

## Cover Sheet

Trust Board Meeting in Public: Wednesday 10 November 2021

TB2021.85

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**Title:** Patient Perspective: Making the Transition from Children's to Adult Services: Preparing for Adulthood

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**Status:** For Discussion

**History:** A patient story is presented to each Trust Board

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**Confidential:** No

**Key Purpose:** Strategy, Assurance, Policy.

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## Executive Summary

1. Making the move from children's to adult services is a complex process, which can be a cause of stress and worry for children and young people; their families and clinicians. It also impacts on education, social care, and healthcare. The process can be very daunting and overwhelming for families, who often have known the same clinical staff for the majority of their child's life.
2. The Trust recognises this and the support or transition to adult services is a quality priority for 2021/2022.
3. Transition is now used to explain two aspects of a person's life. These are the
  - move from children's to adult services
  - transition from one gender to another.

It is important not to confuse the two terms and for the purposes of this story the term 'preparing for adulthood' will be used.

4. This paper describes
  - the experience of a family who went through the process
  - the Quality Priority and progress update
  - YIPPEE's views (the Trust Young People Executive).
5. The key messages from the story are:
  - Each sector cannot work in isolation. Collaborative working across both primary and secondary health care is essential for a successful transition experience.
  - Communication is key between all parties and should be honest and transparent with all working at an equal level.
  - Children's services and parents need to learn to let go and support the young person to be independent to the best of their ability.
  - There needs to be a key health professional who has an overview of all the different aspects involved in a young person's transition/ preparation for adulthood.
  - The Ready Steady Go (RSG) programme is not just a tick box exercise, it needs to be started early and tailored to the individual. RSG does not tell you 'how' to do it. A key person/dept needs to take ownership of the programme. It seems to suit a patient with a linear condition rather than a patient with complex needs.
  - Conversations around end of life issues need to happen when the young person is well and not when in a crisis situation.

- A young adult can still feel overwhelmed and still need emotional support, even though they are an adult.
- Health passports provide the individualised and child centred care, these should be more widely available and used more often.
- There is a place for young adult units, particularly for children and young people (CYP) with complex needs who are now surviving into adulthood.
- Adult services need to understand the complexity of CYP with complex health needs.
- A CYP with a life limiting condition is receiving palliative care through their whole life for them and their family. This is different to end of life care for adults. The family discussed the provision of respite care and felt there needs to be more to support young people and their family, i.e. an adolescent hospice.

### **Recommendations**

The Trust Board is asked to:

- Note the content of the story.
- Actively support transition/ preparing for adulthood within the Trust

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## Patient Perspective: Making the Transition from Children's to Adult Services: Preparing for Adulthood

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### 1. Purpose

- 1.1. The purpose of the paper is to tell the story of the move from children's to adult services.
- 1.2. This will include
  - The story
  - The Quality Priority
  - The work with the Burdett Trust and South of England transition leads.
  - Feedback from YIPPEE.
- 1.3. The paper will conclude with the lessons learned to date and project plan for the Quality Priority.

### 2. Background

- 2.1. Several national initiatives support this important phase for a child receiving health and social care.
- 2.2. The NHS website, [Moving from children's social care to adult's social care](#) describes that until the age of 18 years, the services for children and young people with long term health conditions are provided by child health and social care services. From 18 years they are provided by adult services<sup>1</sup> and between 16 – 18 years the child starts the preparation for adulthood and the 'transition' to adult services. For some children, this should start approximately between 13-14 years old, especially if they have complex health and social care issues. The child centred process involves the child, their family/ carers, health and social care, mental health, education, financial benefits, work, and housing.
- 2.3. The CQC published [From the Pond into the Sea](#) in 2015. The reports' four key messages aimed to facilitate a good 'transition to adult services' by ensuring that
  - Commissioners listen to and learn from young people and their families

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<sup>1</sup> In the Trust, children's use adult services from 16 years old.

- Existing good practice guidance is followed to ensure young people are properly supported through transition
- GPs and community services should be more involved, at an earlier stage, in planning for transition
- Adolescence/young adulthood is recognised across the health service as an important developmental phase – with NHS England and Health Education England taking a leadership role.

The last key message has given considerable focus to supporting children's and young people during this stage in their life. Additionally, setting the scene for successful use of, and engagement with, health and social care services throughout their adult life to maximise their health outcomes and quality of life.

- 2.4. The Nice guidance: NG 43. [Transition from children's to adults' services for young people using health or social care services](#). This guideline covers the period before during and after a young person moves from children's to adult services. It aims to help young people and their carers have a better experience of transition by improving the way its planned and carried out.
- 2.5. [The Burdett Trust for Nursing](#) has sponsored regional 'Transition Nurses' to support the development and implementation of good practice across the NHS. The Trust is an active member of this network.
- 2.6. The Roald Dahl Charity provides specialist nurses and support for seriously ill children living with complex, lifelong conditions. They also sponsor [transition specialist nurses](#).
- 2.7. The [Ready Steady Go](#) programme has been implemented across the Trust to provide a framework to support children, their families and carers.
- 2.8. The Children's and Family Act 2014. The Act gives guidance on the expectations of transition.
- 2.9. The Trust undertook a transition project between 2015 to 2017 with the Thames Valley Strategic Clinical Network. This project provided the foundations for understanding the multi-agency collaborative work needed to support children's transition to adult services and the practical and emotional help for families.
- 2.10. The Trust identified the support of children and young people moving to adult services as a quality priority for 2021/22, to highlight the importance of the process and improve the service across all Trust health services.
- 2.11. This recognises the complex and challenging time for children, their families, and clinical teams as emergency and long-term health services

change. Children may have been looked after by clinicians for extended periods of their life and moving to the larger unknown world of adult services can feel daunting.

### **3. Our Story: Mary and Peter**

Mary was diagnosed in 2001. She was 8 and everything changed at home at that point. We had to talk with a lot of services in health, education, social care, both in hospital and in the community. The learning curve was very, very steep as a Mary's needs changed as she was growing, and her condition changed. She seemed to stabilize after surgery and a stay in Children's High Dependency and Children's Intensive Care. She seems to be coping well and our biggest worry over the last few years has been keeping COVID away from Mary. We have been supported by so many amazing teams – we have got our money's worth and used Oxford thoroughly! It's had its ups and downs, we can now stop worrying and as she is now a teenager, we started to think about Mary being looked after by adult services.

We had high expectations of what to do and what needed to be done and during our transition process – it felt like we were teaching the Childrens services who were handing over and the adult services who were taking on Mary. I felt like the project manager - I set up a risk register and made sure the documentation was done right, proper communication, and right resources were in place. We all thought this should and could be easy but it was really hard work.

We knew that adult services were different, and this set us on edge a bit, there needs to be early engagement from adult services and we didn't know what to expect. We have been managing these multiple services daily anyway, so managing them as individual parts of adult services is no great difference.

Mary was looked after by some really good people. They passed on their knowledge and didn't keep it for themselves, and the people that followed on were equally as good. Mary hasn't needed to spend any time in hospital yet as an adult so we'll have to wait and see how that pans out.

What we were able to do with transition was we took our time and started early. We started around the age of 13-14 years and quickly realised that nothing is really going to happen much before 17 years, but as a family you can make yourself aware of the issues and you can make sure you are bought into the conversation at the right time. It isn't a surprise then.

When Mary was 14, we attended a multi- agency annual review meeting. One team said they didn't know why they were there as they didn't refer or look at people until they are 16-17years old. I had to point out that she needed be there under the Childrens and Family Act and start to talk to us now. The person admitted she didn't know much about transition and the whole room went quiet. It was a real moment,

and we didn't see the person again! I think we embarrassed them – which I was sorry about as I didn't mean that, but I needed to make sure things were going to work for Mary.

**You asked Mary and I what a good transition look like:** This experience got me thinking that really, it's not fair on anybody. Adult services do not need the surprise. Suddenly they get this new child with this level of need, that they've never heard of. There has to be a good sense of connection, communication and engagement with all the various components: in the community, in social care and in health. You can't do it by yourself, and as much as hospitals tend to work within their own island governed by its own fences and boundaries, when you're dealing with transition there are lots of things to be done and healthcare is only one part of it.

**What do you think of Ready Steady Go (RSG):** I think some bits worked but some parts didn't. We think it may be useful if you have one condition but if you have lots of things to consider it is harder. It is an aide memoire for some of the issues. We felt it was geared towards someone with learning disabilities and someone who is physically able so we do think it may be an idea to change some of the questions. I would say the things to make sure to include are:

✓ Healthy Living

✓ Wellbeing

✓ Independent Living

✓ Work

Review more than once a year - don't just do it with your paediatrician. Please think about the frequency of check, and who owns the document. If you say 'can you feed yourself' and the answer is no, so what, who is going to make sure something happens? Where is the plan that comes out of that? And that's where it fails. It gives you a hint but doesn't tell you what to do and how to do it next and that's why transition is bigger than just that document. Just by saying I've ticked those boxes and filed it on our central computer system, therefore I use RSG, no it has to be managed. A paediatrician or lead consultant just ticking the boxes, once a year for 3 years, that doesn't cut it. Ticking boxes is easy, but you need a plan to deliver it underneath.

RSG is a generic framework - it does act as an aide memoire, but an individual plan needs to be done as well. You need to think about why do you want us to use RSG? It might be to have some methodology, but we don't think it does that. It gives a framework but doesn't tell you how to do things and it starts too late. It's coming in at the age of 16/17yrs whereas all the legislation talks about transition at 12/13yrs. RSG only works if it's used early on in the process and if they get to 16yrs it's too late. Parents by this point have already started the process, and services are then behind the times. There were no real measures to check that the child, family and teams felt it's going well and what progress has been made. We have a key worker



that was allocated by the local authority who helped pull some of this stuff together – do you work enough with other services in this?

My transition person mainly worked with people with learning disabilities, and she was fantastic she chatted with me and if I didn't understand anything and she put it in a very friendly way. My family helped a lot but some families might not know and you need someone with that experience and that knowledge to get you through, otherwise it will be just a mess.

As a family you have to learn on the hoof, and you just have to learn quickly. There is no reason why there can't be some sort of induction or some sort of process that helps the parent learn how and what to expect. Many learn and work in different ways. Towards the end of the process, we were in a multi agency meeting more as peers, we were able to have proper honest conversations that I would expect to have around a corporate table.

Different agencies are governed by different processes, but essentially they all say the same thing, parents know best, do the best for the child, make sure the child is looked after. Given the right training and the right support, you can support a parent that may feel confused, overwhelmed or frustrated by embracing them and working as a team.

The team we had in transition were fabulous. Professionals are often rushed, but in our transition meetings we felt heard and conversations continued going out the door. It was a cooperative and constructive environment.

### **Are there any gaps in transition today?**

- We think families want to be better informed – earlier on.
- Do services talk about the services that are needed for children's with more complex conditions, as is likely to become more profound.
- Parents are better informed and their expectations of what has been happening in Children's services are managed going into adult services.
- Mental Capacity - it's pretty hard to let go as a parent. Yes, it's brilliant and fantastic to give the young person power and control over their care, but what 18 year old can manage lots of different services all by themselves? As a parent, I can hardly sort out my own life. This expectation of a tick of a clock and he takes over is naïve of everyone to expect.

Difficult conversations with professionals at 17 and 18 when you are really poorly are hard without your mum or dad, but you are expected to be able to cope, you have capacity. I don't think it's on people's radar enough. It would have been better if it is brought up when I feel healthy and well, when I am mentally stable, and done so delicately.

It's about advanced care plans. During this transition phase where we talk about palliative care being whole life, whereas in adults palliative care is end of life, there's this change in context which people may not have grasped early on.

- Look at RSG - a bit more how and what to look for would be good.
- Some services have Transition leads. Need to make sure there is a team supporting the child and the nurse is part of the team. We had to investigate if I went into hospital, where would I go, would I be supported properly. We had to do that of our own back. If there was someone there who could help liaise with the agencies that would have made life easier.

#### 4. Trust Quality Priorities

- 4.1. A Quality Account is an annual public report about the quality of services offered by an NHS healthcare provider. The Trust's Quality Account<sup>2</sup> sets out the Trust's ethos and commitment to the delivery of compassionate and excellent patient care. The Trust's quality of care has its foundation in the commitment of all staff to their patients and the focus on future excellence.
- 4.2. The summary for Transition of children's to adult services is outlined in Appendix 1.
- 4.3. The Quality Priority is led by the Divisional Director of nursing for NOTSSCaN (Neurosciences, Orthopaedics, Trauma, Specialist surgery, Children's and Neonates division).
- 4.4. The aim is to provide a framework by which the Trust can ensure that children's and young people receive a quality service when transitioning from child-centred services to services for adults. This includes all young people with long-term conditions cared for in OUH.
- 4.5. The Quality Priority was chosen to ensure that all young people we treat receive a quality service to achieve optimum health and psychological wellbeing.

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<sup>2</sup> [quality-account-2020-2021.pdf \(ouh.nhs.uk\)](#)

## 4.6. Progress with the six actions:

	Action	Progress
1	Compliance with Transition from Children's to Adult Services Policy. Include identification of lead service for patients that are under multiple services.	The policy is available on the intranet. <sup>3</sup>  Work regarding a lead service hasn't started yet.
2	Develop a Trust wide multidisciplinary group to develop good practice on Transition from Children's to Adult Services led by a Transition Co-ordinator.	The group is chaired by the divisional director for NOTSSCaN with divisional representation. This is key. Each clinical service currently manages its own transition process. The Burdett Trust for nursing benchmarking standards are currently being piloted. This will be combined to form a Trust wide view. The pilot sites have been identified and include Rheumatology services, Nuffield Orthopaedic Centre, the IBD clinic at the Churchill.
3	Data Audit – EPR Ready Steady Go – Hello compliance.	Not started yet.
4	Patient feedback from children's and adults - inclusive of all backgrounds. Children's will be asked about their experience of transitioning to adult services. The Trust's well established children's patient group, YiPpEe, will assist with this	Both questionnaires have been piloted at the Adolescent Rheumatology Clinic and are ready to be used. Requests for stories and experience have been posted on the Trust's social media account.
5	Staff feedback.	This has been piloted and is ready to use with the Burdett Trust for nursing benchmarking standards
6	Partner feedback – to include General Practitioners and Community Services as some patients will receive services from their GP	Not started yet.

Table 2: progress with the quality Priority actions

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<http://ouh.oxnet.nhs.uk/SafetyQualityRisk/Policies%20Procedures%20%20Guidelines/Safeguarding/Transition%20from%20Children's%20to%20Adult%20Services%20Policy.pdf>

## 5. The views from Yippee (Young People's Executive)

- 5.1. Age-appropriate communication will be needed between patients and healthcare professionals alongside taking time to talk to the child about their health individually, by explaining their condition/s.
- 5.2. Professionals will need to engage the child in their health as part of them helping prepare for adult hood. For example, showing them how to administer an injection for their condition.
- 5.3. A good orientation and induction around the adult part of the hospital would be really helpful. This will include knowing their way around e.g. bathrooms, going around the wards, to be taken seriously especially via communication, 'things to occupy me', Wi-Fi, layout/map, list of healthcare professionals, who their healthcare team will be (personally), ward times/rules/rounds, mealtimes and visiting hours.
- 5.4. Information videos and leaflet explaining transition/ preparing for adulthood.
- 5.5. Our wish list: 16-25 ward/s, more entertainment specific for teenage age group (video games etc), to have times and places where children on the same ward play card/board games together.
- 5.6. Safeguarding; 16–18-year-olds might not always suit an adult ward therefore it is the hospitals responsibility to keep everyone safe, if a child doesn't feel safe they should be able to move to a different ward if they would prefer that.
- 5.7. Instead of a play specialist, young people will need a youth worker – checking in and seeing what they can do to help.
- 5.8. If a young person aged 16 -18 gets admitted to hospital with no other previous records or serious health conditions, they should have the individual choice to go to the children's or adult's services.
- 5.9. When patients from children's services give complaints/feedback it helps the wards improve care, the patients have more power about what they want fixed and what they liked/loved. This is important to learn from problematic issues.

## 6. What have we learned?

- 6.1. Ready Steady Go needs some additional work to provide the 'how' for children's and their families.
- 6.2. The story taught us that families are looking to us to understand the process and our role in supporting their child and family. We need to make

sure that staff understand their part in this multiagency process and delivery of individualised care.

- 6.3. Working with the Burdett Trust for nursing has been very helpful as it has given access to transition lead nurses/ leads across the South of England – to learn and share.
- 6.4. Making the transition to adult services is more challenging for children with complex and multifaceted health, social and education needs which needs to managed well with extensive emotional support.
- 6.5. Services have shown they manage well on their own but would benefit considerably from a Trust wide support with the move to adult services and development of universal excellent practice.
- 6.6. The move to adult services is complex for everyone. Families are worried that they won't get the same level of service when their child becomes an adult. Children's and adult services want to be able to do a good job.
- 6.7. We need to think about whether we should have a 'transition/ moving to adulthood' lead. Other Trusts have them, however they can't be the clinical support to all children's and families moving through this process.
- 6.8. Working together with all agencies with a family and starting early helps everyone feel prepared and gives an opportunity to have complex discussions.
- 6.9. We need to strengthen our policy, training and guidance to make sure a child and their family have a named professional to support them.
- 6.10. Mental Capacity Act. The story taught us that families and children would benefit from some help understanding what is included to help them prepare. The distress felt in the story about a young person having complex discussion about their care on their own came across clearly.
- 6.11. The Quality Priority may not be finished in March 2022, and it may be sensible to extend for a further year to complete the Trust wide work and improve the multiagency working with children's, families and other agencies.

## 7. Conclusion

- 7.1. We have learnt a huge amount by working on this Quality Priority, building on the previous Thames Valley project.
- 7.2. Individual services have developed their own transition pathways and there is considerable commitment to having a higher profile for this work across the Trust to better support children's and families.

- 7.3. The support of the Burdett Trust for Nursing is extremely beneficial to enable the Trust to benchmark internal practice against national standards. It enables us to keep updated with national guidance and practice and develop stronger local working collaborations with providers working with children's and families at this stage in their lives. This in turn facilitates clinicians to develop their pathways within the cohesiveness of the overall Trust policy and approach.
- 7.4. There is considerably more work to do, and it is recommended that the quality Priority be extended for one more year to embed Transition or preparing for adulthood into children's and adult clinical practice.

## **8. Recommendations**

8.1. The Trust Board is asked to:

- Note the content of the story.
- Actively support transition/ preparing for adulthood within the Trust

## Patient Perspective: Making the Transition from Children's to Adult Services: Preparing for Adulthood

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### Appendix 1

Quality Priority: Transition of children's to adult service	Why we chose this Quality Priority	How we will evaluate success
<p>The aim is to provide a framework by which the Trust can ensure that children's and young people receive a quality service when transitioning from child-centred services to services for adults. This includes all young people with long-term conditions cared for in OUH.</p>	<p>To ensure that all young people we treat receive a quality service to achieve optimum health and psychological wellbeing</p>	<p><b>Action 1:</b> Compliance with Transition From Children's to Adult Services Policy. Include identification of lead service for patients that are under multiple services</p> <p><b>Action 2:</b> Develop a Trust wide multidisciplinary group to develop good practice on Transition From Children's to Adult Services led by a Transition Co-ordinator.</p> <p><b>Action 3:</b> Data Audit – EPR Ready Steady Go – Hello compliance.</p> <p><b>Action 4:</b> Patient feedback from children's and adults - inclusive of all backgrounds. Children's will be asked about their experience of transitioning to adult services. The Trust's well established children's patient group, YiPpEe, will assist with this.</p> <p><b>Action 5:</b> Staff feedback.</p> <p><b>Action 6:</b> Partner feedback – include general practitioners (GPs) as some patients will be transitioned to GP services</p>