respond to text messages, emails, phone calls and voice-mail messages) that extended in many instances well beyond their formal work day. Almost all of the parents in the study confirmed that they had made contact with the WellChild Nurse 'out-of-hours'. Although some nurses commented upon the possible intrusiveness (into their personal life) of this way of working, most did not consider this to be problematic. However this approach does potentially give rise to issues of clinical governance and may merit further consideration.

The WellChild Nurses were generally receptive to the suggestion that community nursing services provision, specifically to the parents of children with complex health needs, might be developed to offer more extensive 'out-of-hours' provision. There was, however, very little support from the nurses to the suggestion of a possible need for an overnight community children's nursing service. This view was largely predicated upon a belief that there was a lack of evidence for the clinical necessity for such a service. In addition, the WellChild Nurses identified issues of workforce skills, workforce capacity and lack of financial resources which they felt would limit the potential to develop such a service. It is important to recognise, however, that the WellChild Nurses whose roles involved supporting families who were in receipt of packages of overnight Continuing Care were strong advocates for the provision of such care – and that where clinically appropriate this should be care throughout the 24 hour day.

As discussed above, the development of the content of the semi-structured interviews for this study, had drawn upon the expertise of members of the Parent Reference Group (PRG). This group had been asked to identify gaps in the provision of out-of-hours support based upon their own experience (parent question 5, Table 2, page 12).

A number of specific issues were highlighted by members of the PRG including:

- Difficulties in resolving late notice cancellations of overnight continuing care arising as a result of staff sickness.
- Problems which are beyond the skill set of the out-of-hours GP service, including lack of specific knowledge/experience of 'my child'
- Dealing with unpredictable challenging behaviour
- Need to replace naso-gastric tube
- Travelling times and distances for both parents and staff, particularly in rural settings
- Need to access nurses both for telephone advice and to sign-post/secure further access to expert paediatric medical advice.
- Long gap between 5.00 pm and 9.00 a.m.
- Lack of specialist knowledge in accident and emergency departments.

The issues raised by the Parent Reference Group are very clearly consistent with those reported by both parents and WellChild Nurses within the main study.

Conclusions

The care of children with complex health needs has shifted at a very rapid pace in recent years from taking place largely in hospital settings to the current situation in which ever growing numbers of such children are being cared for 24 hours a day in their own homes. Data relating to the actual numbers of 'complex-needs' children being cared for in the community is somewhat limited and this provides significant challenges in relation to how health care services might need to develop in the future in order to ensure that appropriate professional support and care is available to families caring for such children outside of hospital settings.

During the course of the last thirty years in particular there has been a dramatic growth in the provision of Community Children's Nursing Services, many of which contribute significantly to supporting the care of this group of children. However CCN teams are also supporting children with acute care needs, children with long-term conditions and children who require palliative/end-of-life care and there is tremendous variability within CCN services provision at a 'local' level in terms how they are configured and commissioned to meet this diversity of clinical care needs.

Since its introduction in 2006 the WellChild Nurse programme has provided a particular focus upon the needs of children with complex health needs in the community. The programme now boasts a network of 32 WellChild Nurses. In addition to the Nurse programme, WellChild has always been concerned to ensure that the views and experiences of children, parents and families continue to inform and guide everything it does - "Our work is shaped by those around us: we ensure all our work is informed by the voice of the people we support and work with." (<https://www.wellchild.org.uk/about-us/our-values>).

Based upon semi-structured interviews with a small cohort of parents of children with complex health needs and the WellChild Nurses who are supporting them, this study set out to shine a light upon how those parents experience care for their child throughout the 24 hour day. It has provided a rich insight into those experiences, revealing how many of those parents, supported by the WellChild Nurses have become experts in their child's care. The WellChild Nurses have taken on significant roles as child and family advocates, are identified by many of the parents as key-workers and are clearly working in close partnership with parents, empowering them to take control of their situations. This in itself is a major factor in determining how each of this small cohort of parents have been able to coordinate their child's care throughout the 24 hour day.

Analysis of parent and nurse interviews revealed how, with good anticipatory planning, parental recourse to professional support out-of-hours and in particular overnight, can be kept to a minimum. However on those occasions when parents do need to seek advice, support and care out-of-hours, this study has identified four key questions which form the basis for parental action:

- What time of day is it?
When to call?
- Why am I looking for support/help/advice?
Why call?
- Who do I think is the right person to give me that support/help/advice?
Who to call?
- How do I get in touch with that person?
How to call?

Recommendations

- 1** That WellChild give consideration to how it might contribute to establishing a robust and sustainable information resource/database of the incidence of complex health needs in children throughout the UK.
- 2** That WellChild explore further the relevance of the lead-professional/key worker role in respect of how it relates to current provision and future development of the WellChild Nurse programme
- 3** That WellChild consider how it might work with the WellChild Nurses to ensure that the model is sustainable at a local level ensuring that their role in the provision of 'out-of-hours' care is clearly understood by all stakeholders.
- 4** That WellChild continue to work with parents, WellChild Nurses and other stakeholders in order to establish insight into and understanding of the impact upon families of providing 24 hour care to children in the community
- 5** That WellChild continue to work with all relevant stakeholders in order to ensure that the commissioning of CCN services includes a clear focus upon children with complex health needs in the community. It is important to recognise that this particular group of children and their families are likely to need to access care and support outside of a 'normal' working week. Those who are responsible for both the commissioning and the provision of such services will need to assure themselves that parents are able to access support at times and of a nature that is responsive to the needs of both individual children and to the overall population of children with increasing levels of complexity who are being cared for in the community.

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Appendix 1



Project interview schedule – WellChild Nurses

Project Title: "24-7 Care in the Community"

Name of Researcher: Professor Mark Whiting, University of Hertfordshire

Interview Schedule

"I am here today to talk with you about the provision of 24-7 or out-of-hours care for children in the context of your role as a WellChild Nurse. I wonder if you could possibly start by telling me about your current role?"

PROMPTS:

- How long in current post?
- Nature of caseload, clinical conditions, number of children etc?
- Days/hours of work?

"In terms of your current role, what has been your experience to date of 24-7 care for the children on your caseload?"

"In the context of your work as a WellChild Nurse, for what reasons do you think families might want to access professional health advice/care/support outside of the Monday to Friday, 9-5 week?"

"When parents are looking for advice out of hours, to what extent do you think this is advice that could be dealt with... over the telephone?"

"And in what circumstances do you think parents might prefer to see a clinician face-to-face?"

"Which particular skills and knowledge are parents looking for and which clinicians are the most appropriate for providing advice/home visits?"

"Why doesn't your service operate 24 hours a day?"

"Would an on-call service work? If so how might this operate?"

"What might be the benefits of providing a more extensive service?"

"Could you describe any potential down-sides of extended services?"

"Thank you very much."

Appendix 2

Project interview schedule – Parents

Project Title: “24-7 Care in the Community”

Name of Researcher: Professor Mark Whiting, University of Hertfordshire

Interview Schedule

“I am here today to talk with you about the provision of 24-7 or out-of-hours care for children who are receiving care from a WellChild Nurse. I wonder if you could possibly start by telling me a little about your child?”

PROMPTS:

- Name
- Age, date of birth
- Diagnosis

“Could you possibly tell me a little about the specific care provided by the WellChild Nurse?”

PROMPTS:

- “What days/hours of the week is this available?”
- “And out of hours?”

“In terms of support provided by the WellChild Nurse, what has been your experience to date of 24-7 care (if necessary, offer reassurance that this is not intended in any way to criticise what the WellChild Nurse is offering/providing?”

“Bearing in mind your own child’s care needs why might you want to access professional health advice/care/support outside of the Monday to Friday, 9-5 week?”

“In what circumstances might you be seeking advice that could be provided over the phone?”

“And in what circumstances do you think that a face-to-face contact might be necessary?”

“Which particular skills and knowledge might you be looking for and which clinicians are the most appropriate for providing advice/home visits?”

“Do you think that services should be available 24-7? If so which services, which staff?”

“Would an on-call service work (explain “on-call” if necessary)?
If so what would you be looking for from an on-call service?”

“What might be the benefits of providing a more extensive service out of hours?”

“Is there a down-side at all?”

“Thank you very much.”

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