

CQC report summary: From the pond into the sea

The Care Quality Commission (CQC) monitor, inspect and regulate services to make sure they meet fundamental standards of quality and safety. This report investigates the experience of transition from paediatrics to adult health care services for young people with complex care needs of the.

What they did:

- Met with young people who were living with a wide-range of long-term health conditions, their families and health care professionals.
- Collected information about:
 - The process of transition
 - How well different services worked together
 - How young people were involved in planning for transition
 - The training and skills of staff
 - Peoples' experience after the transfer to adult services

Key findings:

1) The transition process:

- Very few young people and their families, and even health care professionals had knowledge of the transition process.
- The **information** and **preparation** provided by children's services to young people and their parents about the changes they can expect as they move to adult services is **inconsistent and often poor**
- 63% of patients did not have a **lead professional** to support the transition process
- Parents reported they felt as though they were left to coordinate care

2) Funding/budget:

- Some young people and their families were left without equipment, services, respite or other requirements during transition, because of a failure to agree who was responsible for funding them.

3) Transition plan:

- **Planning often started late**, delaying decisions and affecting funding
- **Health passports** existed but were not widely used by those involved in planning with the young person and their family, which meant repeating the medical history, wasting time and causes frustration and stress for those involved. The report highlights the need of **electronic records**.
- 80% of young people do not even have a plan for their transition.

4) Involvement and choice:

- Only 54% of young people preparing for transition and their families felt they had been **involved** as much as they wanted to be.
- There was a **lack of options** or choices when appropriate services were not available locally.
- Records of capacity to make decisions were generally very poor. It is therefore unclear as to the extent that the interests of vulnerable young people are being heard.

5) Carers:

- Overreliance on parents and families to coordinate their child's care. Some services did offer some training to parents/ families but this lead to further reliance.

6) Different health settings:

- Adult health services were often not appropriate for young people
- Parents expressed frustration at the lack of communication between different services – highlighted the need for a **lead healthcare professional**.
- Many adult health services did not get involved in the transition process
- Patients and families had a lack of confidence in the adult health care services, causing anxieties about transitioning
- Lack of GP involvement in the transition process: GPs should be more involved, at an earlier stage as GPs do not change on reaching adulthood.

7) Training for professionals:

- Many professionals did not feel prepared or properly trained for the transition process

8) Transfer to adult services:

- Many young people reported a negative experience of the transition process
- Parents felt they had to 'fight' to get the same services from adult teams that they got from children's services.
- No evidence of checking on how young people were getting on in adult services.

9) Integrated/holistic care:

- Services did not work together to provide holistic care.
- There was little evidence of services being developed with young people and families.

What was found to have worked well:

- Consistent staff, who know the young person's history.
- Adolescent clinics – helped prepare the young people for the adult setting
- Being given good information about what to expect
- Effective communication between hospital and with the young people, their parents and each other
- Pre- transition meetings between the adult healthcare professionals and the patients/ their families

Four concluding recommendations:

- 1) Commissioners must listen and learn from young people and their families
- 2) Existing good practice and guidance must be followed to ensure young people are properly supported through transition.
- 3) GPs should be more involved and at an earlier stage, in planning for transition
- 4) Adolescence/ young adulthood should be recognised as a developmental stage. The report discusses the possibility of a distinct young people's service for people 14-25