healthwatch
County Durham

Young People's Transition from Children's Services to Adults' Services

Research into the experiences of young people and their parents/carers in County Durham

February 2019

Contents

Healthwatch County Durham 3
Executive Summary 4
Background to this work 7
What We Did 9
What We Heard 11
Observations 14
Recommendations 15
Appendix A: Transitions survey 18
Appendix B: Resource sheet 20
Appendix C: Links to websites 22
Appendix D: Literature references 22

Healthwatch County Durham

Healthwatch County Durham is the county's consumer champion for health and social care, representing the voices of current and future users to decision makers.

We listen to patients of health services and users of social care services, along with their family members or carers, to find out what they think of the services they receive.

We advise people how to get the best health and social care for themselves and their family. We provide help and information about all aspects of health and social care provided in County Durham.

We make sure that consumers views are heard by those who provide health and social care. Wherever possible we try to work in partnership with providers to influence how they make improvements.

Executive Summary

We asked the public in County Durham what our priorities should be for 2018/2019. Young People's Transition from Children's to Adults' Services was selected by the public as one of their top four priorities. By transition we mean the process by which young people with additional needs move from Children's Services to Adult Health and Social Care Services.

There is a vast amount of regional and national literature available on transition, which we thought was important to capture. Some of the findings have informed this report but we also wanted to engage with young people and parents/carers in County Durham to see if their experiences mirrored the NICE guideline scope on transition, published in 2014, which stated: '*Although there are agreed principles of good transitional care, there is evidence that these principles are often not reflected in practice, and that transition support is often patchy and inconsistent* (Beresford and Cavet 2009, Clarke et al. 2011, Gordon 2012, Singh 2010, Hovish et al. 2012). *Consequences of poor transitions include broken relationships with health and social care practitioners, disengagement with services and deteriorating health* (Watson 2005, Singh 2009).'

Our aim was to find out more about young people's experiences of transition and how aware they and their parents/carers were of the process. We did this by carrying out a series of different engagement methods to gather their views and experiences, which included an online survey and face to face engagement with relevant groups. We used the NICE Quality Standard QS140 (2016) 'Transition from children's to adults' services', as a framework for our survey an received 89 response.

What People Told Us

When we asked young people and their parents/carers the following:

Do you know of any system in place to help young people move from Children's to Adults' Services?	71% said 'No'
What ages do you think would be a good time to start thinking about moving to Adults' Services?	56% said between the ages of 13 to 16yrs
Do you think it would be a good idea to have literature available (e.g. leaflets, website) about what to expect when young people move to Adults' Services?	100% said they thought it was a good idea

We asked young people who hadn't transitioned, and their parents/carers, specific questions about their experiences of transition to date:

Question	Response
Do you meet with anyone from Children's Services to talk about moving to Adults' Services	80% said 'No'
Have you met with anyone from the Adults' Services team to talk about the move?	92% said they hadn't
Is there a named person (e.g. nurse, consultant, social worker) who can help with the move to Adults' Services, such as by answering questions or supporting you through the process?	73% said 'No'
Do you think it would be a good idea to meet at least once a year with professionals to talk about how the move to Adults' Services is going?	89% felt it would be a good idea
We asked parents/carers of these young people if they feel supported by professionals during the transition process.	Of those who responded 90% said they didn't

We also asked young people who had transitioned to Adults' Services, and their parents/carers, about their experience of the process. They responded:

Question	Response
Before the move did you meet with anyone from Children's Services to talk about transition?	50% said 'No'
Before the move did you meet anyone from the Adults' Services team?	67% said they hadn't
Did you have a named person (e.g. nurse, consultant, social worker) who helped with the move to Adults' Services, such as by answering questions or supporting you through the process?	56% said 'No'
Do you think it would be a good idea to meet at least once a year with professionals to talk about how the move to Adults' Services is going?	100% felt it would be a good idea
We asked parents/carers of these young people if they felt supported by professionals during the transition process.	Of those who responded 83% said they didn't

Summary of Recommendations

Intelligence collected by HWCD evidences that although there are some examples of good practice in relation to young people's transition, there is still a lot to do to improve transition pathways for young people with additional needs. This is mirrored by other regional and national evidence. We have made the following recommendations for commissioners and service providers to consider:

Young people should be put at the centre of a well-planned and integrated transition process to ensure they remain engaged with health and social care providers. This can be achieved by implementing the NICE Quality Standard QS140 (2016) 'Transition from children's to adults' services' for all transition pathways'.

To ensure that the NICE Quality Standard is implemented a Transition Coordinator should be appointed and establish a multi-agency steering group that includes Adult Services. This will ensure a joined up vision, preventing gaps in continuity of care.

An integrated approach to commissioning services should be adopted jointly by Children's and Adults' Services. If 'Transition' is not a commissioned service it is unlikely to be delivered. NHS organisations should work together and, where appropriate, consider joint Transition clinics, to enable young people to attend clinics that are age relevant.

Children's and Adults' health and social care services should plan transition together, to ensure the young person's transition is personalized to meet their needs.

More information needs to be available and easily accessible-100% of respondents felt it would be a good idea to have information (e.g. leaflets or websites) about what to expect when a young person moves to Adults' Services. The young carers we talked to felt a website would be better as leaflets can get lost.

Opportunities for Primary Care to support young people - parents/carers were asked if nurses at their doctor's surgery helped with the young person's healthcare at home. Of those parents/carers whose young person had transitioned, only 25% said they had, which could provide an opportunity for primary care to support young people.

The Queen's Nursing Institute report 'Transition of Care Programme' highlighted that educators felt it was very important that young people's transition should be taught within their teaching programmes. A large percentage of educators that they engaged with reported that transition wasn't currently taught at all. The QNI online learning resource could be used as a framework within the curriculum to address this gap.

Background to this work

We asked the public in County Durham what our priorities should be for 2018/2019. Young People's Transition from Children's to Adults' Services was selected by the public as one of their top four priorities. By transition we mean the process by which young people with additional needs move from Children's Services to Adult Health and Social Care Services.

We wanted to engage with young people and parents/carers in County Durham to find out if their experiences of transition mirrored the findings of others.

The guideline scope on Transition from Children's Services to Adults' Services published by NICE in 2014, stated:

'Although there are agreed principles of good transitional care, there is evidence that these principles are often not reflected in practice, and that transition support is often patchy and inconsistent.' (Beresford and Cavet 2009, Clarke et al. 2011, Gordon 2012, Singh 2010, Hovish et al. 2012).

'Consequences of poor transitions include broken relationships with health and social care practitioners, disengagement with services and deteriorating health.' (Watson 2005, Singh 2009).

In 2014 the Care Quality Commission (CQC) published 'From the Pond into the Sea, Children's Transition to Adult Health Services' and found that:

'Although there are some shining exemplars of good practice, in general transition is poorly planned, poorly executed, and poorly experienced. There are enormous risks for young people disengaging or being lost in the transition process.'

Northumbria Healthcare NHS Foundation Trust and Newcastle University led 'The Transition Programme', a 5-year programme of research (2012-2017). Their findings highlighted these risks:

'There are risks if transition is not successful. Disease control, continuity of healthcare, and co-ordination of care are compromised; and the outcomes of healthcare costs in later life, social participation, and employment or further education are often poor. Specifically commissioned, arrangements for promoting successful transition can fall all too easily between child and adult services and so not be provided.'

These findings were echoed in an enquiry report, published October 2018 by the All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care, 'End of life care: strengthening choice':

'*Medical advances mean there are now 55,000 young adults aged between 18 and continues to grow. However, the transition these young people have to undergo from the comprehensive care offered by children's palliative care to unfamiliar adult services can be daunting and is often not joined up*.'

HWCD was involved in a piece of work carried out by the Queen's Nursing Institute (QNI) in 2016 - 2018. The QNI was funded by the Burdett Trust for Nursing to deliver a new programme to support best practice in the experience of children and young people transitioning from children's to adult community health services. As part of that programme in 2016, HWCD was invited to an event led by the QN,I hosted by Investing in Children, to look at young people's experiences of transition. This work contributed to a nationwide study that the QNI conducted.

Feedback from young people noted that:

'During the change in the young people's transition they confessed they felt uncomfortable meeting new health care professionals. They wanted somebody they know and trust to talk to with their problems and issues regarding health. The young people suggested of having their old and new doctor in the same appointment for their first few appointments of transition, young people agreed that this should be optional depending on the patients' preference.'

Feedback from parents/carers included:

"The families had the general experience that transition is not working well 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. Parents also felt that transition was very much a 'one size fits all' approach and should be holistic and individualised without a set age to transition."

It should be noted that some examples of good practice were reported at the event, e.g. when one young person missed a GP appointment the surgery will write to the family asking if everything is OK and reminding them that they can see the GP for support.

What We Did

Transition is a wide-ranging subject with many young people experiencing more than one transition at any one time. To ensure that we kept the research focused on health and social care transitions we used the NICE Quality Standard QS140 (2016) 'Transition from children's to adults' services', as a framework. This standard was developed as a result of the findings of the NICE 2014 guideline scope (N43).

Our survey was designed around the 5 quality statements recommended by NICE:

Statement 1	Young people who will move from children's to adults' services start planning their transition with health and social care practitioners by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.
Statement 2	Young people who will move from children's to adults' services have an annual meeting to review transition planning.
Statement 3	Young people who are moving from children's to adults' services have a named worker to coordinate care and support before, during and after transfer.
Statement 4	Young people who will move from children's to adults' services meet a practitioner from each adults' service they will move to before they transfer.
Statement 5	Young people who have moved from children's to adults' services but do not attend their first meeting or appointment are contacted by adults' services and given further opportunities to engage.

The strengths of using the quality statements is that they are evidence based, act as a benchmark for best practice and identify actions that need to be taken to achieve the standard.

The public consultation took place during June - November 2018. Our aim was to find out more about how aware young people and their parents/carers were of the transition process and to find out about their experience, what has worked well for

people and what could be improved. We also wanted to ask them for their views on other aspects of transition including:

- At what age young people should start to think about transition
- Who young people should be talking to about the process
- If they have a named professional who could support them through the process

We carried out a series of different engagement methods to gather their views and experiences, which included:

- Creating an online and paper survey
- Talking to young people who had gone through or would be going through the process
- Talking to parents/carers of young people with additional needs
- Talking to organisations who support young people to establish what level of support is available

We attended events across the County and met with regional organisations including:

- Making Changes Together conference
- Young People's Futures event hosted by the eXtreme Group and Investing in Children.
- Durham County Council's Integrated Steering Group for Children & Preparing for Adulthood group
- Durham County Carers Support
- Humankind 'Horizon's' programme
- CAHMS, TEWV NHS Trust

In addition we delivered an engagement session with a group of young carers to get their views on transition. Family Action supported us with this.

We received 89 responses to our survey. Respondents were asked to provide the first half of their postcode. Although not all respondents carried out this request, we were able to identify the following postcode areas:

DL3, DL5, DL13, DL14
DL15, DL16, DH1, DH2
DH3, DH6, DH7, DH8
DH9, SR8, NE16

What We Heard

When we asked young people and their parents/carers the following:

Do you know of any system in place to help young people move from Children's to Adults' Services?	71% said 'No'
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Do you think it would be a good idea to have literature available (e.g. leaflets, website) about what to expect when young people move to Adults' services?	100% said they thought it was a good idea

We asked young people who hadn't yet transitioned, and their parents/carers, specific questions about their experiences of transition to date:

Do you meet with anyone from Children's Services to talk about moving to Adults' Services	80% said 'No'
Have you met with anyone from the Adults' Services team to talk about the move?	92% said they hadn't
Is there a named person (e.g. nurse, consultant, social worker) who can help with the move to Adults' Services, such as by answering questions or supporting you through the process?	73% said 'No'
Do you think it would be a good idea to meet at least once a year with professionals to talk about how the move to Adults' Services is going?	89% felt it would be a good idea
We asked parents/carers of these young people if they feel supported by professionals during the transition process.	Of those who responded 90% said they didn't.

We also asked young people who had transitioned to Adults' Services, and their parents/carers, about their experience of the process. They responded:

Before the move did you meet with anyone from Children's Services to talk about transition?	50% said 'No'
Before the move did you meet anyone from the Adults' Services team?	67% said they hadn't
Did you have a named person (e.g. nurse, consultant, social worker) who helped with the move to Adults' Services, such as by answering questions or supporting you through the process?	56% said 'No'
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We asked parents/carers of these young people if they feel supported by professionals during the transition process.	Of those who responded 83% said they didn't.

Some of the comments we received included:

"We go to half a dozen clinics and they are all talking about it in different ways." Parent

"You have to badger people to get information." Parent

"I felt I had to sort it out myself. It was a very bad time. You need to start it early" Parent

Young Carers Focus Group

HWCD was awarded the Young Carers' Neighbourhood Charter in 2018 and we have pledged to recognise and identify young carers in the work we do. We were keen to get their views on the transition process and worked in partnership with Family Action to deliver a workshop with 4 young carers. The young people were very lucid and articulate about what they thought would make the process an effective one for young people:

They felt that the latest point at which the transition process should be raised with a young person was when a young person was in Year 9 at school. (Aged 13-14 years)

When asked if an annual review should be carried out to discuss and plan transition they felt that at least two meetings a year were necessary. They also felt that the support the young person received should be more intensive when they are 16/17yrs old. Their reasoning for this was that anything discussed in an annual review could be easily forgotten.

They were very clear that it was important to have a named worker whose responsibility it was to support a young person through the process.

They felt it was equally important that a young person moving to an adult service should meet someone from the adult team before they move across. This would help reduce their anxiety.

If a young person was not able to attend the first appointment with the Adults' Services team, they felt it was important that the onus was on the service to contact the young person to rearrange the meeting. This would reduce the anxiety of contacting the service and they wouldn't worry about re-arranging the appointment themselves. They did comment however that this first meeting was important and that every effort should be made to help them attend.

As a result of the engagement work, Family Action has added an additional commitment to the Schools Young Carers' Charter that teachers '*will make sure that extra support is put in place for young carers who are going through transition periods, either when moving from primary to secondary school, or from secondary school to post 16 provision.*'

Observations

We talked to regional organisations and heard some repeated themes. In the Transitions Report produced by Investing in Children as a result of the workshop with the QNI in 2016 young people said that:

> ***'...they felt like the 'odd one out' when going to hospital for clinic visits in reference to the waiting room. Young people would prefer to wait in a waiting room which was age appropriate to them and to be accompanied with other patients in the same age range'***

This view was echoed by the Co-ordinator of the Type1kidz group facilitated by Investing in Children who said that young people are reluctant to go to adult support groups as they are usually attended by people who are a lot older. It was a view also familiar to the Lead for young carers at Humankind, where young people get the option to move to the adult service but they see this as an old person's service.

The phrase 'cliff edge' was repeated in many of the conversations. In 2014 the Strategic Lead for Transition in Adult Services suggested a Transitions Service for young people with sensory, learning and physical disabilities as otherwise there was a sense that young people were falling off a cliff edge at 18yrs. This service was set up for young people aged 14 – 25yrs but has a remit to support young people with specific characteristics, which means that other young people are still at risk.

The Learning Disability Support and Development Worker for Durham County Carers Support also felt that at 18+ there many changes that affect young people with special needs that their parents/carers are not aware of e.g. changes to services, benefits, employment, education and housing.

Durham County Council's recently established Integrated Steering Group for Children aims to ensure that high quality services are delivered that meet the needs of all children and young people. Transition is currently the focus of a working group but will ultimately be a priority for all working groups. This group reports directly to the Integrated Care Board and would appear to be well placed to ensure that all young people with additional needs experience a positive transition. However, this group should ensure that there is representation from Adult Services, to provide a joined-up vision, which will prevent the 'cliff edge' scenario.

Recommendations

Intelligence collected by HWCD evidences that although there are some examples of good practice in relation to young people's transition, there is still a lot to do to improve transition pathways for young people with additional needs. This is mirrored by other regional and national evidence. We have made the following recommendations for commissioners and service providers to consider:

1. **Young people should be put at the centre of a well-planned and integrated transition process** to ensure they remain engaged with health and social care providers. This can be achieved by implementing the NICE Quality Standard QS140 (2016) 'Transition from children's to adults' services' for all transition pathways'. This Quality Standard covers the period before, during and after a young person moves to adults' services, in all settings where transitions from children's to adults' health or social care services take place. It covers all young people (aged up to 25) who are using children's health and social care services that are due to make the transition to adults' services. (For further info see NICE Pathway 'Transition from children's to adults' services overview)

Implementing the NICE Quality Standard will ensure that young people will:

- Start planning their transition with health and social care practitioners by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.
- Have an annual meeting to review transition planning.
- Have a named worker to coordinate care and support before, during and after transfer.
- Meet a practitioner from each Adults' Service they will move to before they transfer.
- Be contacted by Adults' Services and given further opportunities to engage if they miss their first appointment.

2. **To ensure that the NICE Quality Standard is implemented** a Transition Coordinator should be appointed and establish a steering group that includes Adults' Services, to develop a Transition strategy. This will ensure a joined up vision, preventing gaps in continuity of care.
3. **An integrated approach to commissioning services should be adopted jointly by both Children's and Adults' Services.** If 'Transition' is not a commissioned service it is unlikely to be delivered. NHS organisations should also work together and, where appropriate, should consider joint Transition clinics, to enable young people to attend clinics that are age relevant

4. **Children's and Adults' health and social care services should plan transition together,** to ensure the young person's transition is personalized. One size fits all is unlikely to work as it does not address young people's individuality

5. **Information should be readily available in a range of accessible formats** for both young people and parents/carers. 100% of respondents felt it would be a good idea to have information (e.g. leaflets or websites) about what to expect when a young person moves to Adults' Services. The young carers we talked to felt a website would be better as leaflets can get lost. There are some examples of what a website could look like e.g: http://www.uhs.nhs.uk/Ourservices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx (*see Appendices for further examples*)
6. **More primary care staff could support young people with transition.** Young people and parents/carers who completed our survey were asked if any nursing staff visited them at home or helped with the young person's healthcare, e.g. carried out blood tests. Of those parents/carers whose young person had transitioned 25% said they had, which could provide an opportunity for primary care to support young people further.

7. **The QNI's programme focused on providing evidence based information and guidance to District Nurses, General Practice Nurses and Nurse Educators**, to enable them to support young people more effectively through this challenging time and to improve and develop the services and systems. They launched an online learning resource in 2017 to improve nursing care for young people who are in the transition process. The learning resource can be viewed at: https://www.qni.org.uk/child_to_adult/index.ph

8. **The QNI report highlighted that educators felt it was very important that young people's transition should be taught within their teaching programmes**. A large percentage of educators that the QNI engaged with reported 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. Some universities have pledged to develop Transition of Care as a module or course component for the first time; the QNI online learning resource could be used as a framework within the curriculum.

Thank You

We would like to thank all of the young people and parents/carers who took the time to complete our survey and shared their experiences of Transition with us. We would also like to thank the statutory and voluntary organisations who talked to us and who shared their intelligence with us:

Durham County Carers Support

Durham County Council

Family Action, Young Carers

Humankind Horizons Programme

Investing in Children

Making Changes Together

The Queen's Nursing Institute

Appendices

Appendix A: Transitions survey

As a result of a public vote we've been asked to talk to young people aged 13 - 25yrs with extra care needs, and their parents/carers, about their experience of transition. By transition we mean the process of moving from Children's to Adult services. So, whether you're just starting to think about moving or have already been transferred we'd like to hear about your experiences. We want to find out just how well the process is working and, based on what you tell us, we will produce a series of recommendations to improve the service.

Please tell us your age: ______

Do you know of any system in place to help young people move from children's to adult services?

- ☐ Yes
- ☐ No

At what age do you think it would be a good time to start thinking about moving to adult services?

- ☐ 11 – 13 yrs
- ☐ 13 – 16 yrs
- ☐ 16 – 18yrs
- ☐ 18 yrs +

Do you think it would be a good idea to have information (e.g. leaflets or websites) about what to expect when a young person moves to adult services?

- ☐ Yes
- ☐ No

Do you meet with anyone from children's services to talk about moving to adult services?

- ☐ Yes
- ☐ No

Have you met with anyone from the adult services team to talk about the move?

- ☐ Yes
- ☐ No

Is there a named person (e.g. nurse, consultant, social worker) who can help with the move to adult services, such as by answering questions or supporting you through the process?

- ☐ Yes
- ☐ No

Do you think it would be a good idea to meet at least once a year with professionals to talk about how the move to adult services is going?

- ☐ Yes
- ☐ No
- ☐ Not sure

Have the nurses at your doctor's surgery visited you at home or helped with your healthcare, e.g. carried out blood tests?

- ☐ Yes
- ☐ No

- ☐ Not sure

When you meet with your doctor or other professional, are you given the chance to talk with them on your own (if you want to)?

- ☐ Yes
- ☐ No

If you attend a clinic is it for:

- ☐ Children
- ☐ Teenagers
- ☐ Adults
- ☐ Not applicable

Do you think clinics just for teenagers would be a good idea?

- ☐ Yes
- ☐ No
- ☐ Not sure

Are you able to make decisions about your care needs?

- ☐ Yes
- ☐ No

How would you rate the experience of moving to adult services so far?

- ☐ Excellent
- ☐ Good
- ☐ Okay
- ☐ Poor
- ☐ Very poor
- ☐ Not applicable/Not started

Can you tell us why you chose this rating?

If there is anything else you would like to tell us about transition, please use this box:

Please provide the first part of your postcode (this does not identify you, but it helps to see if there are any patterns by area): ______

Appendix B: Resource sheet

Milestone RESOURCE **SHEET FOR YOUNG PEOPLE**

This project has received funding from the European Seventh Framework Programme for research, technological development and demonstration under grant agreement no 602442.

IDEAS OF SOME QUESTIONS TO ASK YOUR CLINICIAN OR KEY WORKER (the person you are seeing in your Child and Adolescent Mental Health Service) IF YOU NEED TO TRANSITION TO ANOTHER SERVICE

1. Ask whoever you are seeing in your Child and Adolescent Mental Health Service **what the plan is**.

2. Do I have to move **at 18 or is there any flexibility**?

3. **Which service** are you thinking I might move to? Is this the only choice?

4. Can I have **some information about the service** – e.g. what treatments does it offer, where is it based, when is it open?

5. Can I **visit and/or meet someone in the new service**?

6. Will I have to be **assessed again**? **What information about me will be passed on to the new Child and Adolescent Mental Health Service**? (Can I see this?)

7. Will **my parents or carers be involved**? Can they come to the first appointment with me (if I want this)?

OR: If **I don't want my parents/carers to be involved, is this OK**?

8. **How soon will I get an appointment**?

9. If there is a wait, **who can I contact if I need any help in the meantime**?

10. **What do I do if the new service doesn't turn out to be right for me**?

11. **Will the new service be able to continue any ongoing treatment I am currently receiving**? Will they have access to this current treatment plan?

YOUNG PEOPLE'S 12 TOP TIPS FOR MAKING TRANSITION WORK FOR YOU

This project has received funding from the European Seventh Framework Programme for research, technological development and demonstration under grant agreement no 602442.

You have a right to be involved in planning your transition.

We hope the following ideas will help you if you need to move services…..

1. Ask whomever you are seeing in your Child and Adolescent Mental Health Care Service what the plan is.
Do this as soon as anyone mentions you finishing at your Child and Adolescent Mental Health Service or maybe moving to adult services.

2. If it's not offered, **ask for a meeting to discuss your options**.

3. Check if there will be **someone to support you through the move** – this person could be from your current service or the new one you may transition to.

4. Ask what **information will be shared about you** – how much will the new service know?

5. Even if the plan is just to discharge you, **make sure you know what to do if you need support with your mental health**.

6. Make sure different services are considered, an **Adult Mental Health Service may not be the only option**.

7. If possible, **visit the proposed new service** or check out their website – gather information to see if you think the service fits you.

8. Moving services should, as much as possible, **go at a pace that is comfortable for you. If it's feeling too rushed, you should say so!**

9. Remember, if the service does not feel right you can **enquire about other options**.

10. Find out if there will **be a waiting list to be seen at the new service**. Is there an approximate wait time?

11. Ask questions **about what support will be in place, or what help you can ask for**, while you wait to be seen by your new services.

12. **Ask if you will remain in your Child and Adolescent Mental Health Service until an appointment date is set up in your new service.** It's important you feel supported every step of the way during the transition period.

Appendix C: Links to websites

- https://www.qni.org.uk/nursing-in-the-community/from-child-to-adult/
- https://research.ncl.ac.uk/transition/
- http://www.healthtransition-walsall.nhs.uk/what-is-transition/
- https://research.ncl.ac.uk/transition/resources/usefullinks/

Appendix D: Literature references

- Care Quality Commission. (2014). From the pond into the sea. London: https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf
- National Institute for Health and Care Excellence. (2016a). Transition from children's to adults' services for young people using health or social care services. https://www.nice.org.uk/guidance/ng43
- National Institute for Health and Care Excellence. (2016b) Transition from children's to adults' services (Quality Standard QS140). https://www.nice.org.uk/guidance/qs140
- NICE Pathway 'Transition from children's to adults' services overview, March 2018 https://pathways.nice.org.uk/pathways/transition-from-childrens-to-adults-services
- The Queen's Nursing Institute Transition of Care Programme, Final Report 2018 https://www.qni.org.uk/wp-content/uploads/2018/09/Transition-of-Care-Programme-Final-Report-2018-web.pdf
- All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care, 'End of life care: strengthening choice' https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/10/Pol_Res_181019_APPG_Children_Who_Need_Palliative_Care_inquiry_report.pdf