

# Community Children's Nursing in the 21st Century:

## Developing and Strengthening CCN Services



With the right education and investment in these services, more young people will receive the care that they and their families need and wish for.

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## Foreword

Community Children's Nurses (CCNs) provide a vital service to children and young people with complex and often long term illnesses and disabilities, delivering care to some of the most vulnerable. They also give physical and emotional support to the families and carers of their patients,

The Queen's Nursing Institute wished to gather intelligence from these specialists about the challenges and opportunities in this area of practice, to understand the trends impacting on the service for the benefit of nurses, commissioners and patients, and to help inform new education and practice standards for the specialism.

The findings of the survey demonstrate the enormous commitment, dedication and enthusiasm of Community Children's Nurses and their confidence in the difference they are able to make for children, families and carers. There is significant evidence for the need and the desire for further education and development in the specialism, via the specialist practice qualification. However there is a lack of capacity in the system to provide for this.

CCNs are also concerned that their contribution can be overlooked by commissioners and policymakers, who lack knowledge of the great potential of CCNs to further the policy goals of delivering more high quality care in or closer to the home. Moreover, many CCNs foresee a steady growth in demand in their services as more seriously ill young people live for longer with multiple, complex health conditions.

In due course, many of these young people will transition into adult community health services, which is a cause for celebration and a testament to the amazing care many of them will receive from their Community Children's Nursing team. With the right education and investment in these services, more young people will receive the care that they and their families need and wish for.

Dr Crystal Oldman CBE  
Chief Executive, The QNI

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**Children have very specific health needs and practitioners need to understand how a healthy child develops towards adulthood.**

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## **Headline Findings**

- 73% of Community Children's Nurse (CCN) teams have at least one member with a relevant Specialist Practitioner Qualification
- Most Community Children's Nurses have worked in the specialty for a relatively short time – 33% for less than five years and a further 25% for less than ten years
- 82% of respondents had a formal mentorship role and 97% of CCN teams offer pre-registration nursing student placements
- Over 70% of respondents did not expect to retire from the profession for 10 years. However 29% of those who responded expected to retire within the next five years
- 47.5% - almost half – of respondents indicated that their teams had to refuse referrals at certain times, due to capacity issues
- 35% of CCNs indicated that they used annual leave entitlement in order to undertake professional development opportunities.

## **Rationale for Survey: New Education and Practice Standards**

The Queen's Nursing Institute (QNI) and the Queen's Nursing Institute Scotland (QNIS) published new Voluntary Standards for District Nurse Education and Practice (2015) and General Practice Nurse Education and Standards (2017). In 2017 the QNI and QNIS undertook to produce new Voluntary Standards for Community Children's Nurses (CCN).

To help inform these new standards, the QNI carried out an online survey with Community Children's Nurses to help understand the current challenges and opportunities in this specialism. This report summarises the responses to that survey.

The survey was hosted on the SurveyMonkey online platform and was open from October to December 2017. It was promoted to nurses via the QNI's email database and through social media. The survey consisted of 33 questions and there were 348 individual responses.

## **Introduction: Community Children's Nursing**

Children have very specific health needs and practitioners need to understand how a healthy child develops towards adulthood, to minimise the impact of illness. Children and their families can find it easier to receive treatment at home, rather than attending hospital, for certain conditions, particularly long term conditions.

There is a clear policy shift to community based, integrated health and social care in all UK countries and an enhanced focus on admission avoidance, early discharge and greater support for families and others caring for children and young people with complex needs in the home and other community settings. The number of school aged children living in the UK with complex needs has increased dramatically by over 50% since 2004 from 49,300 to around 73,000 today (Understanding the needs of disabled children with complex needs or life-limiting conditions, Council for Disabled Children, 2017).

The Community Children's Nursing service is central to the provision of health and care in the UK for children, young people and their carers. Children's Community Nurses are expert practitioners, who consider the care and support needed by the wider family, including parents and carers.

To ensure that the needs of children who are ill or who have a disability are met, four groups have been identified as needing appropriate services (NHS At Home: Community Children's Nursing Services (NHS 2011). These are:

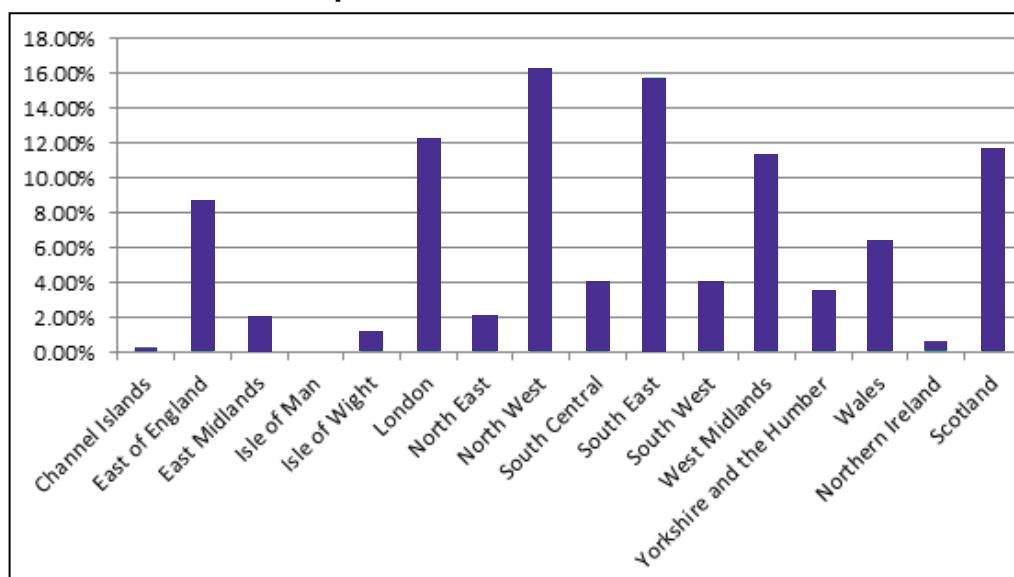
- children with acute and short-term conditions;
- children with long-term conditions;
- children with disabilities and complex conditions, including those requiring continuing care and neonates; and
- children with life-limiting and life-threatening illness, including those requiring palliative and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

Community children's nursing (CCN) services are the bedrock of the pathways of care for these groups of children.

Community Children's Nurses also have a major role to play in the transition of young people to adult community health services, typically when they reach the age of 19. The Queen's Nursing Institute has undertaken a major programme of work, funded by the Burdett Trust for Nursing, to support nurses with tools and information about the transition process. More information can be found on the QNI's website at: <https://www.qni.org.uk/nursing-in-the-community/from-child-to-adult/>

## Survey Results

**Table 1. Location of Respondents**



Respondents were from all four countries of the United Kingdom and one from the Channel Islands. Respondents were employed by a wide range of organisations, with the large majority being employed by hospitals, by community healthcare providers, with a significant minority being employed by integrated trusts as shown in Table 2.

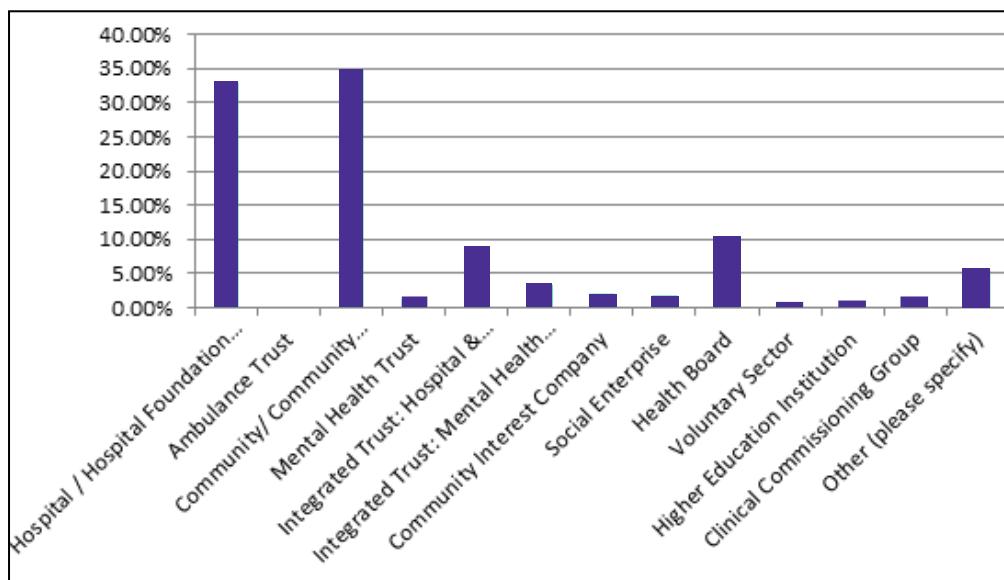
## The Community Children's Nursing service is central to the provision of health and care in the UK for children, young people and their carers.

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Those that responded 'Other' were asked to give further details and indicated a range of private and third sector employers. Respondents were all employed within Community Children's Nursing Teams.

Their job titles ranged from Staff Nurse to CCN Team Lead to associate Directors of CCN teams, reflecting a wide range of levels of seniority.

**Table 2. Employing organisations of staff in Community Children's Nursing Teams**



Respondents to the survey were based in offices in a variety of settings, which reflects the diverse locations in which healthcare workers are based (Table 3).

'Other' included business parks, child development centres, children's hospices, council buildings, community hospitals, and GP surgeries.

Respondents were asked to indicate whether they worked full or part time. 215 respondents, representing just over 62% of the total, said that they worked full time. Of the remainder, the large majority (32%) worked from 20-30 hours per week.

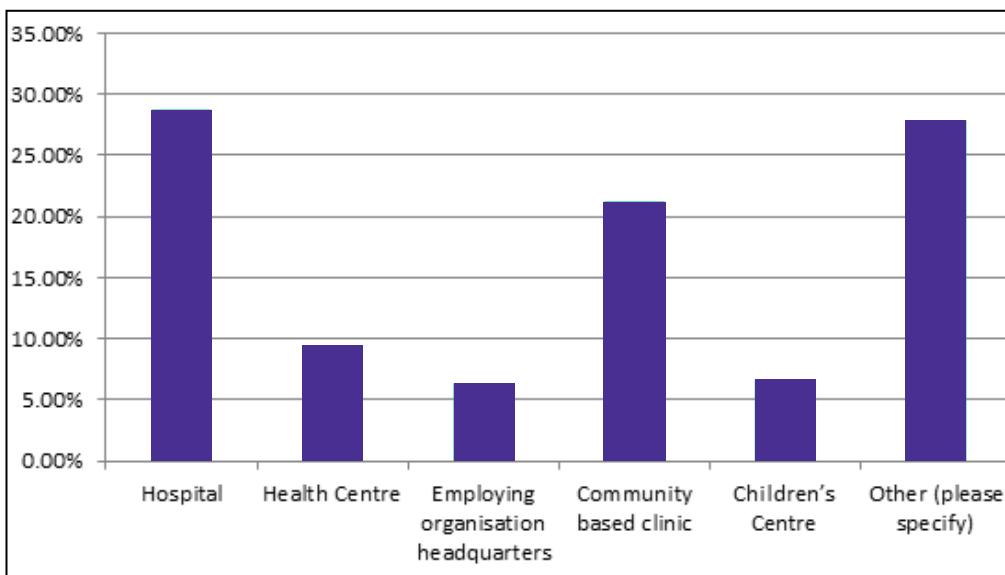


The proportion of those who had worked in CCN teams for longer periods declines steadily over time.

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### Length of Time in Specialism

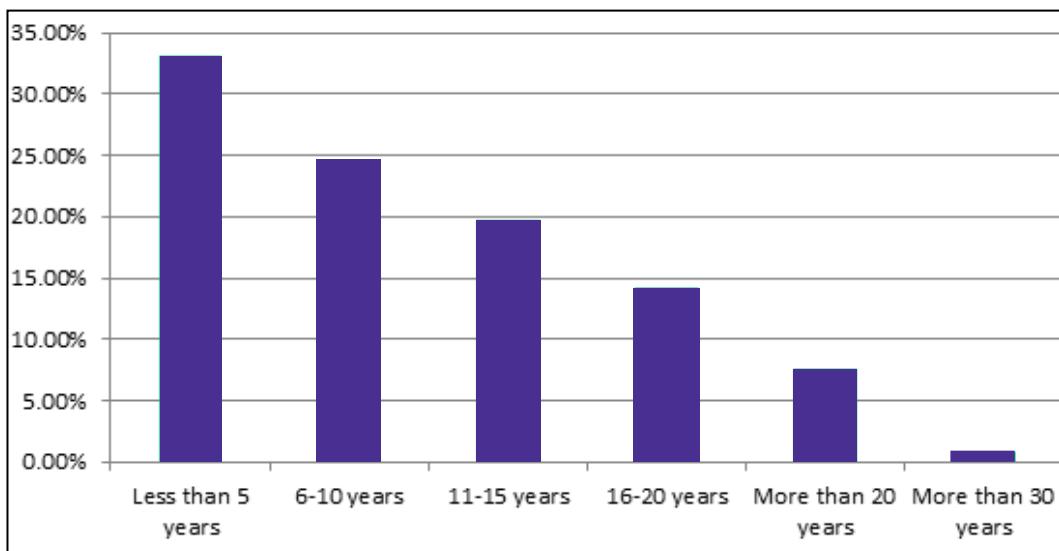
**Table 3. Primary Place of Work**



Respondents were asked how long they had worked in the community children's specialism. The largest proportion, 33%, had worked in the specialism for less than five years (114 out of 345 in total who replied to the question). The proportion of those who had worked in CCN teams for longer periods declines steadily over time, as shown in Table 4. This may reflect the fact that it is a relatively recent area of specialism.

### Expected Retirement Date

**Table 4. Length of time worked as a CCN**

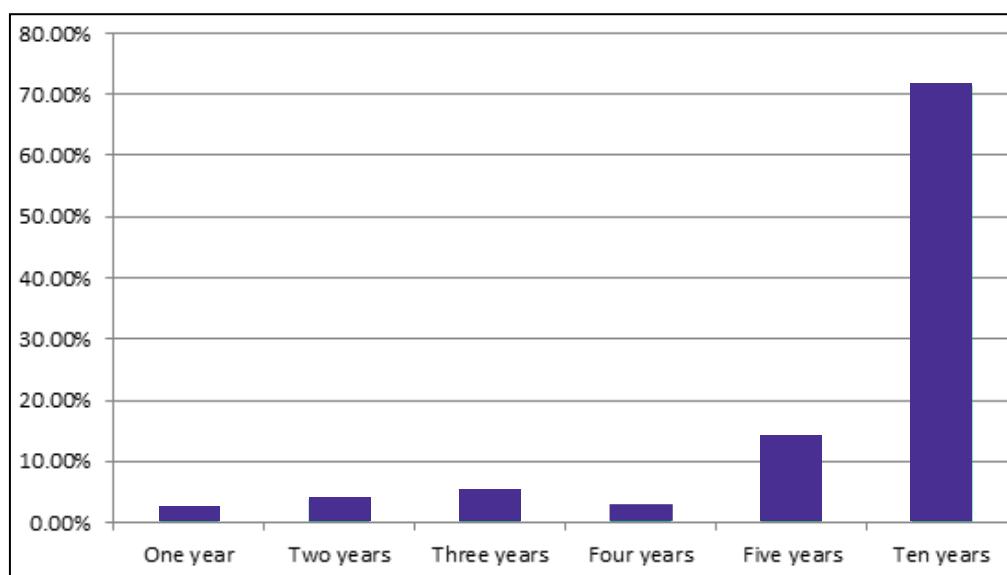


Respondents were asked when they expected to retire from the nursing profession and the responses are shown in Table 5. 234 people answered the question and 191 of these – 71.5% - answered ten years.

81 people skipped the question, which may suggest that they had not considered when they expected to retire, or believed it to be more than ten years, or were uncertain of their retirement date. However, a total of around 29% expect to retire within the next five years.

When the same question asked of General Practice Nurses, over 33.4% predicted they would retire within the next five years (QNI 2016). Therefore, the anticipated retirement date of nurses in these two specialisms is not very dissimilar.

**Table 5. Expected Retirement Date**



### Skill Mix within the Team

Respondents were asked to indicate the degree of skill mix within their team (Table 6). Respondents to the question were able to tick all the job roles that applied within their team.

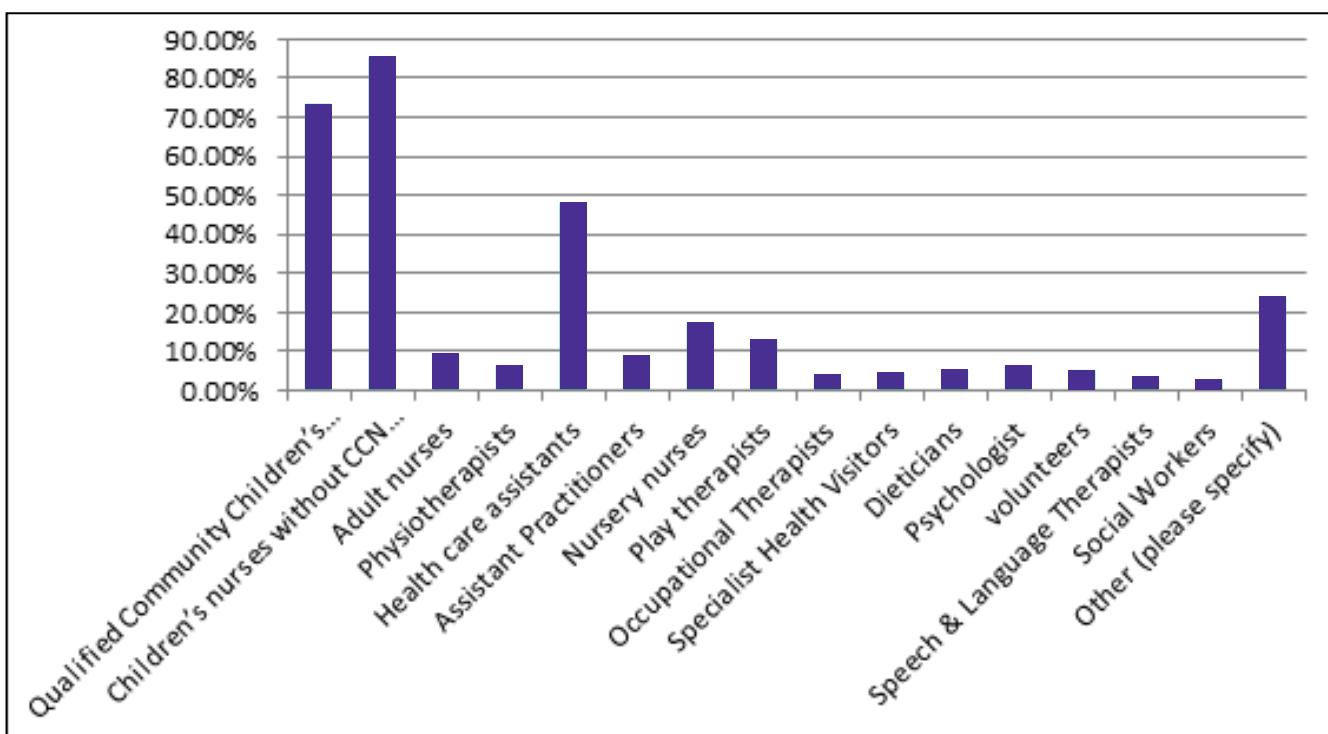
73% indicated that their teams included CCNs with a specialist NMC recordable qualification. This suggests that 27% of teams do not include a CCN with a recordable qualification. 85.5% of teams included children's nurses without the specialist qualification and 48% of teams included Health Visitors. 24% of teams included other staff and further detail of these indicated administrative staff, Learning Disability specialists, Counsellors, palliative care specialists, various specialists and support workers.

Respondents were asked whether, in their organisation, all leaders of community children's nursing teams were required to have a specialist NMC recordable qualification. 130 respondents (38%) said yes, while 208 (61.5%) said no. Ten respondents did not answer the question. Respondents were asked what other qualifications were required in order to become a Children's Community Team leader in their area. Answers were diverse, including a community qualification, experience, an undergraduate or master's level nursing degree, nurse practitioner qualification, or no additional requirement. In some cases, respondents indicated that a colleague in an acute setting managed the service.

47.5% of respondents indicated that at times, their team had to refuse referrals.

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**Table 6. Skill Mix within the Team**



## Demand and Capacity

The survey asked if their team ever refused referrals because of capacity issues. 47.5% of respondents indicated that at times, their team had to refuse referrals. Comments from respondents suggested common themes including recruitment and retention problems, allocating staff to home visits, lack of available colleagues including GPs. In many cases, respondents suggested that the lack of community capacity meant that patients were referred back to hospital settings.

*'This has never been an issue for our team. However, recent recruitment and retention problems are greatly stretching the resources of the team. We have previously moved a Continuing Care package to agency provision due to poor resources and not being able to provide continuity for the child and family.'*

*'Occasionally if there are numerous intravenous antibiotic infusions (lasting more than an hour) referred at the same time, but [this] has not happened recently. If we have an end of life case we may need to prioritise and change planned visits to another day.'*

*'Due to underinvestment we have developed a risk framework identifying the interventions that need to be undertaken by CCNs/Children's Nurses, interventions that could be done if capacity - if no capacity support from alternate resource such as specialist nurses, paediatric assessment units. Interventions that are currently provided by other practitioners such as public health nurses and practice nurses recommending mapping of services and how we work together to ensure positive outcomes.'*



## Individual comments suggest a great degree of diversity in career paths for CCN team leaders.



*'This is rare. We will generally accept the actual referral but may have to negotiate with the acute centre for the patient to return there for part of their treatment. An example would be administration of cytarabine - where there may be a lack of additionally chemotherapy trained staff to administer. Also, sometimes there can be a surge in daily IV referrals where we may need to ask children/young people to use their acute centre for a few doses as we are unable to administer them all within the prescribed timescale across our large geographical area.'*

*'We have a small team and try our best to see all referrals. At times of capacity issues we opt to see patients in a clinic setting in the hospital so they can still be seen promptly and by a team they are familiar with. It also stops them from having to attend inpatient areas with often lengthy waits, as they aren't seen as a priority. This often happens at weekends when there is only one member of staff on and when we are giving end of life care and cover a 24 hour rota.'*

*'Due to staffing levels either due to lack of substantive post holders or due to staff being taken to cover service on the wards there is often a 'hold' on community services other than continuing care.'*

### **Education and Training**

Respondents were asked whether they held the NMC recordable qualification in Community Children's Nursing. 39% responded yes and 61% responded no.

The survey then asked, if the respondent was a CCN team leader, what education and training they had in order to prepare them for the role. There were 208 individual responses to the question, though some of these indicated that they were not team leaders. The types of preparation that were listed by respondents included:

- SPQ in CCN degree
- Qualifications and experience in other community nursing specialisms
- In-house leadership training
- External leadership training
- Mentor and assessor experience
- Experience in other community nursing specialisms
- Experience gained on the job.

Individual comments suggest a great degree of diversity in career paths for CCN team leaders. Examples included:

*'I had nine years experience working as a CCN in the team, before I got the role of team leader willing to complete CCN degree. I finally got a place at ... university in 2014 but they were unable to run the course as there were only two applicants. It would have been very difficult to commute as travelling to Wales for sessions.'*

*'No formal education and training, specific to team leading. Seven years as deputy team leader and currently undertaking an in-house Essential Leadership and Management course.'*

*'I have achieved my SPQ CCN qualification via distance learning from ... university over two years while working full-time as a community Children's Staff Nurse.'*

*I am an RGN, RSCN, Nurse Prescriber, CCN and hold PGCE as well as interview, sickness and appraisal management training. I also hold IOSH qualification which assists with Risk Assessments.'*

*'RGN, RSCN, ENB415, ENB998, BSC hons, V300 NMP (L7), Palliative and end of life care course (L6), Good day at work leadership programme, Incident investigation training, Coaching course, advanced communication skills training.'*

*'I am a children's nurse, have the Specialist practitioner course, nurse prescribing, community practice teacher qualification, coaching qualification and an MBA.'*

*'Based on experience of working in the field. Would love a qualification and would love the whole team to have a qualification to bench mark our practice and recognise the specialist skills and care we provide. Funding seems to be main barrier to accessing courses and not being sure about what course to access.'*

## **Specialist Practitioner Qualification**

Respondents were asked whether their employer provided support for community nurses to undertake the CCN SPQ at a university. 50% responded yes, while 21% responded no and 29% gave comments. These largely indicated that their employer would support nurses to undertake the course in principle, but that a number of obstacles made this unrealistic in practice. The main barriers listed were on common and interrelated themes:

- No course available within reasonable travelling distance
- No courses available at all in Scotland
- No backfill available within the team
- Lack of time available to undertake the course, given workplace and other pressures.

Further comments included the following:

*'The organisation would support CCN education for succession planning, as I am the only nurse within the team with the qualification. But unfortunately in Scotland there is currently no education offered within this sphere of practice, but certainly something I would support.'*

*'I completed the course as a pilot study, online over two years, via Wales University. No longer available due to high percentage of students pulling out of course, as not securing enough time to study/revise.'*

## **Other Educational Opportunities**

Respondents were then asked if no degree qualification was accessible, what other education or development opportunities are made available to nurses leading the CCN team. The question allowed for multiple choice answers, shown in Table 7, representing a total of 240 individual responses. Additional comments included:

*'All the above [Table 7] apply and are well supported. Additional funded modules are available at two local universities - however the new apprenticeship process has caused considerable disarray and the new process is unclear. The other qualification supported in our service is the Nurse Practitioner - Child qualification. This*

When asked if their employer allocated a certain number of days for professional development, 89% responded 'no'.



*has similarities with SPQ CCN and has been easier for some staff to access using a modular format rather than a full-time attendance or two year part-time attendance. This has generally been related to work/life balance/childcare issues.'*

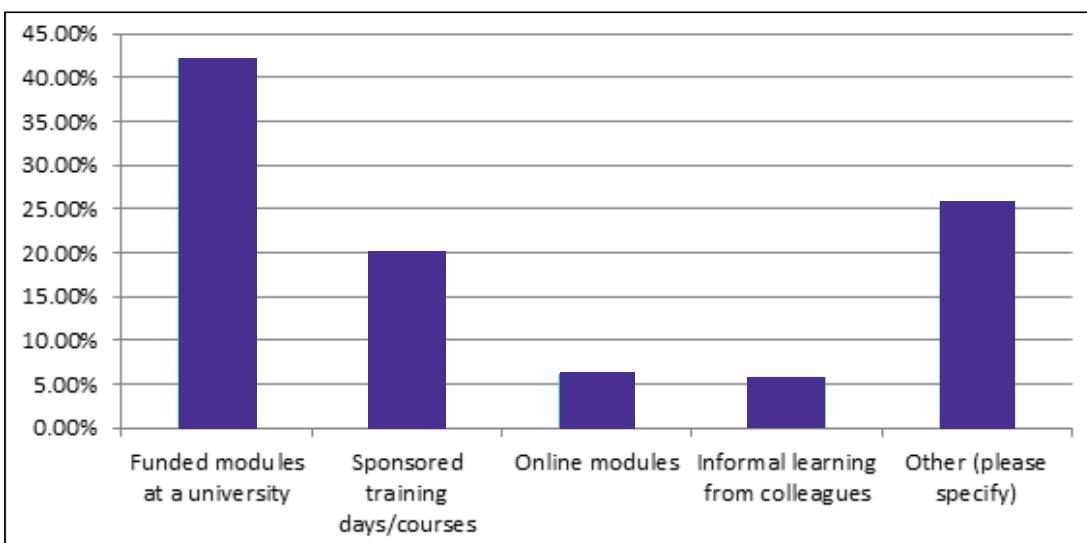
*'Combination of funded University modules, sponsored training days/courses, attending consultant study days, CNS training and study days and informal learning from colleagues.'*

*'Our organisation offers an in-house leadership and management module course but it is not a recognised course. Study days are accessible if needed. I am currently looking into an online module for flexibility.'*

*'Very little funding is allocated and we are often refused conferences and study days or uni modules due to this. They will only fund the SPQ on a rare basis.'*

*'We've been very fortunate to have charity funding from the Hertfordshire Community Nurses charity for short modules and study days, don't know what we would have done without it.'*

**Table 7. Other educational opportunities for nurses leading the CCN team**



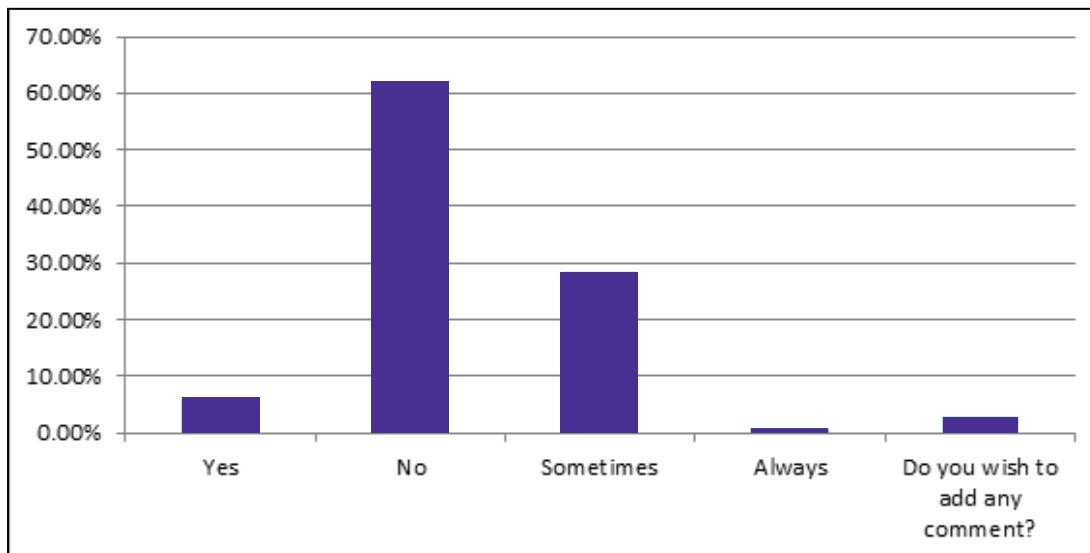
The survey asked, 'does your employer support/encourage your professional development linked to your appraisal?' 94% of respondents said yes; 6% responding no. However, when asked if their employer allocated a certain number of days for professional development, only 11% responded positively and some of those were uncertain about their entitlement: 89% responded 'no'. 35% indicated that they used annual leave days in order to further their professional development (Table 8).



The most common professional development was study days provided by the employer or by a commissioning organisation.

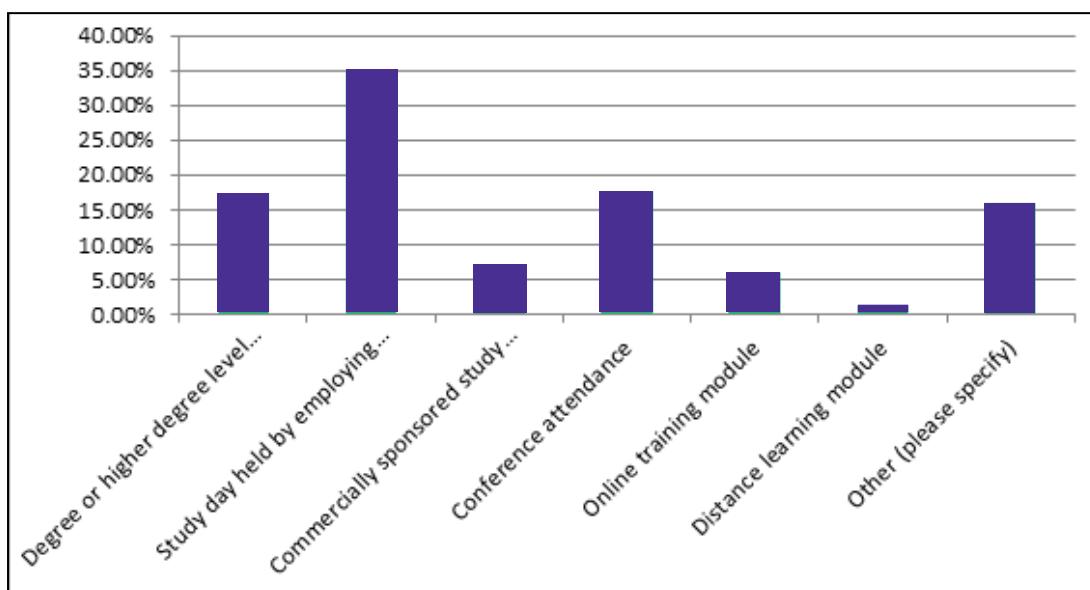


**Table 8. Annual Leave used to undertake Professional Development**



Respondents were asked, apart from mandatory education and training, what type of professional development they had undertaken in the previous year (Table 9). By far the most common response was study days provided by their employer or by a commissioning organisation (35%). The importance of conference attendance (17.5%) was also very evident. Those who responded 'Other' either indicated that they undertook a combination of different opportunities, or indicated that they were supported to undertake activities by an acute trust, charity, commercial sponsor or other organisation. Eight respondents answered 'none.'

**Table 9. Professional development undertaken in the past year**



## Mentorship and Teaching

The survey asked respondents if they were a qualified mentor (i.e. had undertaken a specific NMC approved training course). 82% indicated that they were qualified mentors.

Respondents were asked if they were a qualified Practice Teacher (i.e. had undertaken a specific NMC approved training course) and 11% indicated that they were Practice Teachers.

In response to the question, 'does your team accommodate pre-registration student placements?' almost 97% responded affirmatively.

Respondents were asked if they had any additional comments to offer regarding education and training. 163 nurses had additional comments to offer.

*'Local Uni does not offer SPQ CCN course therefore undertaking the course involves extensive travel for some members of the team. CCN remit is vast and there seems to be a lack of training opportunities targeted at improving the lives of CYP [Children and Young People] with complex health needs and their families around the area local to me. Collaborating with CYP with disabilities and person centred care is lacking.'*

*'It is hard enough finding a course which is Paediatric. Trying to find training/education which is aimed at what we do and the environment in which we work is very difficult.'*

*'Specific courses that are applicable to CCNs are few and far between. I am currently doing SPQ, but it is mostly health visitors and district nurses, and I am travelling a very long way in order to do it as nothing closer, this has also impacted the funding by HEE as it's not a university they have an arrangement with.'*

*'The most valuable aspect of CCN training for me has been learning about community strategy for all public services and how we can all link to ensure the child and family receive truly integrated care. The nursing competencies for provision of care must include the complexities in management of complex care in the community and case management of care packages and how we do this in a co productive way. Transition to adult services is another area which requires skill and knowledge around the transfer of care especially for those requiring CHC. This needs to include managing expectations, mental capacity and advocacy and best interest decision making. A knowledge of finance and entitlements is an added bonus.'*

*'I feel that because the CCN course was not run by universities for a few years we cannot now specify a CCN qualification as a requirement when recruiting team leaders/managers. I think this is a great loss as the knowledge and experience it brought was immeasurable. We are caught in a vicious circle in that nurses do not have to undertake the CCN course to progress because we will not recruit if we stipulate that as a requirement. I also feel that there is not enough relevant bite sized modules that nurses with a wealth of experience could access to understand and better work within the community. The community is not an easy place to work and needs knowledge and skills. There is currently a lack of understanding concerning this and a lack of relevant effective courses.'*

*'The current level of training for pre reg students does not adequately educate them to work in the community without post reg experience. The nature of high risk autonomous practice means that their competency cannot be assured.'*

**'It is vital this course is available to CCN teams to ensure children and young people's needs are recognised, met and for future provision of services.'**



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*'We only have two staff with the CCN qualification out of 20 CCN staff.'*

## **Unique Skills of Community Children's Nurses**

Respondents were asked what the main three benefits of undertaking the CCN specialist practice qualification were, in their opinion. There were 250 responses, which highlighted the following key skills. Those answers that were given most commonly are indicated with a number.

- Gaining a better understanding of the CNN role and developing relevant skills: 70
- Clinical knowledge acquisition: 63
- Self-recognition and peer recognition of SPQ status: 51
- The opportunity to network and share practice ideas: 47
- Benefiting from strong nurse leadership: 30
- Improved ability to undertake service planning and development: 22
- Gaining personal and professional development: 21
- Gaining a greater appreciation of available services: 20
- Improving understanding of health policy and related politics: 20
- Gaining confidence in oneself and autonomy in one's practice: 20
- Being able to better address patients (including patients with complex needs): 19
- Raising the profile of the CCN role: 17
- Gaining nurse prescribing skills: 12
- Access to current evidence-based knowledge: 11
- Improving one's ability to provide holistic care: 10
- Access to research
- Gaining time to reflect on one's practice
- Gaining funding
- Increasing one's band
- Improving continuity of care
- Improving knowledge of the social determinants of health.

The survey then asked what Community Children's Nurses were most proud of in their professional life. The most common themes in their responses were:

- Keeping care delivery within the Community
- Supporting families and children
- Qualifications achieved, training undertaken, skills acquired
- Providing strong leadership to junior nurses
- The ability to work holistically
- Strong teamwork

Several respondents elaborated on the theme of being able to work with the whole family, gain their trust and be able to support their child to live at home:



*'I am sure there are a lot of very well qualified hospital nurses who are keen to move into primary care, but the pathway isn't clear.'*



*'Being able to view the child as part of the family and within the community and enable a speedy return to normalcy for children... the privilege of nursing children in their own home or as close to home as possible.'*

Another respondent quoted a parent who said, *'I felt safe to bring my child home.'*

## The Next Five Years

Respondents were asked what changes they believed were most likely to impact on their service in the next five years. The numbers of responses are given below, which provides an interesting snapshot of the concerns of this part of the community nursing workforce:

- An increased focus on community work: 74
- The impact of austerity and reduced funding: 70
- Increased incidence of children with more complex needs: 48
- Workforce shortages: 44
- NHS Privatisation: 20
- Changes to nursing education: 19
- Increased workloads: 18
- A move to a 7-day working week and increased hours: 15
- Higher demand for and expectation of services: 12
- Recruitment related difficulties: 10
- An increased skill mix within teams will become more necessary: 10
- An increased importance of information technology: 9
- Increased importance of palliative and end of life care: 8 mentions
- The apprenticeship levy: 3
- The removal of the pre-registration bursary: 2
- The introduction of Nurse Auxiliaries: 3
- The impact of Brexit: 3
- An increased need for flexibility: 3
- Lower relative pay: 1

Examples of the comments given indicate that many CCNs envisage growing caseloads of more complex patients in the near future. They also indicate uncertainty about which services would have the capacity to meet the growing demands and doubts about the setting of care delivery, if there is insufficient investment in community services.

*'Increasing numbers of CYP with complex needs surviving into adulthood, the SEND Reform requiring children to remain in children's services until they are 25 years old, increasing numbers children with both behavioural as well as physical co-morbidity and lack of trained staff to accommodate their needs.'*

*'There will be more children discharged from hospital quicker which will increase caseload capacity and will need to develop more and varied skills to allow this. Skill mix on the team is needed to allow this, a team leader will be necessary, bigger base required which could mean moving from the hospital - this would not be beneficial as we would lose our close working relationship with Paediatricians and PNAPs. Currently work Monday-Friday; this will change to at least 6 day service.'*

*'More ambulatory care with short stay units in emergency departments, so CCNs will need enhanced clinical assessment skills, be prepared to work around the clock (currently we only do 24 hour care for end of life*

*children). Increasing number of complex children in the community with care packages.'*

*'Ever increasing complexity of children and young people; training needs of carers in schools/colleges/social care including Personal Assistants - applying effective delegated duties; provision of clinical equipment and clinical consumables - necessary for care at home/school/college/social care setting; provision of health funded Continuing Care packages to support families.'*

*'The move away from the medical model of disability - increasing trust from health and care professionals that the CYP and their family have it within them to find the right solutions to manage their health on a day to day basis. Facilitating person centred approaches to care provision to enable families to live the way they would like and get the support that is right for them (as described by them) working in true partnership with the HCPs and other people who are important to them. Humanity, kindness and recognition/acknowledgement of the strengths that each person holds within them - working together for the ultimate purpose that the individual and their family express.'*

*'Some areas of the country are decommissioning CCN services therefore I see hospital costs in these areas rising. I feel nurse prescribing is a very underutilised skill which could make a massive difference for children and families. I have conducted some research on this and I hope to publish it next year to make a change to how CCNs work. There are many challenges for CCN teams employed by social enterprises where they are restricted greatly in what they are allowed to do. We need more trained CCN specialists to deliver the care required to the children in the community.'*

The survey also asked what would be needed in order to enable CCNs to embrace with these developments. The responses focused on the following key themes:

- Increased provision of training and education: 87
- More adept workforce planning (recruitment and retention): 79
- Increased funding to entire service: 43
- Strong leadership and management: 28
- Boosting morale and the profile of the CCN role: 17
- Integration of primary care services: 13 mentions
- Acquiring up to date equipment: 10
- Clarifying the role of the CCN: 8
- Resilience: 6
- Communication: 5
- Ensuring a broad skill mix: 4
- Flexibility: 3
- Building teams 3
- Clarity about tasks: 1
- Voicing opinions: 1

Illustrative comments included:

*'Recognition of the unique role and contribution that CCNs have with the child and family; investment in CCN services; investment in CCN education Development of CCN education to include prescribing, diagnosis and clinical decision making incorporating advanced practitioner practice.'*

*'Strong leadership. Brave commissioning. An understanding of the potential of the role. An encouragement to be experimental and test out new ways of working. Availability of various courses such as CCN SPQ,*

**'I feel nurse prescribing is a very underutilised skill which could make a massive difference for children and families.'**

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*ANP prescribing. Working in conjunction with the AP and Nursing associate workforce. Integrated acute/community organisations/leadership.'*

*'Working together with all partners in health, social care, charities and education to ensure high standard of care is available and also regionally... as a Network. Including/inviting commissioners to meetings. Ensuring wellbeing of staff and ensuring resilience to cope, good supervision and strong leadership.'*

*'Robust supervision in order that CCNs can manage the reducing resources with increasing demand and the emotional toll that takes. More online/modular training for specialist areas which appear to be increasing, e.g. rheumatology/bladder and bowel interventions/ technology dependent children at home.'*

*'A new way of CCNs accessing training to become specialist practitioners; development of new practice teachers; evidence-based, national standards for CCN services; dual posts for junior nurses to enable development of community skills in addition to acute hospital skills.'*

Respondents were also asked if they had any other comments about the role of the CCN. Responses focused on the value of the role, but also its low profile within the health service, leading to a lack of appreciation of the potential of the role in supporting children and their families, at a time when many other services are struggling with demand:

*'It is a great job with flexibility and variety but many people are scared to make the jump to community.'*

*'More students should be mentored in the community setting to inspire them to consider a position in the community once [they have] sufficient experience.'*

*'As a smaller group within the health service, it seems we can be overlooked. With continued pressures and increasing need for care to be delivered in the community setting, CCN services need to be developed as a priority in order to meet the growingly complex needs of CYP.'*

*'CCNs are underused even by the hospital very few professional know what their job role is as lots of areas are commissioned differently- need a basic level of care which all areas of the country offer- very much a post code lottery.'*

*'I enjoy my job immensely but feel there is little support and information to support us quite often, seems to be once child is discharged, hospital often wash their hands of them. Communication is key and it seems to be impossible at times to get information which I feel impacts on child's care.'*

*'I feel the CCN course should be available for all persons wishing to undertake the course for personal and professional development. Colleagues in other areas who have completed this course have excelled in their CCN roles.'*

*'There needs to be a dependency scoring tool that is used across the board – I am constantly being asked to justify why there is a CCN team and what we do.'*

*'There has never been the national recognition of the role. I am always mindful that so much is done on goodwill.'*

*'Palliative care is a very important part of our role that is often not recognised.'*



CCNs are able to reduce the reliance on hospital services, which may put a larger physical and emotional burden on children and their families.

\*\*\*\*\*

## Conclusion

The QNI survey of around 350 nurses working in Community Children's Nursing teams suggests great confidence in the growing importance of their role, to deliver high quality healthcare to children and young people with chronic illnesses and disabilities closer to or in the home. Community Children's Nurses are thereby able to reduce the reliance on hospital services, which may be less appropriate and which may put a larger physical and emotional burden on children and their families.

Predictions from nurses working in this field are that demand for their services is growing and will continue to grow, due to an increasing population and a growing number of young people living for longer with serious health conditions that require intensive and ongoing support. There are widespread concerns around the capacity of the CCN teams to meet this growing demand and almost half of respondents reported situations where they had to refuse referrals. In practice this frequently means that patients must attend hospital.

Community Children's Nursing services are not universal in every part of the UK: as a relatively recent specialism, there is not a long heritage of CCN services compared to, for example, the District Nursing service. Commissioners in different regions have taken varying approaches to how care is planned and delivered and there is a lack of knowledge around the specialism. Community Children's Nurses are concerned that their contribution is not well understood by commissioners – a concern shared by nurses in other community nursing specialisms, who are less 'visible' than their hospital counterparts.

While most CCNs believed their employers were supportive of their continuing professional development, this was not always realised in practice, due to the everyday demands of delivering the service to patients. A significant minority of respondents take annual leave in order to further their professional development.

The availability of the Specialist Practitioner Qualification is not sufficient to meet the demand of all of those who believe they would benefit by undertaking the qualification. In Scotland no courses at all are available and in many parts of the country, the nearest course is too far away to be practicable. This inevitably acts as a major brake on the education of nurses in this specialism and is likely to lead to a lack of consistency in education and practice.

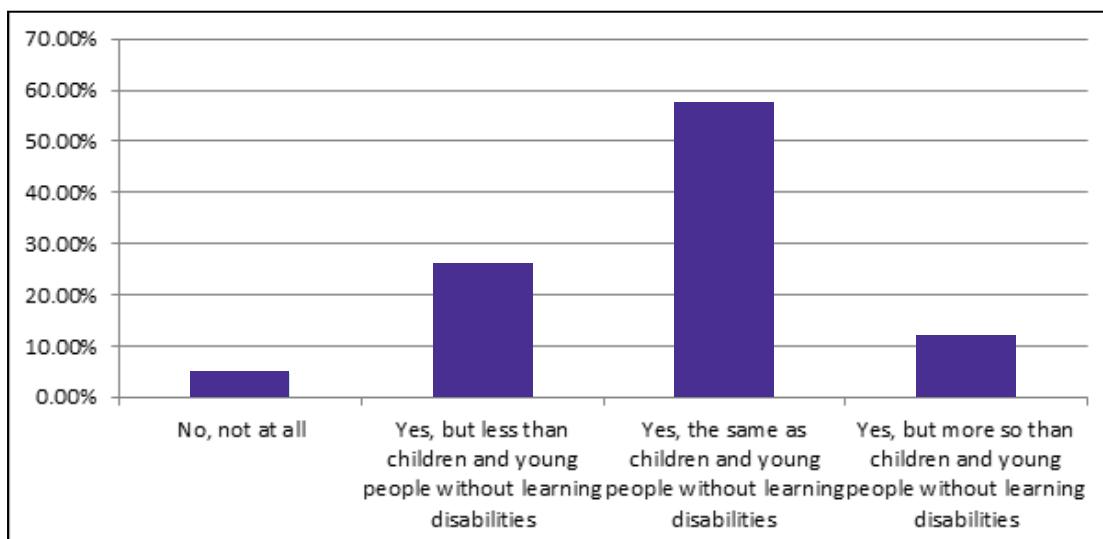
The new Voluntary Standards for Community Children's Nurse Education and Practice published this year will go some way to bringing greater consistency to the courses that are offered and inspiring other universities to consider offering this important specialism.

## Appendix

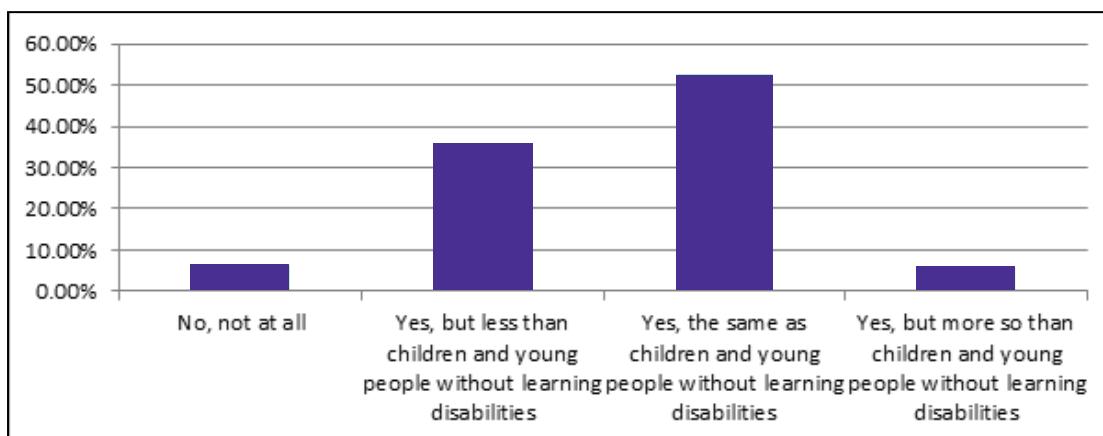
### Equality of Access in Child Health

In the survey, respondents were asked for their views about equality of access for children with special needs. Their responses are shown in Tables 10-13.

**Table 10. In the community, children and young people with learning disabilities have access to high quality healthcare that meets their particular needs.**



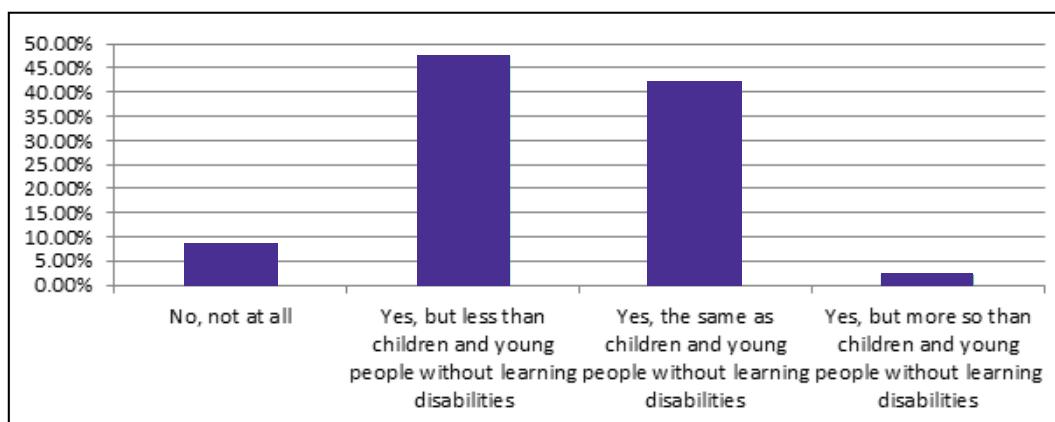
**Table 11. In the community, children and young people with learning disabilities have access to appropriate information about their care and treatment.**



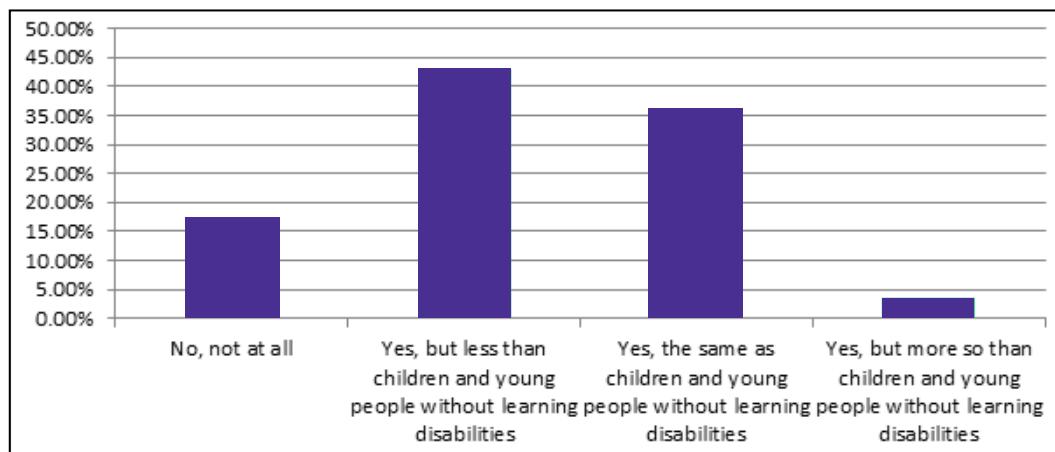
The new Voluntary Standards for CCN Education and Practice will go some way to bringing greater consistency to the courses that are offered.'



**Table 12. In the community, children and young people with learning disabilities are appropriately involved in making decisions about care and treatment.**



**Table 13. In the community, children and young people with learning disabilities are appropriately involved in planning services**



The Queen's Nursing Institute

The Queen's Nursing Institute was established in 1887, originally to train and organise the supply of District Nurses on a national basis. From the 1970s, the charity expanded its remit to provide educational and other forms of support to all nurses working in the community. The Queen's Nurse title was reintroduced in 2006 and there are now over 1200 Queen's Nurses working in England, Wales and Northern Ireland. In 2016, QNI Scotland reintroduced the title. All community nurses, including Community Children's Nurses, are eligible to apply.



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