



Health Transitions in Brighton & Hove – Young People with a Learning Disability Report Summary

The report looks at the current position of health transitions for young people with a learning disability in the City. The key recommendations from national good practice guidance are compared against current local practice, including identifying existing good practice. Six themes are identified as presenting barriers to the process of health transitions. Eight recommendations are put forwarded as suggested changes in local delivery.

Barriers

1. Lack of statutory health transition

There is no statutory obligation to provide a planned and structured health transition for any young person with a disability or complex health needs, whereas a statutory obligation does exist for transition with regard to education and social care.

2. Lack of specific learning disability focussed national good practice examples

Whilst there is a range of national good practice guidance about health transition for young people with disabilities and complex needs, the case studies tend to focus on condition or disease specific examples.

3. Lack of shared access to health, education and social care records

There are no centrally combined health files for young people, or secure shared access across health, social care and education to facilitate effective information sharing.

4. Low awareness of adult specialist health provision

There is a lack of knowledge and information available in children & young people's services about exactly what health service provision exists once someone is an adult. Information about new initiatives in health in adult services is not being consistently passed to staff in CYPT.

5. Lack of equivalent to specialist paediatricians in adult services

Concerns were consistently raised about the lack of an equivalent to the paediatrician once people reach adulthood. The lack of a dedicated co-ordinating health professional with relevant specialist knowledge and the loss of continuity were frequently raised concerns.

6. Lack of information about health transitions

Currently there is no standard information available from health services themselves about the process of health transition and what can be expected.

Recommendations

1. Implement Health Action Planning

Implementing Health Action Plans (HAP) locally could enable the consistent identification of health issues that need to be addressed as part of a young person's transition. Whilst

not providing a comprehensive medical history, a HAP could provide detail on the health needs of a young person and the actions needed to address those needs.

2. Health professional information exchange

Clear information for practitioners in children & young people's services about current health care provision relevant to the adult learning disability population – both specialist and mainstream – is required. Information would need to include any eligibility criteria for services, referral routes, and location & contact details. It would also be helpful to provide equivalent detail to adult specialist health services about provision for children & young people.

3. Build on existing good practice

Some pockets of good practice already exist, in particular the practice of offering a joint appointment with the young person prior to discharge from children's services with the clinician/discipline from adult services they are being referred to. If a joint appointment is not possible, a case discussion could also be useful. A standard case summary template could be developed to facilitate handover between clinicians.

4. Improving links with GP practices

The standard case summary could also be shared with GP's to ensure they are fully informed. In addition, a smoother pathway from children's services to accessing the annual health checks and health action plans available to adults with a learning disability from their GP practice would be beneficial.

5. Information for young people, parents and carers

Young people, parents and carers need to be provided with clear information about the services they are able to access as adults. The information should be available from a variety of sources to ensure optimum coverage.

6. Health skills development

National good practice guidance recommends that a programme of preparation and education to facilitate health transitions. Further research would be needed to establish the content of any existing education around health locally, and nationally, and to see what would need to be developed to meet local need.

7. Health Transition Pathway

There are very few examples of learning disability specific pathways in the national good practice guidance, but there are some examples available from other areas of the country. A pathway would set out the responsibilities of health services & professionals at each stage of transition.

8. A health transition workshop

In order to progress the recommendations outlined above, a workshop event for key professionals could be held to decide how to move these areas forward.

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