Part 2. Getting started with transition – How to develop your transition process as a health care team

Introduction:

In part one of the Bladder & Bowel UK professional's transition guide, there is information about the foundations of holistic transition and how to navigate the transition pathway with the child/young person, their carers, and your adult colleagues. This part two explores the process of assessing your own area and offers suggestions on how to develop a local transition process (if this is currently absent).

An informal review by Bladder & Bowel UK into transition processes for children and young people has concluded there is a need for an improved transition experience. Further work is required to remove the barriers that result in some NHS providers struggling to deliver safe and effective transition. These barriers include issues with funding, resources; inadequate inspection and scrutiny of the transition process and lack of understanding of children and young people's needs. All of these should be evaluated as part of the development of a local transition process.

There is a wealth of publications that aim to improve the transition experience of young people aged 11 to 25 years with a Long-Term Condition (LTC) as well as the experience of their families/carers. The publications provide a consensus that staff need help to achieve this. Relevant documents include:

- Department of Health – Transition: Moving on well 2008
- Essence of care 2010
- CQC - From the Pond to the Sea 2014
- The Care Act 2014
- NICE guidance (NG43) and Standard 2016 (QS140)
- RSG (2016) Implementing Transition – improves long term outcomes.
- It happens to me to 2018
- Community Currencies for transition NHS England 2020/2021
- Core capability Framework for the Care of Young People and Transition (2022)
- National training package for the care of young people and transition

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- Burdett Trust 2022
- National framework for transition 2023
- A guide to using benchmarking for Transition 2023
- Transition information Network @Council for disabled children.org
- Alder Hey 10 steps transition Pathway @tensteps transition.org
- Ready Steady Go Pathway@readysteadtgo.net

What do we mean by best practice guidance for transition?

Best practice standards provide the framework for maintaining or improving effectiveness and efficiency in a healthcare system. The benchmarks for transition have been developed in collaboration with young people, parents, and health professionals and offer a practice guide to support transitional care. Benchmarks provide a systematic approach to assessment and stimulate change through the development of best practice. They can be used to show what services are doing well and where improvements need to be made e.g. whether:

- Services are adhering to NICE guidance and standards.
- The service is benchmarked against "Your Welcome Criteria"
- All eligible patients have Transition plans in place.
- Regular review of patient experience and engagement data to confirm positive patient experience is being collected and evaluated e.g., right information at the right time; attending appointments; active young person engagement in their health care.
- Services actively monitor and review patients over eleven years old who are within children's services. This should include six monthly transition plan reviews and risk assessments.
- Services meet the transition elements of the NHS England specialist - service recommendations, if relevant.
- Services have a live patient register in place. This is a list of all patients in transition which includes details of name, age, professionals involved, and key members for the transition process, planned date of transition, and transfer.
- Service specific long-term health outcome measures are in place e.g., bladder scan results, ultrasound scan records, medication protocols, etc.

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Where to start?

- You may begin by assessing your service using transition benchmarks.
- Assess your service against the NICE guideline and standards for transition, which includes asking young people, families and staff about their experiences and expectations.
- Assess your service against the You're Welcome criteria.
- Identify gaps in practice and areas of deficiency: start to understand the current whole transition pathway for young people ages 11 to 25 years for your area, including funding challenges and differences in service delivery models, between adult and children's services, but also between different specialities. Allow for opportunities for services to engage and for collaborative working and networking.
- Identify which professionals will need to be involved in providing transition care to patients in your service and seek out engagement and stakeholders.
- Identify all adult-receiving services including other Trusts and GPs or community care – are there services to transition too? What existing frameworks are in place?

Mapping – what is this?

- Utilise the 'benchmarks for transition tool' to assess the best practice factors as appropriate to your service.
- Discuss with your colleague(s) the indicators you think have been achieved within your service.
- List the evidence you will use to demonstrate the achievement for each indicator.
- Add any additional indicators and examples of evidence you think are relevant to your service.
- Seek independent consultation for your findings and discuss with key stakeholders.
- Identify what training and education is needed including transition education events, a transition website, courses for staff on transition, information leaflets.
- Consider what transition programme and documentation tools are needed – examples below:

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What is the 'Ready Steady Go Hello' Model?

- They are a series of questionnaires/statements to prompt discussions. They are a gateway to ensuring a developmentally appropriate, individualised transition process.
- They may be used to develop individualised transition plans. They direct on how to discuss with the young person, and their family where appropriate, the individualised input/support they need and how to implement interventions holistically.
- It is freely available online to download or print and be used by any service
- Peer reviewed and evidence-based resources that have been widely adopted
- Suitable for Paediatric and adult services

What is the 'Growing up Gaining Independence' Model?

- This is a straightforward framework to enable clinicians to encourage and support young people to develop the skills, knowledge and understanding needed for successful transition.
- It is triggered by a recognition that the young person aged 11years and over is emerging towards adulthood. It may help prepare young people for adult specialist healthcare if this is required.
- It is designed to work with other tools, such as Ready Steady Go, as well as with established good practice.
- It can be used as a stand-alone tool.

What is the Ten Steps Transition Model?

This programme provides a generic and simple transition pathway for healthcare professionals. The steps to follow are:

- Recognise the need to move on.
- Empower young person and support parents.
- Transition plan.
- Review circle of support.
- Refer on to lead in adult medical service.

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- Joint reviews: children's services leading.
- Identify route into urgent care.
- Young person (16+) confident to move.
- Joint reviews: adults' services leading.
- Young person (18+) confident in adult services.

What needs to be considered next to move forward with transition in your service?

- How to secure the time and funding for the development of your transition pathway and its implementation. You may wish to utilise the evidence base to support a business case.
- Have conversations with the multi-disciplinary team to ensure clear definitions of roles and responsibilities. It is recommended that you include youth support worker teams CAMHS and LD CAMHS and transition social workers.
- In conjunction with the wider team and relevant adult teams, choose the transition programme and documentation tools that you are going to use. Ensure all staff have training on its use and implementation.
- Introduce all patients from 11 -12 years to your chosen transition programme and documentation tool. Do this for all new patients who are older than 11years when referred.

Summary:

- One size does not fit all. Transition needs to be individualised to the services, but importantly for each young person's situation and preferences.
- Moving from a children's service or services to managing their health condition(s) as an adult is a process for the young person and their healthcare professionals. It is not a one-off experience.
- Support for gradual transition is the ethos for all involved in the young person's journey.
- Co-ordinated between child and adult teams and working together is key.
- Adult services need to ensure that they are young-people-friendly.
- Documentation needs to be accessible to all the team(s) and ensure written documentation is provided to the young person and their families.

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- Maintain inclusion of parents, including once the young person is over eighteen if this is what they want, or is appropriate to their situation, considering the Mental Capacity Act 2005.
- Assessment of readiness for transition is a key focus of any tool you use.
- Involvement of the young person's GP is paramount as they influence the commissioning of services.

The development of Transition within the NHS is evolving, and we intend to keep this guide updated in line with the best practice evidence as and when this is published.

Further information

Find more information about child bladder and bowel health in our information library at www.bbuk.org.uk. You can also contact the Bladder & Bowel UK confidential helpline (0161 214 4591).

For further advice on bladder and bowel problems speak to your GP or other healthcare professional.