The Queen's Nursing Institute

Transitions of Care
Online Survey 2016 Summary

Approach

The Queen's Nursing Institute consulted with key stakeholders to obtain the perceptions and experiences of clinicians and young people transitioning into adult community services. Qualitative and quantitative feedback has informed the online learning resource available at: https://www.qni.org.uk/nursing-in-the-community/from-child-to-adult/

Transition surveys

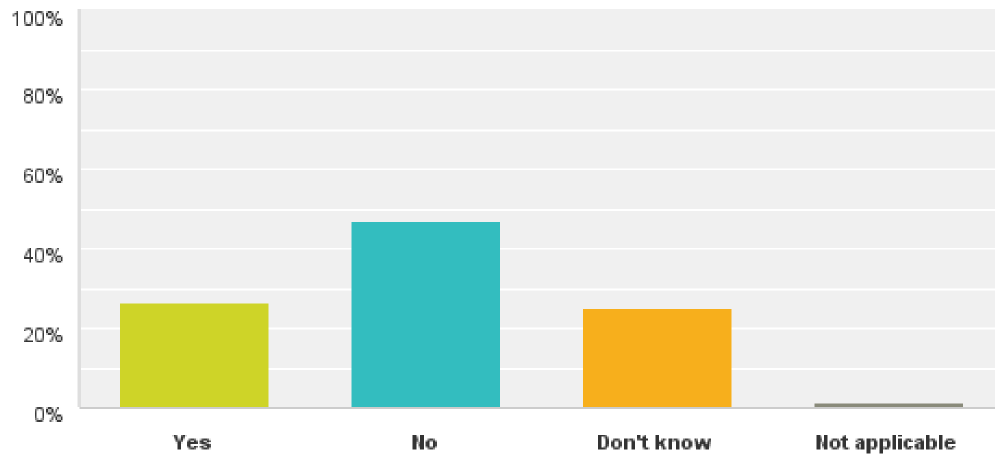
Three online surveys were developed by a range of Queen's Nurses, Educators and a young adult with personal experience in the transition process from children's to adult community services. The survey details were advertised within the general and community nursing press, social media and to QNI networks. The surveys included a general survey for clinicians, an educator's survey and a young people's/families/carers survey. The surveys were open to responses between March and September 2016 and 450 responses were received.

A. Results from General Survey for Clinicians

1. Lead Practitioners and dedicated teams

Respondents were asked if there was a Transition to Adult Services lead in their organisation.

46.9% (n= 186) said that there was no lead, 26.7% (n=106) said there was a lead whilst 24.9% (n=99) said that they didn't know; 1.5% (6) said the question wasn't applicable to their practice.



Comments included:

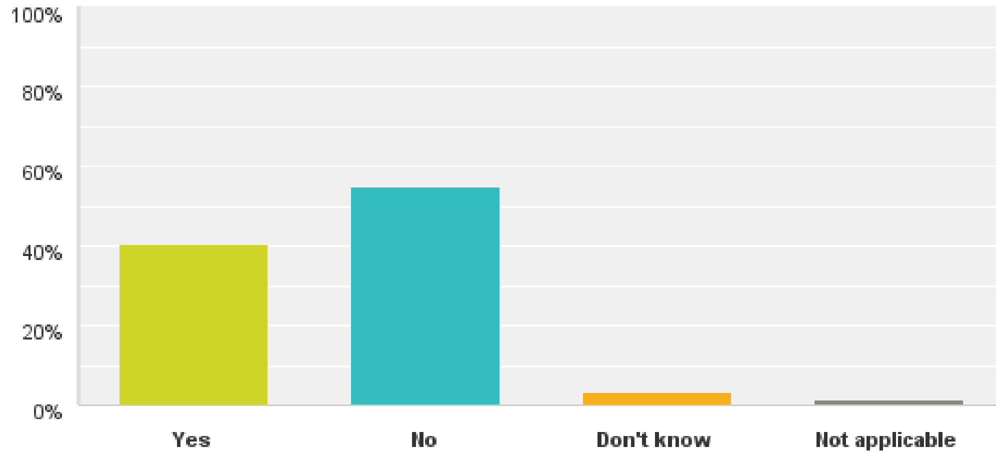
“There are specialist nurses and allied professionals with experience in this field. I don't think there is a designated lead in adult community services but there may be in the children’s sector.” (Clinical Nurse Specialist for Safety and Quality)

One respondent said that they have a Quality and Safety Lead role within an NHS Community Health Trust, who links with children’s services when a young person is transitioning onto adult caseloads:

“There is support for District Nurses and Allied Health Professionals who are admitting patients onto their case load. We link with the Children’s and families Quality and Safety lead to standardise an approach as a community and Trust.”

Respondents were asked if there were keyworkers in their teams who have sole responsibility for working with young people.

54.7% (n= 217) said there was no keyworker in the team who had sole responsibility, 40.6% (n= 161) said they had a key worker, 3.3% (n= 13) responded that they didn’t know and 1.4% (n= 5) said that the question was not applicable to their practice.



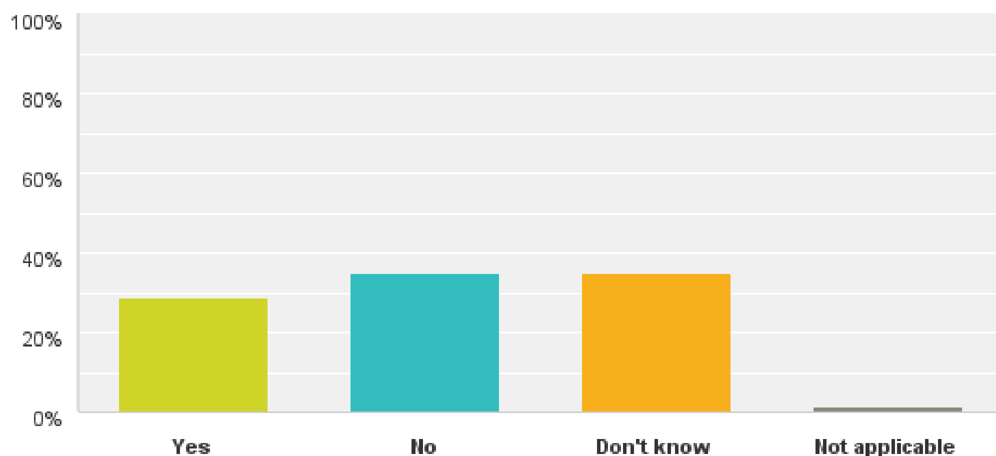
A Transition Service Lead nurse from an Acute NHS Trust commented:

"We have a business case approved in principle by commissioners. There will be three employed keyworkers for patients with complex long term conditions. Key workers for other specialities will need to be identified within the current service structures." (Transition Service Lead Nurse)

"As community nurses we support adults over the age of 18 with health and social care needs, access to services and support patients and their carers. Our role mainly encompasses reacting to referrals received through our single point of contact, largely following up care requests received from acute hospital care." (Community Staff Nurse)

2. Transition Policy

Respondents were asked whether there is a Transition to Adult Services policy in their organisation. 35% (n= 139) responded No, 28.7% (114) responded Yes, 34.8% (n= 138) didn't know and 1.5% (n=6) said this question was not applicable to their practice.



Comments made to this question include:

"Believe a policy was implemented a few years ago as the acute sector often faced issues with patient 16-18 and where to place them so a policy was put in place but not one for the community setting." (District Nurse Student)

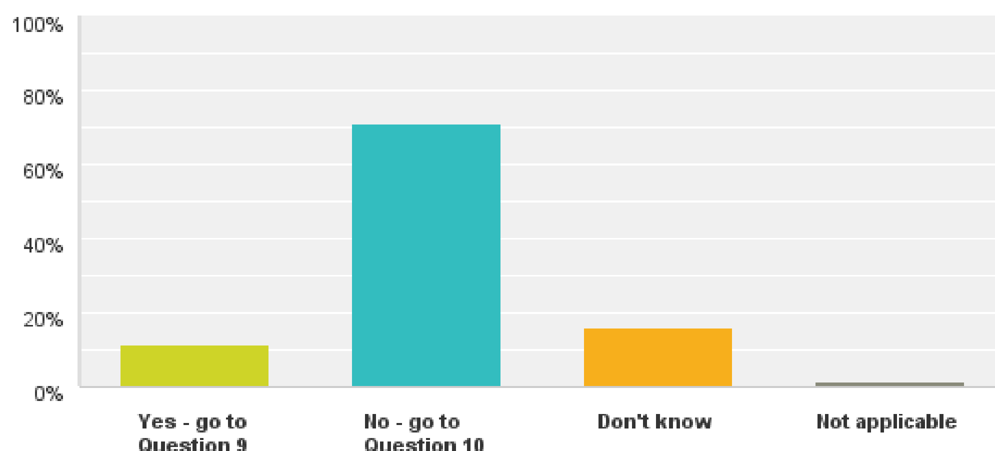
"I have searched and not been able to locate one. I do not think there is such a policy at present but there is certainly a need for one." (District Nurse)

"We have developed in the past jointly with social care but it has not been updated according to organisational changes." (Children's Nurse Consultant, Community NHS Trust)

3. Training

The survey asked if their organisation provides specific staff training on Transition from children's to adult services.

70.78% (n= 281) respondents said no, 11.59% (n= 46) said yes, 16.12% (n= 64) said they didn't know and 1.51% (n= 6) said the question wasn't applicable to them.



Comments to this question included:

"We have a professional engagement team and we work with clinical experts to provide a portfolio of training which includes motivational interviewing, communication skills as well as hosting a 'learnzone' environment for professionals and we provide training tools and resources on well-being, holistic needs assessment care and support planning, guides to completing treatment summaries and top tips on key specialist areas like consequences of treatment and much more." (National Programme Lead Cancer Treatment and Recovery, Voluntary Sector)

The respondents who said they did receive training from their organisation were asked who provided this training and did they feel it was useful to them. Comments included:

"I think the providers are external. I have been to external training specifically put on by hospices which has been very good. The in house training is trying to cover transition for all

services (physio, social services, nursing) but the children who we see have great needs that are very specific and often palliative but they still need to go through transition. It is not one size fits all." (Children's Community Nurse)

"I have gone on various training sessions but it's not always that suitable or relevant to community nursing." (District Nurse)

The survey asked the respondents who did *not* receive transition training what, if any would they like to see provided. In excess of 270 comments were made. These included:

"The training should come from adult and child services. Often the child service simply discharges the patient once they get to the adult age and asked the GP surgery to then refer to the adult service. We are then required to summarize all the treatments and management and refer on. The transition should be between child and adult and not be a requirement of GP surgeries to manage this. The problems involve mental health, diabetes, Paediatric, cystic fibrosis clinics etc." (Advanced Nurse Practitioner/ Manager in General Practice)

"Training for all staff around communication, needs of young people and parents, transition guidelines and policies." (Senior Lecturer, District Nurse Programme)

"Clear guidance on the transition policy and best practice on how best this can be followed. Transition is not always seen as a priority and young people are often waiting for an allocated worker in adult services for a considerable length of time due to capacity issues." (Senior CAMHS Practitioner)

4. Skills

The survey asked what skills are needed to support young people on their caseload. Over 350 comments were received and almost all spoke about the need for good communication skills, including:

"Communication skills especially re engagement, knowledge and understanding on what may influence this age group, training on use of social media and apps etc." (Young Persons Diabetes Specialist Nurse, Community NHS Trust)

"Communication skills - There are often needs for advocacy support and also challenging decisions by other professional organisations. Communication needs to be adapted according to work with young person and their parents. Assessment skills-determining the needs of the young person and family to judge level/type of transition support needed." (Transition Worker, Social Enterprise)

"Effective communication, understanding of key challenges for client group, awareness of Multi-Disciplinary Team members involved for advisory/sign posting." (District Nurse)

"Community staff requires knowledge of legislation, local and national systems and processes and excellent communication skills. Flexibility and ability to work across boundaries." (District Nurse)

"We have to understand how they will access the adult community services they are likely to need. We need to link in with key professionals to give the teen and their family knowledge and information re who to turn to. We need to provide current information re the teen's health needs to adult services. We need to do joint visit(s) with the District Nurse to help to provide a smooth transition. Equipment needs/ordering and change in provision needs to be addressed. Need to address training needs of District Nursing service." (Community Children's Nurse, Community Health NHS Trust)

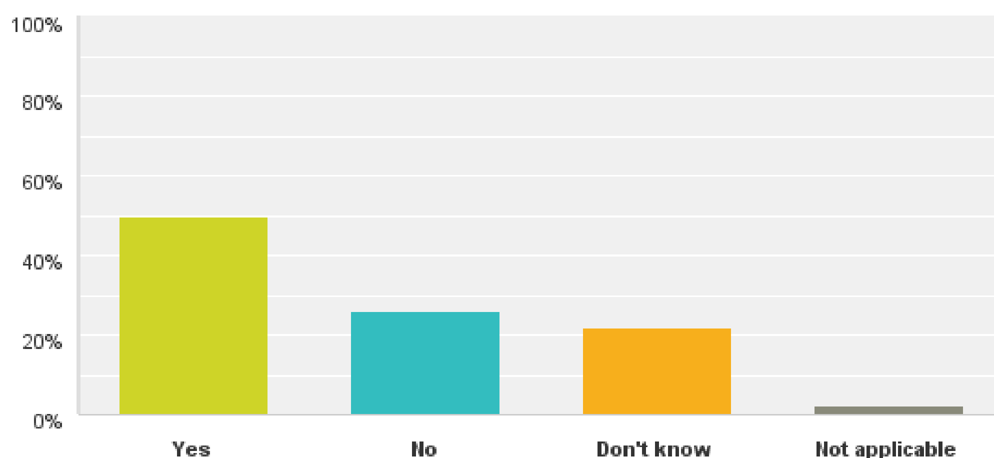
"I don't currently have a caseload but in terms of nurturing the development of those who will be caseload holders, I would suggest the following: awareness of the emotional challenges for teens such as family and friends dynamics, body image, fears about work/college, peer pressure, they are experiencing alongside transitioning from one service to another ~ exploring different ways of communicating such as texting ~ building networks with specialist services such as for diabetes and with colleagues who have developed some expertise in this area." (Lead Transition Nurse Specialist, Community Health NHS Trust)

"Knowledge of the wider range of services that may have been or still involved in the patients care that may not be 'typical' to an older, housebound patient. Up to date clinical skills for any health needs and knowledge of local services and charities in the geographical area. A friendly and approachable manner." (District Nurse)

5. Transfer Summaries

Respondents were asked if transfer summaries were provided by/to their service to give key information about the young person who is transitioning.

26.2% (n= 104) said No, 49.9% (n= 198) said Yes, 21.7% (n= 86) said they didn't know and 2.2% (n= 9) said that the question was not applicable to their practice.



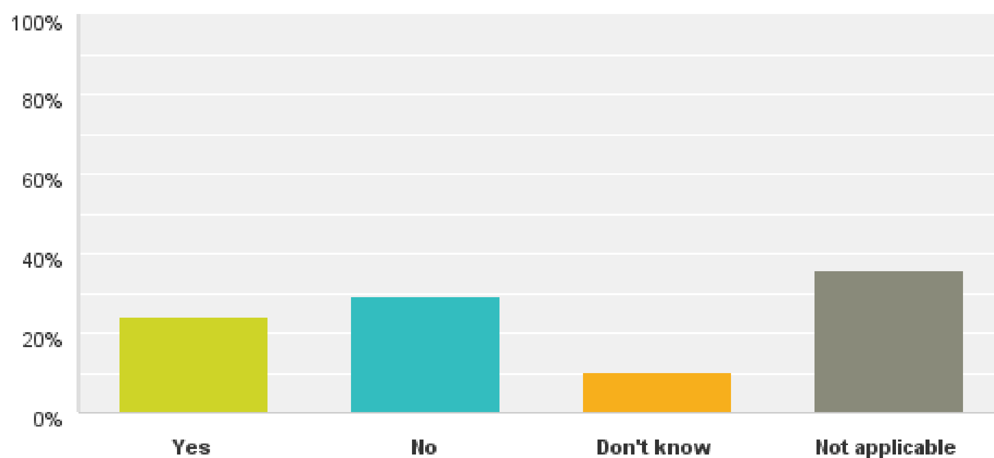
Despite almost 50% of respondents saying that transfer summaries are provided, many commented that the information that they received did not give an accurate handover of the needs of the young person:

"We provide discharge plans that detail contact details of identified adult services. We do not provide detailed summary of needs as often there are other organisations that hold more detailed information. We may coordinate the transfer of this information." (Transition Worker, Social Enterprise)

"On the two occasions younger people have transitioned into my geographical area, all information was sourced from the referral form faxed to our single point of contact. Many details are omitted or incorrect." (Community Staff Nurse, Community NHS Trust)

Respondents were asked if transitions for young people on their caseload were well co-ordinated between services to enable the clinician to feel supported in their role.

Respondents answered 29.5% (n=117) No, 24.2% (n= 96) Yes, 10.3% (n= 41) didn't know and 36% (n= 143) felt the question was not applicable to them.



This question generated many comments including:

"I would indicate yes and no to this answer. My role involves the coordination of such services and therefore this does make a difference to young people. Given I am employed to do this demonstrates there is a gap and often without my involvement the young people and their families will either be left to flounder or transition work commence too late." (Transition Worker, Social Enterprise)

"Transitioning to adult continuing care was challenging as their criteria was different to ours and they wanted us to undertake their assessment instead of working with us to complete. Also their service varied very much from ours." (Children's Continuing Care Sister, Community NHS Trust)

"In my experience no the transition process in not well coordinated the young person often left without knowing who they are to contact if an issue arises and families are left frustrated." (Staff Nurse, Private Health Care)

“I work with a number of different hospitals and link with transitional nurse and consultants to ensure good transition. I don’t discharge from my caseload until I know everything is in place.” (Children’s Community Nurse, NHS Mental Health Trust)

“It depends on the needs of the young person. I am the only one transitioning in my area and it can feel like you are out on a limb. Due to a lack of services within adults it can feel like the young person is not being supported effectively despite your best efforts. There is a lack of communication at times and there can be duplication of work as a result. Each case we are learning how to improve it.” (Transition Manager, Community Health NHS Trust)

“The District Nursing team felt very isolated - no handover from children’s services and the family were very unsure that we were competent with our care (funding & reassessment of needs).” (District Nurse, Community NHS Trust)

6. Key Support Areas

The survey asked respondents in which three areas of Transition did they feel most supported to care for the young person on their caseload. Many respondents said that they had no support in clinical practice, whilst others had more positive comments:

“Adult transition nurses have got involved very early with children, attending meetings, meeting the family etc. This is fantastic!”

“Where there has been effective communication between all professionals/ services working with the young person. Some families are happy to be in the community rather than in hospital” (District Nurse, Community NHS Trust)

“Having an IT system which shared information and good support by GP”

The survey asked what three areas gave most concern when caring for a young person on the caseload who is transitioning from children's services to adult services. More than 350 comments were received to this question and the feedback includes:

“Lack of experience in caring for young people - fear of unknown.” (District Nurse, Community Health NHS Trust)

“Lack of continuity of a lead professional for the family to go to in the community.” (General Practice Nurse, GP Surgery)

“Acknowledgement that young people are at different developmental stages and some require longer and better supported transition.” (Sister, Community Health NHS Trust)

“Inequality and inequity depending on young person's condition, e.g. Cystic Fibrosis - usually there is a smooth and well organised transfer compared to the problems that arise when transferring the care of a young person with multiple complex conditions.”(Clinical Nurse Manager Children and Young People, NHS Acute Trust)

"Lack of 'ownership' - falling between professionals i.e. a child worker, an adult worker and a transition worker all involved with no individual leading." (District Nurse, NHS Community Health trust)

"Criteria for secondary care are sometimes different in adults compared to paediatrics. For example, a child with asthma will be under the Paeds respiratory team for monitoring and treatment at a lower threshold to an adult. Thus sometimes you have to transition to Primary Care / GP's. The repeated concern is that the patient will fail to engage with adult services and will be lost to follow up." (Paediatric Respiratory Nurse, NHS Acute Trust)

"An alarming number of patients tell us they have no idea what is happening with their transition. One typical response from a 16 year old I spoke to today: "I haven't transitioned yet but I don't have a clue what to expect and have no idea when it's happening". More information is needed in advance, to give patients time to process and learn about changing environment / expectations." (Young People's Officer, Social Enterprise)

7. Gaps in the Process

The survey asked if the clinicians felt there were any gaps in the transition process when a young person leaves or is placed on their caseload. A selection of comments from the 250 received include:

"Main concern is that they are poor attenders and in adult services we are limited in the time available to chase up and provide more accessible services."

"Adult community nurses do not carry out the same role as us and so sometimes find there are gaps where there are things we would normally do for a family that District Nurses don't have capacity for." (Community Children's Nurse, Community Health NHS Trust)

"Huge gaps - the Young Person just "appears" without any support to them, the family or community services. There is no support with this from our community Trust – The General Practice Nurses struggle as well" (District Nurse, Community Health NHS Trust)

"Equipment issues where children's services provide different equipment with funding and adult services don't have the same funding." (Community Matron, Community Health NHS Trust)

"Sometimes the family are so good looking after their children who have complex needs that the families are not known to any community nursing services but because they have become harder to mobilise or become harder for the family to manage as they have become adults they could do with support in adulthood but it is very difficult to identify these children." (Community Children's Nurse, Community Health NHS Trust)

"There are huge gaps. Some children have very complex needs and require ongoing support from multiple teams. I think parents feel there is a big jump in terms of the support and services available and things very much seem on a 'as required' basis. These children need ongoing support and these families require emotional support as well as nursing support and advice. It seems some adult services find it difficult to know how their role fits in to the

bigger picture. Other services simply will not see a young person unless a specific need comes up, i.e. they develop a pressure sore". (Children's Community Nurse, Community NHS Trust)

"The varying ages of when a service transitions and accepts services, i.e. could be 16 or 18, in some case they may go from 16-18 with nothing at present or with the incorrect service as there is no designated service, especially mental health. Services unwilling to be flexible with accepting referrals as they are under 18. Lack of community specialist nurses within adult services." (Transition Practitioner, Community NHS Trust)

"The family expects the same support and following assessment this may not be assessed as the same level of support particularly as it can be expected for some of the care to be undertaken at the surgery as district nurses see housebound patients which very often these patients are not."

"The main gap evident in clinical practice when caring for adolescents initially begins with poor referrals from other services when transitioning into our care, this is compounded by the lack of consultation information available due to sharing of critical information to allow for a smooth transition to allow for a continuation of care. There also appears to be a lack in training and education for community nurses in caring for young adults, resulting in staff learning on the job so to speak." (Community Staff Nurse/CSP Student, Community NHS Trust)

"The patient's mother was concerned that in transferring to adult services the carers had to change. The new carers did not have the same ability to respond to a crisis, such as providing immediate suction to the patient. Suitable carers had to be found and trained. The mother found this annoying and did not appreciate the need for the service to change." (Community CNS for Quality and Safety, Community NHS Trust)

"To gain a wider understanding of the transition process the respondents were asked to describe one nursing scenario they had experienced when caring for a young person who had transitioned from children's services to adult services and 263 examples were given – a few of these include "Adult continuing care did not assess until 18th birthday, in spite of lots of planning from age 14 in children's services - this caused huge distress for the family." (Nurse Consultant, Independent Sector Provider)

"I had a girl with diabetes leaving education and attending college. Hard to transfer on as no attached nurse. Home life hard and family difficult to engage. Expected to just handover to GP as unable to engage others but emotionally hard as she needed continual support as non-compliant with medications". (Operational Lead Nurse, NHS Mental Health Trust)

"Young person attended a special school. Most medical needs completed by nursing staff. Supported by Specialist at Regional Specialist Hospital. Needing regular finger pricks for bloods. Family were not trained to do this. Were told by nursing staff in school to go to GP for bloods. GP not happy to do and not their role they said. District nurses won't undertake nor chase the results and send to specialist. I have struggled to find appropriate support for family. They go from complete dependence (not helped by our service) to being left feeling

stranded. Would have helped if we looked to transition much earlier on and armed the family with better knowledge and independence." (Senior Sister Community Children's Nurse, NHS Acute Trust)

"I have only been involved in a couple of transitions. One that was quite difficult was a young boy that accessed a local short stay unit a couple of times a month. He had cerebral palsy and severe sleep apnoea. Because of this he required a nurse overnight to support his respiratory function and needed regular stimulation. Transitioning to an adult short break unit was challenging as they would not fund a nurse overnight as it was felt he could be supporting by their care staff. Family anxious about this decision however we worked with the new unit and a nurse worked a couple of weeks of nights with the care staff to help them get to know him and get to know when to stimulate him when he has apnoea. Adult continuing care criteria different to ours and their involvement was minimal with the family whereas ours were much more supportive and hands on. Transition of health care needs managed by GP." (Children's Continuing Care Sister, Community Health NHS Trust)

"Incontinence products which child had had delivered for years not available by adult community services. Children's nurses had time to pop in to deliver continence products and chat with family, whereas adult community services would only visit as a nursing need arises."

"Referred male patient for bowel care to community District Nursing team. No real information on how far his Duchenne muscular dystrophy had progressed. No information about family dynamics. No *information about equipment he was using. Family felt very let down as they had not been prepared for a new team taking over. Supplying equipment to support them was a nightmare. No information about planned respite." (District Nurse, NHS Acute Trust)*

"The most recent was a young lady with cerebral palsy who was being well looked after by her family. We thought that it would be an easy transition to adult services, just to the district nursing team for care of her gastrostomy but because she was going to college and had "health needs" she had to go through continuing health care in adulthood to get the funding for her residential placement. We were unaware that this would happen and it has been a rush to try to get this sorted out by the District nurse who had it sprung on her." (Children's Community Nurse, Health Board)

"The transitions where communication and hand over has been planned well in advance and helped with transition, staff are keen to interlink with children services as often young person is very dependent for all care and may be unable to voice own needs so have needed to work closely and build relationships with family members. Also applied when young man went into respite care and community nursing asked to get involved regarding tissue viability." (Community Nursing Clinical Lead, Community Health NHS Trust)

"Young person with cancer transitioned from child health to adult health. I was given minimal information by hospital and young person's knowledge was poor. Difficulty working with parents who wanted all information regarding young person but consent not given by the young person to discuss. With young person's permission worked with GP, district nursing service, school nursing service and Macmillan to establish services appropriate for

the young person and support for parents. Positive outcome." (District Nurse Practice Teacher, Community Health NHS Trust)

"A child with complex needs living very rurally who attended tertiary centre and main consultants based at tertiary, would now require district nursing involvement and CCN team understanding who would be the appropriate consultant in adults to take lead role. Also the need for A/E to have an action plan in place if the young person presented acutely ill and requiring quick and prompt action by medical staff to prevent ICU admission. After lots of conversations instigated by the CCN team an acute adult consultant listened and understood the issue, devised an emergency plan which when tested worked well. Parents were confident that in an acute episode their child would be looked after appropriately and safely now that the children's ward safety net had been removed." (Team Leader Children's Community Nursing, Community Health NHS Trust)

"A child who we started to fill in the paper work for transition, this caused the mother great anxiety so needed to be done slowly. These were then sent but appeared to get lost but did they? The adult services did not appear to want to engage until nearly her 18th birthday. she was a very complex child and 2 months on we are still working through problems as the adults could not give the care we did, needed training did not know who was meant to be doing what etc." (Senior Respite Nurse, Community Health NHS Trust)

"One patient is almost 19 years old, she is a very complex patient and adult services would not complete the CHC assessment prior to her 18th birthday. Therefore the patient does not go to panel until well after their 18th birthday and then there are the negotiations around who pays for what! The patient is now almost 19 years old and remains in paediatric services. This is apparently due to a lack of skill in the adult community sector to carry out a CHC assessment and a lack of clinical skills in the community adult sector to care for this young lady." (Trust Transition Nurse Lead, NHS Acute Trust)

"I was involved in MDTs where a patient had reached the age of 20 and was transferring to adult community services to continue support with cerebral palsy and respiratory issues. The patient has a life-limiting condition. The patient's mother was hostile during these meetings as she felt frustrated by the poor transition. She did not appreciate the need to change services due to funding and age limits. The patient could not remain with children's' services or continue to attend his specialist day centre. Many heated discussions took place between the mother and AHPs at these meetings. The mother would often decline any input from DN team, stating that she did not feel we could help and she could manage. All she wanted were supplies to continue managing the patient at home. It took some time and several visits to gain her confidence." (CNS for Quality and Safety, Community Health NHS Trust)

"In our trust the patients are transferred at the age of 19. We started this transition when the patient was 18. Family especially the mother were very anxious about the transition. We organised a meeting and I was invited to attend as well as meeting at the house with a staff member from the children's services team. Continuing health care funding (CHC) was an issue but this was dealt with by the CHC team. The meeting at the house included the GP,

consultant, and new consultant, family, care agency, OT, Physio and the patient. We continue to have 3 monthly meetings. The main difficulty we encountered was the family's expectations for the District Nursing service to visit as soon as they called us and it took a long time for the family to understand the differences between t the two services as we unable to just visit when they requested it." Community Practice Teacher District Nurse, Community Health NHS Trust)

"A young man with Duchenne Muscular Dystrophy was referred to me when he made the transition from paediatric to adult services. I had little knowledge or experience of working with this condition / age group as most of my patients are elderly with LTC. I had no formal handover what so ever, but conducted my own initial assessment to gain the relevant information. I liaised with the Continuing Health Care Office and negotiated that they would complete the HNA and DST. I liaised with other members of the MDT who were involved in his care. The family were very concerned that the level of support they would receive from adult community services would be much less than that they had received from paediatric services, and as a District Nurse I felt ill equipped to bridge this gap." (Community Matron, Social Enterprise)

8. Summary of general transition survey

In total 397 people from mixed clinical disciplines responded to the general transition survey. Many comments received highlighted the fact that transition from children's services to adult health services is a time of physical, emotional, social and psychological change for young people and often an anxious time for families and carers and professionals. Young people have to understand and adapt healthcare services that are very different from the services they have used as a child.

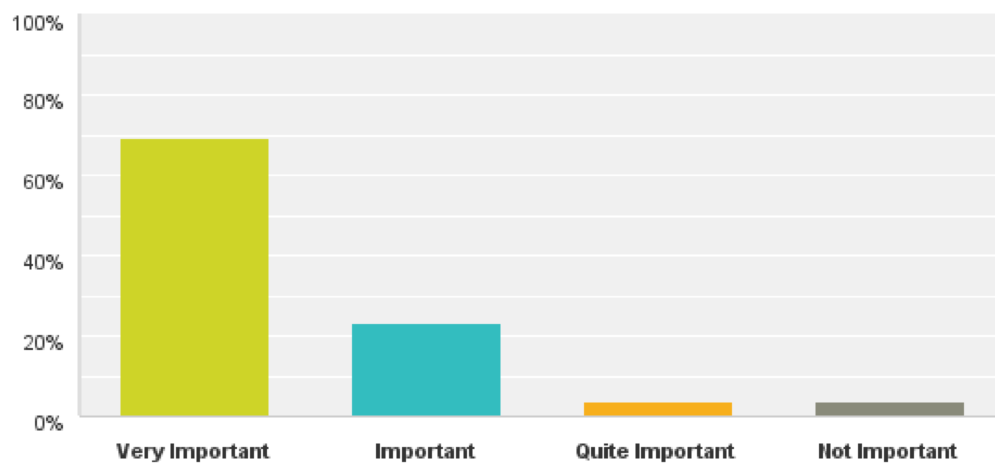
The data from the on-line survey demonstrates similar problems with communication between children's and adult services often cited as a main concern, lack of equipment and care gaps in service. An example being when a young person is discharged for children's services at the age of 16 years and require District Nursing services within their own home but the DN service unable to accept the person referred until they reach 18 years of age. Generally the survey found that healthcare professionals felt they were not adequately equipped to manage the transition pathway, as they felt they lacked appropriate training and experienced problems with access to transition resources.

B. Educators' Survey

To inform the development of an online resource for educators, the QNI gathered information about any education or training currently delivered to nursing students about transition from children's to adults' services.

Educators were asked, how important was it to include information about transition from children's to adult services in the programme taught?

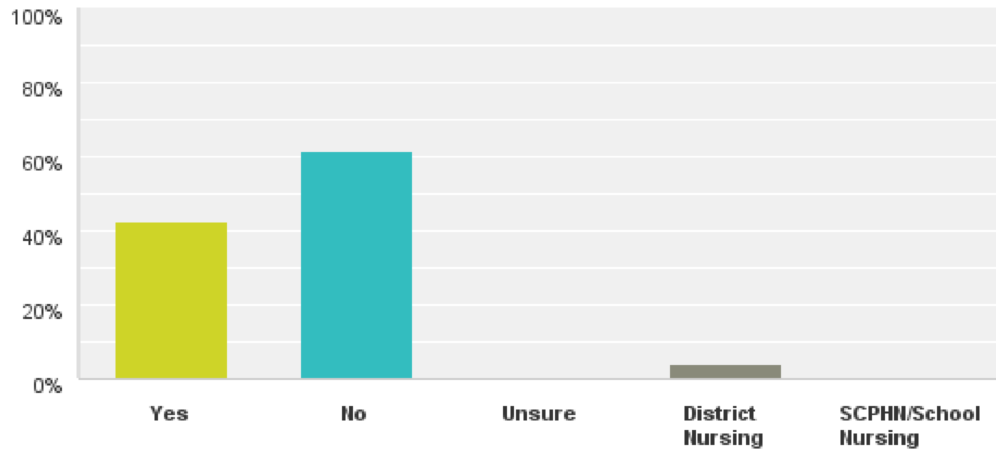
Results showed that 69.23% (n=18) felt that this question was very important, 23.08% (n=6) felt it was important, 3.85% (n=1) felt it was quite important and 3.85% (n=1) felt it was not important.



One educator said that she felt it was important to teach transition to primary and community care nurses whilst another educator said that it would be more beneficial to teach General Practice Nurses, as "*they would see more patients than District Nurses*".

The next question asked if the programmes that were currently taught addressed the issue of transition from children's to adult services.

42.31% (n=11) responded Yes and 61.54% (n= 16) responded No.



Some comments from educators include:

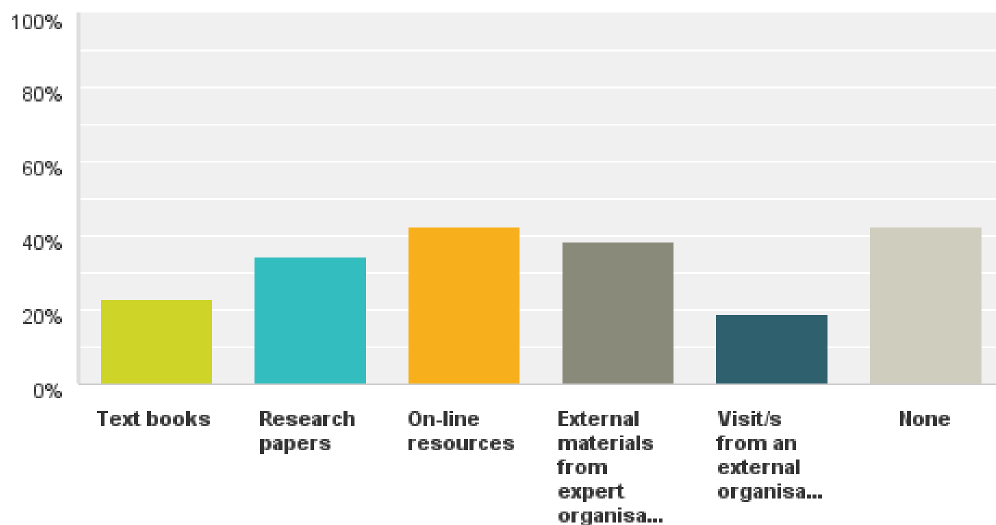
"No – no transition teaching given in either pre or post registration training."

"This is such an important topic and yet it is not taught at our university."

"Following our students participation in the QNI focus groups around teen transition, we will consider how to include this in the curriculum, moving forward."

The survey asked within the current programmes of teaching, what study materials and content was offered on issues relating to transition from children's to adult services.

From the answers given, 23.08% (n=6) educators said that text books were used, 34.62% (n=9) used research papers, 42.31% (n= 11) used on-line resources, 38.46% (n=10) used external materials from expert organisations and 19.23% (n=5) had visits from an external organisation. 42.31% (n= 11) used no study materials as their organisation did not teach on transition.



Some comments from this question include:

"The university arranges lectures on transition from clinical colleagues"

"Transition is mainly focussed on school nursing and the Health Visitor 0-19 agenda"

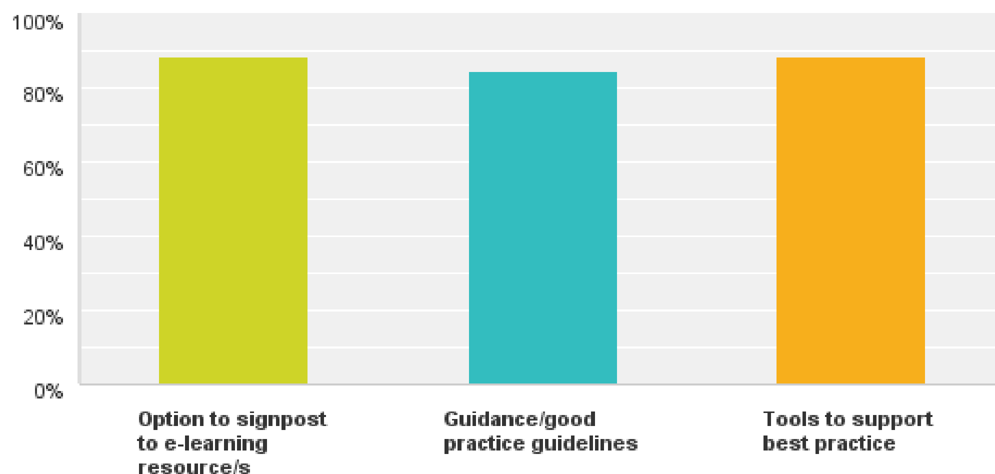
"Young people themselves come to discuss their experiences on some course e.g. pre-registration child course and Adolescent Healthcare course"

Course Materials

The survey asked the educators what materials would help complement the programmes currently taught in relation to transition from children's to adult services (more than one answer choice could be selected).

88.46% (n= 23) thought an option to signpost to e-learning resources would be beneficial, 84.62% (n= 22) said guidance/good practice guidelines would be of benefit and 88.46% (n= 23) said tools to support best practice would be beneficial.

Several educators made suggestions that easier to access policies and guidelines would complement the content of their teaching, as it was time consuming to access these for their students.



Future Resources

The survey asked what the educators would like to see covered within a QNI online learning resource that would support their students to learn about transition from children's to adult services. Many respondents said that they would like information around communication skills and motivational interviewing. Other respondents asked for transition guidelines and policies to be included in order for them to be able to sign-post to their students and one Educator who taught on the Specialist Practitioner Qualification in District Nursing said:

"On the district nursing programme, all the students will be adult nurses and might not have an understanding of the characteristics of child services. It would be helpful if online teaching resources included a description of the characteristics of child services so that district nursing students/adult nurses had an appreciation of any difference in philosophy or delivery between child services and adult services. At the same time, whilst district nursing students are going to be familiar with the principles of working with family carers, more often than not, the family carers they work with will be the sons and daughters of the patient. They will not be parent-carers. It would be helpful to include content pertaining to whether the expectations and experiences of parent-carers are in different to those of what district nurses would regard as more traditional carers.

Summary of Educators' Survey

The feedback from the educators' survey was small in number, with 26 educators responding. However the survey data reflected the data analysed from the five university focus groups, in addition to feedback from educators who attended the four general focus groups that were delivered around the country.

Overall, educators said that they felt it was very important that young people's transition should be taught within their teaching programmes with a large percentage of educators saying that transition wasn't currently taught at all. All respondents said that an online transition learning resource would be very beneficial with content to include communication skills and transition guidelines and policies in order to signpost their students more effectively.

C. Young People's Survey

The QNI sent out a third survey specifically for young people to complete to seek their views on transition in order to ensure that nurses are supported with relevant information and to inform the content of the online learning resource for nurses and educators. In addition to young people responding there was also input from family and carers.

1. **Transition Process**

The survey asked if the young person felt there was a process to support their transition from children's to adult community services. 39.13% (n= 9) said that there was a process to support transition, whilst 60.87% (n= 14) said that there was no process.

Comments included:

"I am a parent carer of a 21 year old with complex needs. The process is very poor at the moment. Even though there is a Transitions Team there are parent carers and young people who even at leaving college at 18 don't know what is out there for them - yet they should have had the information in advance in order to be able to plan. Social care does not cover health, and I don't speak to the health care lead very much about the community health services only about residential college and the health funding side of things".

"As a child growing up with illness, having been supported all the way through, to then becoming an 'adult' where support seems to have vanished, no I don't feel well supported. This comes from all types of health services, from hospital to GP. We're expected to grow up and become independent, yet we are not taught or guided through this process, simply 'dumped' in. Transition, as it stands is simply a word which has no meaning to me and I'm sure many others. There is no system and therefore, there cannot be a good process. Encourage us to become adults, rather than expect it to happen overnight".

2. **Designated professional**

The survey asked if there was a health professional that the young person could talk to about their move from children's to adult community services. Over 50% (n= 12) said they did have someone they could talk to, 31% (n= 7) said there wasn't a health professional they could talk to whilst 13% (n= 3) were unsure.

Comments included:

"I suppose it would be the health commissioner who deals with the health part of residential college. But there are a lot of problems with health issues and services yet I have not thought of speaking to the health commissioner about them. I just deal with them as they come along. My son uses about 10-30 health services regularly every year either once or several times, and though we have a social worker, I as parent carer do the sorting out especially if there are any problems."

3. **Feeling involved**

The survey asked if they felt involved in decisions about their healthcare.

65.22% (n= 15) said they did feel involved, 30.43% (n= 7) said they didn't feel involved with decisions and 4.3% (n= 1) were unsure.

Comments included:

"As a parent carer I am frustrated at the resistance to get some services. At the moment I hear that we have to have a relevant consultant to do referral to the relevant service (wheelchair, orthotics, back, nutrition, epilepsy) yet my son is discharged from all services so we are told we have to go to GP each time we need to be seen by a different service - very frustrating. We have over the summer seen or spoken to the nutritionist, local wheelchair service, posture and mobility service, and continence service. If someone is discharged then are they more likely to get missed off when they have a health need if they don't know who to go to or how to do this and they have no keyworker to co-ordinate it all (or a parent carer to do it instead)."

"I feel like I should be involved, but wasn't given the right support in the run up to becoming an 'adult'. I am so used to my parents being involved, but I feel like I should be involved, but wasn't given the right support in the run up to becoming an 'adult'. I am so used to my parents being involved, but now in adults it seems they push families away, rather than encourage us to work together and for me to become more independent."

4. Correct information

The survey asked if the young person felt they had the right information to manage their healthcare in an adult environment. 52.17% (n= 12) said they did feel that they had the right information, 34.78% (n= 8) said no they felt they didn't have the right information and over 13% (n= 3) were not sure.

One parent made the following comment:

"Some services are not sure or aware of guidelines for taking equipment outside of the borough…. can our son take his wheelchair/ standing frame/ slings/ etc. out of borough to take to a residential college? Not had an answer on that one and one of the NICE guidelines is rather vague about cross-border issues."

A young person made the comment:

"I would have liked the process to have been more organised. Communication is a massive barrier throughout the industry and that makes it difficult, as a patient to stay on top of things. I feel that better systems could be put in place to ensure that everyone can cater to a patient's needs and that the patient feels comfortable with the process."

5. General Practice Nurses

The survey asked if the young person had ever made contact with their General Practice Nurse in order to be supported with their needs. 34.78% (n= 8) said they has made contact, 52.17% (n= 12) said that they hadn't made any contact and 13.04% (n= 3) said they were not sure if they had ever made contact.

A parent made the comment:

"Not had any advice from anyone about doing that. We assumed we have a social worker and just ask her for anything we need, although hadn't thought about talking about all the issues we have. We have good supporting from what used to be the Learning Disability Team OT who uses her service to provide the support we need i.e. instead of referral to orthotics the LDT have taken it on themselves to look at our son's shoes and purchase the right type. They did at first ask if we had a relevant consultant who could refer us back to the hospital Orthotics but we don't and we can't get in as the hospital Orthotics department has discharged us. Have other problems with getting a temporary registration with GP - receptionists locally are loath to register us unless our son has a problem, yet how do we access all 10-20 services when we need them - so far we have needed nutritionist, continence service, delivery of feeds and feeding equipment from Home Care company, and 2 wheelchair services. Who pays for these services if our son is not registered temporarily in his home town?"

Several young people gave the reasons why they go to their General Practice Nurse examples given are they attend for their flu jab, to have their ears syringed, to have wound dressings renewed and to have travel vaccines. One young person said that they would not go for any complex health condition but would rather attend the hospital which is familiar to them.

6. District Nurses

The survey then asked if the young person had ever been contacted or visited at home by a District Nurse. 27% (n= 6) said that they had, over 68% (n= 15) said that they hadn't and 4% (n= 1) said that there were unsure.

7. Overall experience

The survey asked the respondents to rate the experience of their transition so far. Over 17% (n= 4) said their experience was excellent, 26% (n= 6) said good, 4% (n= 1) said OK, 17% (n= 4) said poor and nearly 35% (n= 8) said very poor.

Comments received include:

"Very stressful. Delays in making decisions. Paperwork rarely sent out confirming anything - seems to be some resistance and a comment of "That's the way it is here!"

"I felt very supported by the Teenage Cancer Trust and my consultants all the way through my treatment and afterwards but towards the end felt a bit isolated."

"Poor when we had to do it initially but have improved over time. Just took a little while to settle and get our initial appointments at hospital."

The survey asked if the respondent would describe their experience of transition from children's to adult community health services so far. Comments ranged from a very negative experience of transition to a positive experience. A selection from the comments made include:

"No support from children's services in the hospital to get me into community adult services. I know that when I go to the GP surgery that I will have to tell him all my medical history again which is SO frustrating & a waste of my time."

"Not good at all - I am 15 and have been promised a transition day at the hospital where I would meet community nurses but nothing has happened yet."

"It's frustrating and upsetting. I've spent a lot of time in adult services now and each one makes me sadder than the last, we are left to our own devices and as someone who has grown up surrounded by health services, this was a shock. I'm treated differently to when I was when I was a child and feel that adult practitioners don't really care. I become just 'another patient' rather than a cared for individual."

"My experience from children to adulthood has been amazing, as I feel that I have gained a lot of independence and self-confidence."

"I feel there is a lot of support for young people but as you grow older and services drop off you can feel a bit left on your own however I understand that there has to be a cutoff point eventually but this could maybe be tailored to the person and where they feel they are in life."

The survey ended with asking for any further comments:

“If I ever have problems with my chronic health problem, I don't even bother to go to the GP - mum takes me straight to A+E at our local city hospital because I know that if I can't be stabilised in A&E then I will be admitted straight to a ward. It would only waste time if I go to my GP because they would probably tell me to go to the A+E department anyway! I feel more secure that something will be done in hospital - I have no faith in GP services at my local surgery.”

“I'm really worried about moving from children's as they know all about me. If I'm not well my mum takes me straight to the emergency room as she says my doctor at home doesn't know enough about my problem. Then I get to go on the children's ward and get sorted out.”

“Hope I get a transition day soon as it's all very scary to think I will be moved to where nurses and doctors don't know about me.”

More positive comments included:

“I am very happy with all the advice and support the Health Transition Team have given me over the years. I really enjoy the workshops from speakers who also have disabilities who share their experiences and I enjoy the workshops that help with living independently and the process of driving independently.”

Summary of Young People's Transition Survey

The results from the young people's survey mirrored the findings from the focus groups attended by young people and/or family/carer. These are detailed separately on the QNI website.

Many respondents raised concerns that they were moving from a “safe” children's service to an unknown adult service, where they often felt unsupported with their health and social needs. Poor communication between children's services and adult community services were frequently cited, with inadequate or no clinical handovers happening between services that left the young person and their family feeling isolated.

Examples were cited of young people who felt abandoned and lost in the healthcare system with concerns about moving from familiar services to unknown adult services. Several young people felt they had been failed in their transition pathway as they were insufficiently informed and prepared for the changes they would encounter.

Several comments from parents included concerns about the funding and supply of equipment aides required for their young person particularly when moving from one geographical area to another i.e. young person moving from the home environment into a residential college in a different part of the country and wanting to take their equipment aides with them. Other parental concerns included comments about feeling overburdened and overwhelmed with new systems and feeling excluded from the decision-making process about their child's care.

Respondents gave examples that although they would access primary or community services for some health needs e.g. wound dressings or vaccinations, they would be

reluctant to use these services for more complex health needs and would attend hospital services(usually via the A+E department) where they felt more secure to get their health problem dealt with quickly.

There were some positive examples given by the young person and family/carers of good healthcare delivered both in the home setting when they were housebound and in the GP surgery. Examples include having a named keyworker or health coordinator to support them through an unfamiliar system until the adult system became the norm.

The survey reflected comments made by some focus group participants that having a transition key worker in post in community adult services resulted in a seamless transition process with the young person gaining independence and self-confidence to manage their health needs.

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