Systematic review of transition models for young people with long-term conditions: A report for NHS Diabetes

Executive summary

For many young people with long-term conditions (LTCs), transition is based on a single transfer event from paediatric to adult care, rather than a planned and structured process taking into account young people's individual needs. This can have adverse consequences for both the long-term health of young people with LTCs and the health service. With this in mind NHS Diabetes commissioned Leeds Metropolitan University to undertake a systematic review, the aim being to provide an overall picture of the current situation in relation to transition services for young people with LTCs. The review questions were:

1. What models or components of models are effective in ensuring a successful transition process for young people with LTCs?
2. What are the main barriers and facilitating factors in implementing a successful transition programme?
3. What are the key issues for young people with LTCs and professionals involved in the transition process?

The review drew on 29 published studies (including 16 systematic reviews) of transition from paediatric to adult secondary health care services for young people with LTCs. These were derived from an electronic search of databases from inception to August 2012.

Key findings

The findings from the review show there are various transition models and no single model was identified as the most effective. Components of individual models that facilitated successful transition were, however, evident.

Transition needs to be:

- Centred on young people and placed in the context of young people's lives and their changing circumstances.
- Age-appropriate and take into account young people's maturity, cognitive ability, need in respect of LTC, social/personal circumstances and psychological status, as well as inclusion of the whole family.
- A streamlined progression from paediatric to adult services as part of a planned and structured process embedded in service delivery.
- A multidisciplinary approach with involvement from professionals in general practice, community paediatricians/nurses, etc..

Transition needs to include:

- Self-management education as part of a specific education programme, incorporating an assessment of young people's self-management competencies, self-confidence and readiness to transition.
- Close collaboration between paediatric and adult services with designated transition clinics attended by paediatric and adult health care professionals (HCPs).

- A transition coordinator to maintain a link with young people and liaise with various health, education and social sectors.
- Participation of young people and their families with written and verbal communication between paediatric HCPs, adult HCPs and young people and their families.
- A consideration of young people's concerns regarding the transition process (feelings of abandonment on leaving the paediatric team and anxieties around acquiring a new adult provider), lack of access to HCPs in adult care and differences in care between paediatric and adult services.
- The joint preparation of a young person's portfolio that moves with the young person, to alleviate young people's fears and provide reassurance that their new provider will have all the required information about their medical history, etc..
- Training of HCPs to treat young people with LTCs and to utilise effective interpersonal and communication skills.
- Resources to develop, maintain and evaluate transition programmes.

Recommendations

The following recommendations are based on the review findings and are important as an evidence base, in terms of the ways in which the transition process needs to change to improve the continuity and quality of care for young people with LTCs and their long-term health outcomes.

Young people-centred

Every transition programme needs to be built around timelines that are tied to individual young people's developmental stages and circumstances, rather than a rigid schedule devised to suit HCPs/ organisations. The process should start as early as possible and be flexible taking into account young people's age, maturity, cognitive ability, need in respect of the LTC, social/personal factors and psychological support.

A planned and structured process

A transition programme should be embedded in service delivery with a written protocol/'roadmap' detailing the steps involved, so that organisations, HCPs, young people and their families are fully aware of what transition entails. The process needs to include designated transition clinics attended by both paediatric and adult HCPs and orientation tours of adult clinics. There needs to be provision for post-transition support and monitoring, as well as evaluation of young people's outcomes after transition.

Self-management education

Transition needs to be based on a continuous education programme through which young people receive education and skills training to equip them to take control and manage their condition. This should include an assessment of young people's self-management competencies, self-confidence and emotional skills and readiness to transition.

A transition coordinator

There is a need for a nominated individual to take on the role of transition coordinator. Such a person is responsible for overseeing the management and administration of the transition process and for maintaining a link with the young person, in order to ensure young people's care remains consistent. The transition coordinator can help to alleviate any fears and concerns the young person has in relation to leaving paediatric care and moving to a new adult provider.

Multidisciplinary approach
Transition needs to encompass inter- and intra- agency communication and coordination. Integrated primary care and social service involvement throughout the transition process is an important aspect of transition.

Collaboration and communication
Close collaboration and documented communication between paediatric HCPs, adult HCPs and young people and their families is essential, before, during and after transition. The creation of a young person's portfolio is advocated to ensure the new adult provider has all the required information about a young person's medical/life history. Young people and their families need to be involved in the preparation of the portfolio, participate in discussions and be provided with choices and appropriate information, in order that they can make informed decisions about their on-going care regimen. Cross-clinic coordination is essential.

Training of HCPs
A greater emphasis needs to be placed on training HCPs to treat young people with LTCs and the importance of effective interpersonal and communication skills. These should form an integral part of undergraduate education and continuing professional development.

Resources
Individual organisations across all sectors need to be committed to providing the necessary resources for developing, maintaining and evaluating transition programmes, in order that young people with LTCs and their families derive the maximum benefit from their transition experience.

A full report is available that includes the review methods and a full reference list, and which presents detailed findings from the review. The citation for the full report is: Kime, N., Bagnall, A-M. and Day, R. (2013) Systematic review of transition models for young people with long-term conditions: A report for NHS Diabetes London; NHS Diabetes.