

Facilitating the transition of young people with long-term conditions through health services from childhood to adulthood: the Transition research programme

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Plain English summary

The Transition research programme

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Plain English summary

When young people with long-term health conditions, such as diabetes mellitus, cerebral palsy or autism spectrum disorder, move from childhood to adulthood, their health may worsen and their social participation may reduce.

'Transition' is the process that addresses the medical, psychosocial and educational needs of young people during this time. 'Transfer' is the event when health care moves from children's to adults' services.

Our research included young people, families, health-care staff, commissioners who buy health care, and managers who deliver health care. We undertook interviews, administered questionnaires and considered value for money. A young people's advisory group guided us throughout.

Our findings and implications were as follows.

- Commissioners and managers thought that transitional health care was the responsibility of children's services. This is inappropriate, as transition extends well beyond childhood.
- Developmentally appropriate health care underpins good health care for young people, including those in transition. We developed a toolkit to assist its introduction.
- Good practice, led by enthusiasts in one setting, often did not generalise to other specialties or to adults' services. Organisation-wide approaches are needed to establish better transitional health care.
- Shared planning of transition between adult clinicians, child clinicians and general practice is important.
- Young people adopted one of four approaches to transition: 'laid-back', 'anxious', 'wanting to be in control' or 'socially oriented' (i.e. welcoming the involvement of family, friends and health-care staff). Discussing a young person's approach would make communication with them more individual.
- Over 3 years, we collected information from 374 young people with diabetes mellitus, cerebral palsy or autism spectrum disorder. Three features of transitional health care linked to better health outcomes:
 1. Appropriate parent involvement. 'Appropriate' meant that the young person and their parents were happy with how much and the way in which the parents were involved.
 2. Young person helped to be confident about managing their health condition.
 3. Young person meeting the adult team before transferring.
- Economic analysis found that the first two of these features might be good value for money.

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