A multi-method review to identify components of practice which may promote continuity in the transition from child to adult care for young people with chronic illness or disability

prepared by

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Executive Summary

Background

The number of young people with chronic diseases and disabilities entering adulthood in need of supportive care is increasing. There is evidence to suggest that services are failing to manage this transition effectively, with the result that the health and well-being of these young people is compromised and their potential unrealised. Efforts should be made to ensure that young people and their families are supported during the transition, building a firm foundation for their adult life. As a first step toward better transitional management a review of current practice was commissioned by the National Co-ordinating Centre for NHS Service Delivery and Organisation (NCCSDO). This report details the findings of that review.

Aims

The purpose or objectives of this research study - what it set out to do

The review aimed:

• firstly, to identify practices which address continuity during the ransition from child to adult care

• secondly, to assess the merits of those practices, determining evidence permitting) good practice.

The review also sought to identify any underlying mechanism or models which may be useful in developing continuity.

About this study

A multi-method approach for the identification of practices promoting continuity was adopted, using multiple searches with distinct but complementary strategies. The following three search strategies were employed:

• a systematic review of effectiveness focusing on the identification of good practice models

• a systematic literature review focusing on five tracer conditions:

diabetes mellitus, learning disability, cystic fibrosis, congenital heart disease and muscular dystrophy

• a review of established research and practice networks based on contacting key stakeholders and a survey of two large metropolitan areas.

The outputs from the searches comprised journal papers, written reports and survey data, and were termed 'items'. Each item was examined to identify what the practice or practices were within it. The methods used to support or promote the identified practice were also appraised. Once all the items had been examined and appraised, and the practices identified, a thematic analysis was undertaken to locate those practices under headings that captured the core elements of those practices.

Main outputs

A large range of different practices were identified by the review which were organised into three main domains reflecting the primary focus of the practice, comprising the service, the young person and the family.

The practice components identified in the service domain were subcategorised into structures, processes and outcomes. The main outputs from this part of the review were as follows.

• Structural components included: transitional workers; transitional

teams; professional continuing education; information for professionals; use of existing continuous services; inter- and intraorganisation liaison and agreements; organisational planning; frameworks; and fostering equity and accessibility.

• Process components included: preparation for transition; active management of transition; case management; accountability for the process; strong therapeutic relationships; advocacy; joint management of care; flexibility regarding point of transfer; specific communication systems; and regular audit of service provision.

• Outcome components were either disorder-specific or generic such as user satisfaction. Outcome components provide benchmarks against which service quality may be measured.

• Components of practice regarding young people include: specific service provision; development of skills of self-management and self determination; support for psychosocial development, involvement of young people; peer involvement; support for changed relationships with parents/carers; provision of choice; provision of information; and focus upon the young person's strengths for future development.

• Components of practice regarding parents and carers include: support for adjustment to changed relationships with young people; parental involvement in service planning; family-centred approach; and provision of information.

In addition to these components of practice a service development framework based on a seven-stage process for addressing continuity has been constructed.

1. Identifying the care group or user population.

2. Identifying the key dimensions of the transition.

3. Involving stakeholders.

4. Identifying transitional needs for each dimension of the transition.

5. Transitional planning at the individual, organisational and interorganisational levels.

6. The provision of the appropriate resources to support the transitional plans.

7. The evaluation of the transition at each proposed level.

Four models of continuity promotion were also identified during the analysis.

1. Direct transition – focusing on good and communication and interagency collaboration.

2. Sequential transition – developing special services for young people to help them adjust to adult care.

3. Developmental transition – providing specific support to help young people develop physically, psychologically and socially in adapting to their new care role and in maximising their potential.

4. Professional transition – flexibility in moving expertise between child and adult services.

Limitations of the review

• A paucity of high-quality primary research.

• A focus on explicit rather than implicit practices.

• The assignation of strength of evidence was at the methodological level.

• No external validation of the coding schedule developed as part of the thematic analysis.

Recommendations

• Continuity in the care transition must be examined in parallel with the young person's physical, social and psychological growth and development.

• Continuity at transition is multidimensional and researchers and practitioners should try to account for all these dimensions even when focusing on only one or two.

• Practitioners and researchers need to be specific about the dimensions of continuity which they aim to address.

The components for practice, framework and models of continuity promotion developed through this review need to be further refined and explored through primary research in practice settings.

• Continuity at transition needs to consider the perspectives of the services, the young person and the family.

• In reporting or evaluating an intervention or practice aimed at addressing continuity through the transition, the following factors should be considered and addressed in the report:

– the nature of the user population

– the dimensions of continuity being addressed

– a careful description of the structure and process of the intervention

– for multiple interventions or whole programmes, examination of both the individual and aggregate impact of the elements within the programme

– outcome measures which are appropriate to the dimensions of continuity being examined

– following the young person through the transition and, where feasible, long-term follow-up.

Implications of the study for policy and practice and, if appropriate, future areas for research.