

Young Peoples' Transition project: Focus Group Summary

The Queen's Nursing Institute (QNI) is funded by the Burdett Trust for Nursing to deliver a programme of work to improve the experience of a young person transitioning from children's services to adults' community services, with specific focus on District Nursing, General Practice Nursing and Educators.

Approach

The QNI consulted with key stakeholders to obtain their views, perceptions and experiences of young people transitioning into adult community services.

In order to understand the key issues affecting transition of care the following activities were undertaken:

1) A literature search and review to provide a summary of the existing research on young people transitioning from children's services to adult community services.

<https://www.qni.org.uk/resources/childrens-adult-services-literature-review/>

2) A comprehensive consultation with stakeholders through three online surveys: a general transition survey, an educators' survey and a young people and family/carers survey. This will soon be available on the QNI website.

3) The delivery of ten focus groups to gain a wider understanding on transition from a wider audience.

This report provides an in-depth analysis of the focus groups.

The qualitative and quantitative approach to the project has enabled the data analysed from the feedback to inform the development of an online Transition of care learning resource for all clinicians supporting young people. The resource is available to access on the QNI website: <https://www.qni.org.uk/nursing-in-the-community/from-child-to-adult/>

Focus Groups

Since the Transition project commenced in March 2016, the QNI has held ten focus groups, which have included a young people and families group; five university groups comprising post graduate community nurses undertaking specialist degrees in community nursing, university lecturers, practice teachers and mentors; and four general focus groups that have

included community nurses, pre-registration nursing students, hospital nurses and managers. The community nurses attending these groups have covered a wide range of professionals including District Nurses, General Practice Nurses, School Nurses, Community Children's Nurses, Nurses from Learning Disabilities, Mental Health services and Specialist Nurses.

The areas in the country that were visited include London, Birmingham, Peterborough, Hull, Darlington, Durham and Sheffield. The groups were all oversubscribed and the Project Manager has been invited back to several universities to present the transition project to the new cohorts of pre- and post-registration nursing students commencing courses in the academic year 2016/2017.

The sizes of the focus groups were limited to 25 participants to enable all attendees to contribute; however the university groups were much larger in numbers. The groups were facilitated by members of the QNI team experienced in managing focus groups and delivered in the following way:

- Open group discussion and feedback on the experiences of the attendees on their current management of transition of the young person
- Group work to identify the barriers that prevent effective transition
- Group work to identify good practice to successful transition
- Feedback by whole group following smaller group discussions
- Open discussions, sharing ideas with the whole group.

All focus groups were posed the same questions:

- What needs to be in place to improve transition?
- What have you tried that works?
- What key components should be covered during the transition process?
- What is the ideal transfer arrangement between children's and adult services?

To widen the voice of the young person within the QNI transition project, all focus groups were also asked questions from the NHS England Youth Forum. The Forum gives a voice to young people to express their thoughts on the health issues that matter most to them. It works directly with NHS England, Public Health England and the Department of Health enabling them to have a real impact on the health services that young people use. The questions asked were:

- Young people's views are really important and young people have ideas – how do you get ideas/input from young people about transition?
- Transition is really important for young people as they move from children's to adult services – how are you helping to make transition as smooth as possible?
- How are you making sure adult services welcome and retain young people once they have transitioned from children's services?
- How do you make sure that issues can be addressed when transition is not going smoothly?

A summary of the responses to those questions is given below from page 6.

All focus group attendees were enthusiastic about wanting to improve the experience of young people transitioning from children's services to adult community services. Participants gave many case scenarios from their clinical practice and young people and their family members/carers gave examples of their personal experiences with the transition process.

The discussion around what needs to be in place to improve transition was discussed at length within all the groups and issues such as poor communication and lack of co-ordination between services, frequently resulting in poor transition for the young person and their family were cited on numerous occasions. Some examples from these discussions include:

"Transitioning to adult community services was challenging as children's services was so different to ours and they wanted us to undertake the young person's continuing health care assessment instead of working with us to complete even though they had known the young person for many years. Also their service varied very much from ours and the family were very aware of this. As a District Nurse I really wanted to do the best for the young person on my caseload but at times I felt totally out of my depth."

"In my experience as a General Practice Nurse, the transition process is not well coordinated between children's services and adult community services. The young person is often left without knowing who they are to contact if an issue arises and the families are left worried, anxious and frustrated."

A common theme emerged from the comments around the need for better communication between services with discussions around differing information technology (IT) systems in hospitals, GP surgeries and community providers resulting in fragmentation of records:

"I work as a General Practice Nurse in a town surgery and due to the lack of information in adult community services it feels like the young person is not being supported effectively despite our best efforts. There is a total lack of communication via IT systems – no system is the same – the GPs are on different systems to the District Nursing services who are on a different system to Social Services. There is so much duplication of work and so much information not being shared between professionals to the detriment of the young person."

Two parents from the young people's and family group said that:

"I would have liked the transition process to have been much more organised. Communication is a massive barrier throughout the health service and that makes life very difficult for parents. IT systems must be put in place in order for community adult services to be joined up with children's services. The Practice Nurse had no idea of my son's health needs when we arrived for an appointment – there was nothing on the GP system to say what was going on with my son."

"My daughter was suddenly discharged from children's services due to reaching 16. She was told to attend the GP surgery and ask for a referral to adult community

services. This resulted in a six month wait for an adult community appointment and they knew nothing about her medical history."

Participants gave many examples that identified current gaps in the transition process when a young person is placed in adult community services. Some examples are given below:

"As a Children's Nurse working in a hospital outpatients' clinic, I feel that transition arrangements are slowly improving and links are now being made with the various adult services. However some teams, e.g. District Nursing, are not supported or informed or have the capacity to care for these young people at an appropriate time e.g. before their 18th birthday"

"I work as a District Nurse and it's not easy to take patients into adult community services from children's services – the District Nursing Services in my area of the country do not accept any involvement at all until the 18th birthday – this leaves a huge gap for the patient and their family- maybe of 2 years! Who supports the patient then?"

"As a parent, this 18 year cut off frightens me with the District Nursing service – if my child becomes ill I will have to take her back to hospital via A+E."

A student nurse spoke about a young person she had involvement with whilst on placement with the District Nursing Team:

"Transition was very poor – The District Nursing Team did accept the patient as they were nearly 18 but the out-of-hours service refused to visit the patient which deeply upset the family as their daughter had to be admitted into hospital in the middle of the night."

The issue of the potential gap of services and lack of flexibility of two years from the age of 16 years to 18 years was a concern raised by many participants in all ten focus groups with one District Nurse saying:

"I know a family with a vulnerable young daughter who should be transitioning to adult community services but our District Nursing service does not accept any referral until the person is 18 years old and she is 17. This person also needs adult social care input as she has significant disabilities but has to wait for six months or more for care support to be out in place. This causes me so much anxiety as they are not having their needs met either by health services or social services. The impact is detrimental to their health and wellbeing and this keeps me awake at night."

Discussion around good practice and what works well with successful transition generated comments again around the need for good communication between services:

One District Nurse said:

"Brilliant liaison between hospital and District Nursing team for post-operative care for a 19 year young man following abdominal surgery- the nurses felt really supported to care."

Whilst a General Practice Nurse commented that:

"A community paediatrician visited the GP surgery to handover to the GP and Practice Nurse"

The following comment was made by a Children's Community Nurse:

"Hospital adult transition nurses have got involved very early with children, attending meetings, meeting the family etc. They will then liaise with community services if care is needed in the community setting."

And a School Nurse made the comment:

"In some hospitals there are transition days for young people where staff explains the process and tour patients around the hospital. They also welcome community staff when extra needs have been identified and the young person needs healthcare in primary or community care."

Several participants within the groups said that their area of practice used the "Ready, Steady, Go" programme for transition. The programme, originally introduced at University Hospital Southampton NHS Trust, is a suite of resources designed to deliver transition for young people across all settings. Its follow on programme, "Hello to adult services," is a tool for Health and Social care service managers in children's and adults' services to work together in an integrated way to ensure a smooth transition. This was discussed in several of the focus groups, with clinicians saying they found it a very useful and workable programme to use within their clinical area.

A nurse working in a children's hospital said that the Ready, Steady, Go programme was used on the wards and suggested that the paperwork could easily be transferred to any clinical setting when the young person transitioned to adult community services:

"We use the Ready, Steady, Go programme and we have used it successfully on many occasions. We never assume that the child knows anything so we start right from the beginning. I can give many examples of children with long term and life limiting health conditions who don't even know what their condition is. Starting at the beginning with the basic question of "what do you know about why you are here" is vital in knowing where to start the transition process. It will also give a wider perspective of how the family or carer is likely to work with the programme and support they are going to need."

"Our School Nurses have helped the District Nursing staff with information when a teen goes onto their caseload. We use the Ready, Steady, Go programme which our hospital use when the teen is ready to transition into adult community services – it seems to be the only programme which works well for most settings."

Questions from NHS Youth Forum

Participants in all the focus groups were then asked to consider a selection of questions posed by the NHS Youth Forum:

Dear NHS

Transition from children's to adults' services

In healthcare, we use the word transition to describe the process of preparing, planning and moving from children's to adult services. Moving away from one team to another can be scary and it doesn't always go smoothly.

We believe everyone working with young people who are going through this journey must recognise the need for a planned and supported transition process for young people as they move from child centred to adult services and lifestyles.

The NHS Youth Forum have come up with questions that they think are important for everyone to ask, and keep asking, healthcare professionals and decision makers about what they are doing to improve transition for young people.

The NHS Youth Forum

Question 1. Young people's views are really important and young people have ideas – how do you get ideas/input from young people about transition?

Many participants within all the groups suggested that excellent communication skills were paramount to engage with young people to get their views and ideas on transition, but some primary and community nurses said that they sometimes felt uncomfortable with their lack of knowledge on where to signpost the young person with his ideas. One General Practice Nurse said:

"A young man came to the GP surgery for a routine Practice Nurse appointment. He requested that he would like to be linked with another young person of similar age and health problems and who was due to start college at the same time as him. The Practice Nurse was unsure on how she could help but she contacted a youth group in the area that ran a weekly group for young people with a learning disability. She told her patient about the group and before he was due to start college he had found a friend by attending the youth group"

Another General Practice Nurse said:

"I work as a Practice Nurse and I have asked one young patient from the surgery to link with another young person with the same medical problem to be an advocate or peer – of course all parties had to be in agreement with this but it's working really well."

Question 2. Transition is really important for young people as they move from children's to adult services – how are you helping to make transition as smooth as possible?

This question generated a lot of discussion with one university lecturer suggesting that:

“On the District Nursing programme all the students are adult trained nurses and might not have an understanding of the characteristics of children's services and the transition process. It would be helpful if the QNI online resource could have current guidelines and policies within it so our lecturers could have a greater understanding of transition and therefore be more informed within our teaching.”

Several young people spoke of their varying experiences when moving into adult community services ranging from feeling very supported by commenting:

“I had a brilliant children's nurse who came with me to a planned GP visit. She stayed with me all through the appointment and made time to speak to the Practice Nurse as well. I felt so supported and my mum was so pleased on how smooth my transition went.”

Whilst another young person with a poor transition experience said:

“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.”

Question 3. How are you making sure adult services welcome and retain young people once they have transitioned from children's services?

One young person expressed the view that adult community services had never been welcoming, saying:

“I have had no support from children's services to get me into adult community services. I am 18 and quite independent with my health problems but I know that if I need to go to the GP surgery I will have to tell him all medical history again which is SO frustrating and a waste of my time.”

One District Nurse spoke of a positive experience of multi-disciplinary team working she had when a young person was referred into the community nursing team for a continuing health funding reassessment:

“I arranged to visit the patient and her family with a Social Worker who fortunately had known the family for several years. She took the lead during the assessment and the patient's reassessment of needs was approved for further funding. As a District Nurse I learnt a lot from that meeting but it made me realise how much support our community

team needs, particularly around funding issues to enable us to get it right for our younger patients."

Question 4. How do you make sure that issues can be addressed when transition is not going smoothly?

This question caused much debate, as many examples were given on transition experiences that didn't go smoothly in comparison to transitions that went well and there didn't seem to be an answer on what to do or to contact when the transition process was poor. A few examples of conversation include:

"I am a parent and my son is now 18. I now have no parental responsibility. However the last year has been a nightmare and I've lived on eggshells and constantly wondered when will be the next time I find him collapsed on the bathroom floor because nobody told me there was a risk. There's no understanding of what it's like to be a parent of a 17 year old - in your house for whom you have responsibility - for whom you suddenly have no input into their care. Shouldn't transition follow a more holistic natural path - leaving home, going to University, starting a job... Transition at 17 is inappropriate to say the least. My 18 year old now has to re-transit to University in September. A whole year of getting used to one practitioner and then leaving home and getting used to so many other things. They didn't need this upheaval and I'm worried sick."

A Community Nurse Clinical Manager added:

"This is work in progress but now thankfully the paediatric teams and the adult community services teams are in regular dialogue with each when a young person is transitioning over and this helps to support the young people going through this process."

Whilst a District Nurse said:

"We now have a transition community nurse who started in the team recently. Our nurses are pleased as we have really floundered in the past on who to contact and what to do. We really want to be professional and it has been very hard to walk into a young person's house and not have the answers for them or their family. Generally young people are so very well supported in children's services and it's often a huge shock to the patient when a District Nurse arrives to start their care or when they attend the GP surgery and they have no confidence in the services. We have had examples of mum and dad taking their young person back to the A+E department with a health concern as they know they will be sorted and they have much more confidence to go that route into healthcare. I'm sure our new transition nurse will make a positive addition to the community team for the young people and for us."

Overview from the Young People and Family Focus Group

A focus group (young people and family) organised by and facilitated with 'Investing in Children', took place to discuss personal experiences with their health care transferring from children's services to adult health services.

A. Young people's Discussion

Community Health Care Services

The young people discussed their involvement with the community health care services. They pointed out that often the time of appointments was inconvenient, due to parents/guardians not having time to participate as support for the patient. They mentioned, especially with physiotherapy, that too much was expected from the patient to do as homework, as well as not having support from their parents to do exercises at home. Young people stated they wanted choice of time for appointments and flexible timing to see their health care professionals.

Transition Experience

During the young people's transition process, they felt uncomfortable meeting new health care professionals. They wanted somebody they knew and trusted to talk through their problems and issues regarding health. The young people suggested meeting their previous and new doctor at the same appointment, for their first few appointments during transition. Young people agreed that this should be optional, depending on the patient's preference.

Information and Feedback

Young people felt that information about their own health was generally aimed at their parents.

However, all young people had been asked to fill in the QNI young people's survey about their care and they did comment that completing surveys was a useful way of providing feedback.

Appointments

Young people said that choice and flexibility of times is important, as they were often given a date/time of an appointment with no option to state personal preference. If the young person was unable to attend, it could be up to three months before an appointment was rescheduled (hospital or primary/community services). This could lead to young people missing out on things they wanted to do in school and socially. Young people also would like weekend services from GPs for urgent care.

Medication

Young people said were they were unhappy with information provided with the medication they were prescribed. Young people also stated that they felt like their doctor didn't look into possible side effects of the medication, as they were just "forced to take the

medication", despite the risk of side effects. This underlies the issue of good communication discussed elsewhere.

B. Parent Discussion

Parents participating in the focus group had very mixed experiences of healthcare and transitions.

Impact of Diagnosis

Two of the parents had faced a long wait before their children were diagnosed and received support and also said they found it very difficult to trust and get support from healthcare professionals. Following diagnosis, the families had experience of specialist care, GP care, community care and social workers.

Community Healthcare

Some parents had experienced community healthcare and said it was extremely helpful if someone came into the home to provide care. An example given was of one young person who had to travel in excess of one hour to hospital to have a blood test, which the parent felt could be done in a community setting to save on travelling time.

Accessing Support

All families agreed that there is a critical need to provide support for families in a community / local setting. This is for families who have gone from being 'healthy' to having a long-term medical condition and for those families who are living with a child / young person with complex medical needs. Some families said they felt they needed to be *"close to breaking point before we could access support."* The families also felt that there needed to be a lot more support for families who have young people transitioning to adulthood. One parent commented that *"the future is scary because there are lots of unknowns which we could get support with"*.

Parents found it very challenging having young people formerly dependent on them moving towards being independent. They felt certain triggers like the responsibility of the young person making clinical appointments or remembering to take their medications could make worries and anxiety worse. The families also said support could be a lot more useful and practicable if they were simply asked, 'How are you managing?' when accessing healthcare services. The families felt that specialists and community care could do more to anticipate and identify particular times when support may be needed and provide this.

The families also commented that building trusting, supportive relationships was sometimes hard and their experience was that care and communication was often disjointed. An example of good practice was given of a young person missing a GP appointment and being contacted by their surgery to ask if everything was alright and reminded that they can see the GP for support.

Experience of Transitions

The families all had experiences of poor transitions and all parents said that transitions had not been explained to them and none of them fully understood what it involved and what would happen. One parent said that healthcare professionals kept saying that they would be "*going through transitions*" and now they are accessing adult services they are still not aware of what the transitions process was, i.e. the young person was in children's services and suddenly found themselves in adult services.

Parents also felt that transitions were very much a 'one size fits all' approach, when they should be holistic and individualised without a set age to transition. Parents were extremely worried about their children attending adult care.

Summary from the young people and family group

In summary, families thought that support needed to be better within all aspects of healthcare, particularly in diagnosis, transition process and community health. Families reported that it was hard to build long-lasting, trusting relationships because of poor experiences in the past and that a 'one-size-fits-all' approach should not be taken by any healthcare team. Families said that their understanding of transitions was extremely vague and no-one could define what transitions were and what did / should happen during this period. All families felt that community health could play a role in joining up care and supporting the whole family.

Summary of general focus groups and educator groups

In summary, the feedback from the focus groups reflected the overall findings from the online surveys and the literature review that were analysed to inform the online learning resource. These are detailed separately on the QNI website.

Many participants from the groups were concerned about poor communication between services, leading to the lack of coordination in the healthcare services that young people required when transitioning. They also raised concerns around the lack of support that District Nurses and General Practice Nurses received both prior and during care delivery to their patients transitioning on to their caseloads. Feedback from the university focus groups confirmed that transition was rarely taught on modules both on pre- and post-registration nursing courses.

The lack of joined-up IT systems was frequently raised by the groups, with the concern that clinical information about the young person was not shared amongst professionals. This led to a disjointed transition for the young person, their family/carer and for the professional, as finding clinical information was so time consuming.

There were positive examples given on services communicating well with each other prior and during transition. An example given is where there was a clinician in post in community adult services with a specific role to support the young person, family/carer through the transition process. Many participants felt that if a nurse had a transition keyworker role and responsibility within the clinical team, this would ensure a more seamless transition process

for all involved. The successful examples of transition appear to be where clinicians across all disciplines work closely together to improve transition for young people and their families/carers.

There was agreement by all participants in all focus groups that the proposed QNI online learning resource would be of considerable benefit to clinicians and educators, increasing their knowledge on young people's transition processes, which in turn would benefit and impact on the young person, their families and carers.

**Candice Pellett OBE, Queen's Nurse
February 2017**

Acknowledgements

The QNI would like to thank the following for their help and support with hosting our focus group events:

- Investing in Children, County Durham
- University of Hull
- Sheffield Hallam University
- London Southbank University
- Teeside University (Darlington Campus)