

Models of transitional care for young people with complex health needs: a scoping review

R. Watson,* J. R. Parr,† C. Joyce,‡ C. May§ and A. S. Le Couteur*

*Institute of Health and Society, Newcastle University

†Institute of Neuroscience, Newcastle University

‡North Tyneside Primary Care Trust, Newcastle upon Tyne, and

§Faculty of Health Sciences, University of Southampton, Southampton, UK

Accepted for publication 18 June 2011

Abstract

Background Young people with complex healthcare needs (CHNs) face the challenge of transferring from child to adult health services. This study sought to identify successful models of transitional care for young people with CHNs. Three conditions were used as exemplars: cerebral palsy, autism spectrum disorders and diabetes.

Methods Scoping review: using search terms concerning transitional care, four databases were systematically searched for papers published in English between 1980 and April 2010. Additional informal search methods included recommendations from colleagues working with young people with each of the three conditions and making contact with clinical and research teams with expertise in transitional care. Inclusion and exclusion criteria were applied to define the papers selected for review. A separate review of policy documents, adolescent health and transition literature was also undertaken; 10 common summary categories for the components of high-quality services were identified. All papers were coded using a framework analysis which evaluated the data in two ways using the 10 transition categories and four elements of Normalization Process Theory that are important for successful implementation and integration of healthcare interventions.

Results Nineteen papers were selected for review. A very limited literature of models of service provision was identified for young people with cerebral palsy and diabetes. No models were identified for young people with autism spectrum disorders. Furthermore most publications were either descriptions of new service provision or time-limited pilot studies with little service evaluation or consideration of key elements of effective implementation.

Conclusions Despite agreement about the importance of effective transitional care, there is a paucity of evidence to inform best practice about both the process of and what constitutes effective transitional care. There is therefore an urgent need for research to evaluate current transitional care practices for young people with CHNs.

Keywords

autism spectrum disorders, cerebral palsy, Normalization Process Theory, transition, transfer, type 1 and type 2 diabetes

Correspondence:

Ann Le Couteur, BSc Psychology, MBBS Medicine, MRC Psych Psychiatry, FRC Psych, FRCPCH, Institute of Health and Society, Newcastle University, Sir James Spence Institute, 3rd floor, Royal Victoria Infirmary, Newcastle Upon Tyne NE1 4LP, UK
E-mail: a.s.le-couteur@newcastle.ac.uk

Introduction

Transitions are important features in the lives of all people. They may be especially difficult for young people with complex

health needs (CHNs) – defined as those with a physical or mental health impairment with the potential for substantial and long-term adverse effects on their ability to carry out normal day-to-day activities (UK Parliament 2005).

As part of adolescent development, young people with CHNs have to negotiate the transfer of clinical care from child to adult health services. However, this handover of healthcare provision (referred to as 'transitional care') is only one aspect of their developmental transition process (McDonagh & Kelly 2010). Transitional care in health is defined as:

a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented healthcare systems. (Blum *et al.* 1993)

In the UK, the publicly funded National Health Service (NHS) typically determines that the transfer of healthcare from child to adult services for young people takes place between the ages of 16 and 18 years at about the same time as most young people are leaving full-time education (Kennedy 2010). This combination of significant changes in more than one aspect of adolescent life may add to the uncertainty and stress experienced by young people. Recently there has been interest in the reorganization of child and adult clinical services to allow a longer transition phase from 14 to 25 years – one example of this is that UK diabetes services have developed age-banded clinics in many services (Datta 2003; Allen *et al.* 2010). In recent years, several UK policy documents have focussed on the needs of children and young people with CHNs (see Appendix I). These policies emphasize the importance of considering the wide range of developmental tasks that young people normally complete at the time of transfer from child to adult services – the policies stress the need for an individualized/young person-centred approach to transitional care. The policies also recognize the difficulties young people experience as they negotiate their transfer from child to adult healthcare provision and emphasize the effects of transitional care on overall health (Department of Health 2001, 2007a, 2010a; Dovey-Pearce *et al.* 2005; Scott *et al.* 2005; Department of Health & Department for children schools and families 2008a). Unsuccessful transition results in suboptimal use of healthcare such as failure to attend outpatient appointments, and negative health outcomes such as increased rates of emergency presentations to hospital, disease complications, and long-term health and social problems (Stevenson *et al.* 1997; Watson 2000; Nakhla *et al.* 2009).

Although policies stress the importance of supporting young people through transition, there is little evidence about the best ways to develop and then evaluate effective transitional care in healthcare provision (Allen *et al.* 2010; Bowen *et al.* 2010; McDonagh & Kelly 2010). Further despite the physical and mental health implications of unsuccessful transition for young people with CHNs, there is a paucity of evidence about what

constitutes effective transitional care for this group of young people (While *et al.* 2004). Therefore a scoping review of models of transitional care was undertaken using methodology that enabled the inclusion of a broad range of literature (Arksey & O'Malley 2005; Brien *et al.* 2010). Three common complex healthcare conditions that result in a range of healthcare needs were chosen: cerebral palsy (CP), autism spectrum disorders (ASD) and type 1 and type 2 diabetes as exemplars of complex physical impairments, neurodevelopmental problems and chronic illness respectively. These conditions were chosen as they are common, and all UK NHS Trusts that provide services for young people will do so for at least one of these groups.

The aims of this study were:

- To identify models of transitional care from child to adult health services for CP, ASD and diabetes, using a broad range of literature including peer reviewed publications (1980–April 2010).
- To seek evidence to inform 'best practice' about transitional care for children with CHNs.
- To investigate whether the identified models of transitional care have been evaluated.
- To use Normalization Process Theory to evaluate whether aspects of service sustainability had been considered.

Methods

Scoping review

A scoping review was conducted following the method of Brien and colleagues (2010) using MEDLINE, EMBASE, CINAHL and SCOPUS. The search terms included known Medical Subject Headings for CP, ASD, diabetes and key words such as transition service, shared care, transfer, adolescent, young adult and teen. Information was also sought from UK researchers and clinicians with expertise in the chosen conditions. Papers were only included if they reported a model of transitional care for young people with CP, ASD or diabetes transferring from child to adult health services; a 'model' was defined as a clear description of new or existing transitional care arrangements from child to adult healthcare services for young people aged 14–25 years. Papers were excluded if they were about a different condition or did not report the specific arrangements.

Development of the analytical framework

Framework analysis is a qualitative method originally developed by the Social and Community Planning Research Insti-

tute to be used in applied policy research. Framework analysis provides a systematic analysis process that can be replicated by others (Ritchie & Spencer 1994). An analytical framework was designed for this review according to the principles outlined by Ritchie and Spencer (1994). The first axis (transition categories) of the framework was developed using a general inductive approach (Thomas 2003). The published UK and international policy documents, guidelines relating to transitional care in health and the adolescent health literature (outlined in Appendix I) were used to derive 25 frequently reported components of transitional care. These components were then collated into 10 summary categories of high-quality transitional care.

The second axis [Normalization Process Theory (NPT) Elements] used four elements of NPT identified as being important for the successful implementation of new services into established practice. NPT is an evidence-based theory approach that can be used to investigate how complex interventions, such as service reform (e.g. in this scoping review, the establishment of transitional care), become part of everyday practice (or normalized) in healthcare settings. NPT is derived from the 'Normalization Process Model', originally developed by May and colleagues (2007), to explain the operationalization of complex interventions in healthcare settings. However, this original model did not adequately explain how complex interventions such as new service developments become incorporated into everyday practice. This led onto the expansion of the model to NPT. The theory focuses on the 'work', or purposive social action, undertaken by individuals (patients and staff) and groups (service teams) and how this new 'work' becomes successfully incorporated into clinical care (May & Finch 2009). NPT has been used to evaluate a range of different healthcare interventions (Gunn *et al.* 2009; Gask *et al.* 2010; Kennedy *et al.* 2010). For this review, in relation to the implementation of transitional care services, the four elements of NPT were defined as:

- **Coherence** of the service (what is the work?): whether the service users experience the transitional care service as valuable to them and staff in the clinical settings agree about the usefulness and purpose of the new clinical work they are undertaking.
- **Cognitive participation** (who does the work?): this refers to whether service providers see the transitional care service as a legitimate part of their work and whether users and providers support the service over time.
- **Collective action** (how does the work get done?): the focus here is the ways the transitional care service is provided and

used by staff and service users respectively within existing contexts (e.g. clinical settings).

- **Reflexive monitoring** (how is the work understood?): includes the ways in which providers and service users individually and collectively evaluate the transitional care service in formal processes (evaluation) and informal reflection (personal judgements, comments).

Procedure

Using the analytical framework developed for this study, the papers selected from the scoping review were scrutinized using framework analysis (Ritchie & Spencer 1994). There were 40 possible combinations, one for each combination of transition category and NPT element. Each combination was coded by the reviewers (as present or absent) using evidence from the selected papers (Fig. 1). The 18 models were coded independently by C. J. and R. W. Any coding disagreements were discussed with a third researcher, A. L. C., and a consensus sought (Higgins & Green 2009). Approximately a third of the papers, purposively sampled to reflect the range of models and conditions reviewed, were coded blind by A. L. C. Once all papers had been coded, a summary table was completed (Table 1).

Results

The database searches and expert recommendations yielded 350 papers (Fig. 2). Using the study inclusion and exclusion criteria, 19 papers (reporting 18 service models) met the study criteria (asterisked in *References*). These included 14 diabetes service models from Australia, USA, Canada, UK, Italy, Spain and Denmark; four service models for young people with CP from the USA and UK. All of the CP models included young people with a range of physical disabilities and CHNs (including CP). The excluded papers included reviews of services provision rather than descriptions of specific services, papers focussing on other conditions and service recommendations. No models of transitional care for young people with ASD were identified from database searches or expert recommendations.

Table 1 summarizes the results of the framework analysis for the 18 service models. Each shaded box indicates that the reviewers coded at least 50% (nine) of the models for the particular combination of both the transition category and NPT element. The numbers in each box are the number of models where that combination is present (further details available from corresponding author). Table 1 illustrates the limited reporting in some key aspects of the provision of transitional

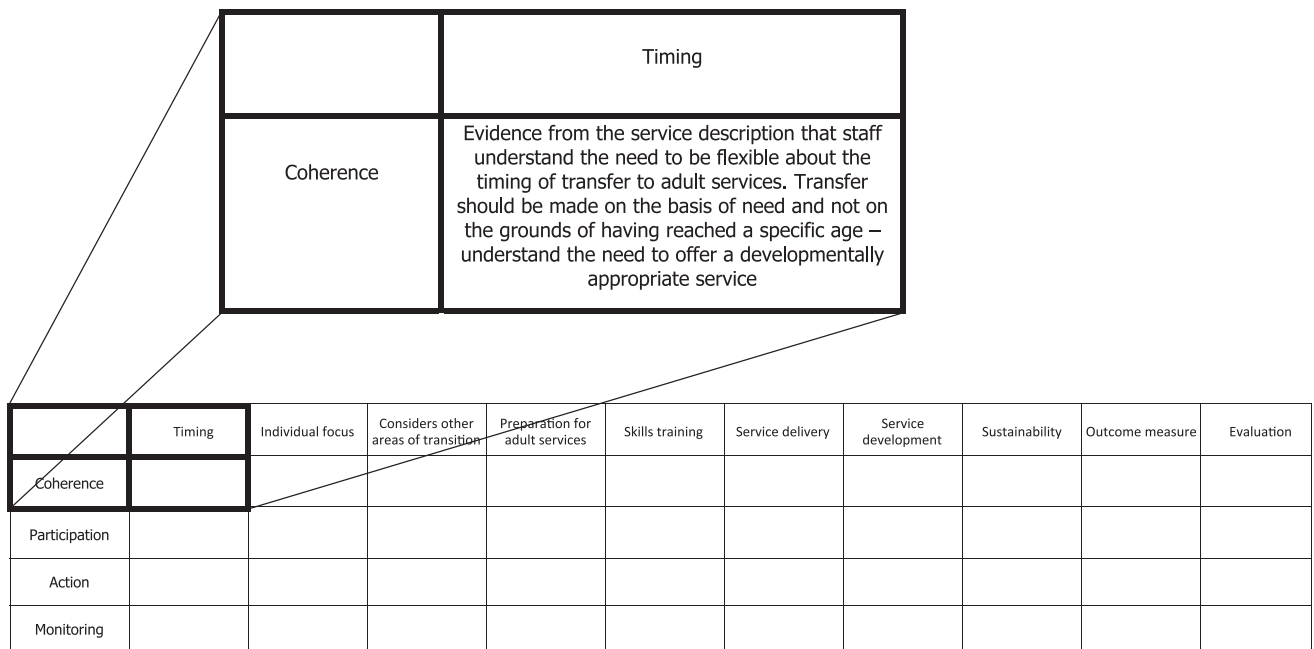


Figure 1. Framework coding example (Parfitt 2008).

Table 1. Summary of framework analysis for the 18 transitional care models

Normalization Process Theory elements	Transition categories									
	Timing	Individual focus	Considers other areas of transition	Preparation for adult services	Skills training	Service delivery	Service development	Sustainability	Outcome measures	Evaluation
Coherence	12	6	4	9	6	12	16	5	6	8
Participation	9	10	3	8	5	18	7	2	2	0
Action	10	15	8	12	8	17	9	5	12	6
Monitoring	6	5	5	4	6	16	12	7	11	6

Each shaded box indicates that at least 50% of the selected models were coded by the researchers for the presence of the combination of both the transition category and Normalization Process Theory element. The numbers relate to the number of models coded as providing evidence for the combination of the relevant transition category and Normalization Process Theory element. Further details are available from corresponding author.

care such as considering other aspects of transition, skills training, sustainability and evaluation.

All papers were either service descriptions of relatively new clinical services or reports of time-limited pilot studies. Most models provided some information about the experiences of service users and providers that informed service development, through satisfaction surveys and informal feedback. However, this information on user and provider experience was not systematically reported in the papers. Few service models provided information about service evaluation or formally reviewed the experience of users and providers against any outcome measures. Most papers focussed on the need to provide an individualized healthcare plan for each young person and two-thirds of studies reported an understanding of

the need for flexibility in the timing of transfer. Only eight of the 18 models considered other aspects of adolescent development.

Four papers provided some information about sustainability such as future planning or funding of the service. Sustainability was usually discussed as a problem of securing funding. In one service the costs of the diabetes transition programme were reported as being recovered through savings made by a reduction in hospital management of acute complications (Holmes-Walker *et al.* 2007). Parfitt (2008) described how their new transition service was developed without any extra funding through internal reorganization of existing services. One paper discussed the high costs of their programme (Gerber *et al.* 2007). Tan and Kilmach (2003) highlighted the need for large-

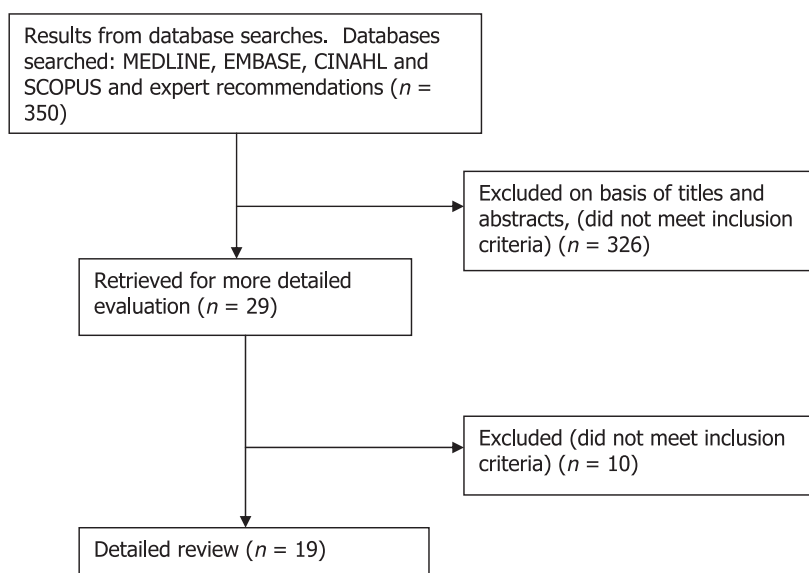


Figure 2. Flowchart for scoping review procedure.

scale replication studies in order to encourage more funding to develop effective transitional care.

Most studies reported disease specific outcomes over less than 6 months, for example, glycosylated haemoglobin levels, number of emergency admissions to intensive treatment unit, clinic attendance (Orr *et al.* 1996; Vanelli *et al.* 2004; Vidal *et al.* 2004; Gholap *et al.* 2006; Johnston *et al.* 2006; Van Wallegghem *et al.* 2006, 2008; Holmes-Walker *et al.* 2007; Cadario *et al.* 2009; Xenakis & Goldberg 2010). Only six of the 19 papers provided information about control groups or comparative data for the reported outcomes; most of these papers used as the comparator retrospective data from their clinics gathered before the introduction of the new service.

Normalization Process Theory analysis

Table 1 shows that most papers provided detailed descriptions of how the transitional care service is provided (**collective action**) but report little information about whether users and service providers experience the new service as valuable to them (the **coherence** of the service), and even less about whether service providers saw the new service as a legitimate part of their work and whether users and providers support the service over time (**cognitive participation**). There was also very limited reporting of any evaluation of the effectiveness of the new services although there were accounts of informal reflections such as patient satisfaction and personal judgements (**monitoring**).

Three studies were identified with the highest number of combinations of transition categories and NPT elements. Cuttall and colleagues (2005) describe a one-off weekend resi-

dential camp for young people with diabetes approaching transition. Parfitt (2008) describe the process for young people with diabetes moving from an adolescent clinic into adult services. Betz and Redcay (2003) discuss a transition model for young people with special healthcare needs, including CP. This model covers several aspects of transition including housing, employment and education as well as healthcare. Service descriptions taken from these three models are used below to illustrate the elements of NPT.

Coherence – Betz and Redcay (2003) reported that staff had an understanding of the need to consider all aspects of a young person's transition needs including healthcare, education, community living, employment and social and leisure activities. Cuttall and colleagues (2005) reported that staff demonstrated an understanding of the adjustments that the young people needed to make when moving from child-oriented to adult-focused services. Parfitt (2008) discussed the need to be flexible about the timing of the transfer as there is no one 'right time' for all young people.

Cognitive participation was the least reported element of NPT. Where the involvement of those professionals providing the service was discussed, it tended to be in terms of the role of a champion or enthusiastic leader who was responsible for driving forward the service development. For example, the model reported in Cuttall and colleagues (2005) was proposed and delivered by a youth worker in the service, who has since gone on to report on a similar model for renal patients (Watson *et al.* 2009). In Parfitt's model (2008), the author, a paediatric diabetes nurse specialist, describes herself as 'pivotal in the planning of the development, managing resources and

co-ordinating the process' (p. 30). Overall in the 18 models there was little information about the role of other staff members, whether they had received any specific training, their engagement with the new service or their continuing support for it. Indeed, from the information presented in the papers, it was not possible to understand whether these services and the underlying models would survive the loss of their champions or co-ordinators.

Finally, there were very few accounts of formal **reflexive monitoring** work (service evaluation). This is in contrast with the accounts of informal reflections (patient satisfaction; personal judgements). For example, Betz and Redcay (2003) reported that individual recommendations were always reviewed with the young person. Cuttell and colleagues (2005) stated that all the young people expressed confidence about their transfer into adult services after taking part in a weekend residential camp.

Discussion

This scoping review identified four reports of models of transition services for young people with CP, 14 models for young people with diabetes, and no models for young people with ASD.

The lack of any published models of transitional care for young people with ASD moving from child to adult healthcare provision highlights the urgent need for further service developments for this common neurodevelopmental disorder. Our findings are consistent with the recent findings of the Transition of Care from Child and Adolescent Mental Health Services to Adult Mental Health Services (TRACK) study (Singh *et al.* 2010); it reported that among young people with mental health problems, 'Those with neurodevelopmental disorders . . . were most likely to fall through the child and adolescent mental health services – adult mental health services gap'. There are likely to be a number of factors contributing to this lack of published models of service provision including a possible perceived lack of need and the current lack of adult services to transfer to (Department of Health 2010b; Singh *et al.* 2010; Sloper *et al.* 2010).

Despite earlier publications identifying the needs of young people with CP (Bax *et al.* 1988), our review identified only four transitional care service models, published in the USA and UK (between 2003 and 2010). Advances in medical practice have led to an increased life expectancy for young people with CP. Of our three chosen conditions, children with severe CP have the most complex CHNs, and need easy access to healthcare –

this requires robust transitional care arrangements to be in place across the UK (Stevenson *et al.* 1997).

Most of the diabetes studies were published in the last 6 years. These reports were all very different, for example, one was a pilot study of a one-off residential camp (Cuttell *et al.* 2005), another was a pilot of an e-learning computer training programme (Gerber *et al.* 2007), and another was a paediatric to adult transfer clinic based in the same hospital (Vanelli *et al.* 2004). Diabetes is a common health condition that has considerable resource implications for NHS services (in total, for all age groups), diabetes accounts for 9% of acute NHS expenditure (Allen *et al.* 2010). This review has identified 14 diabetes transition models of which five were UK based. Further, few provided any information about service evaluation or future sustainability. A recently published National Institute for Health Research report highlights that many NHS providers have developed diabetes transition services in response to the publication of national guidelines, despite the lack of an evidence base for the recommendations. Perhaps, for some services, the lack of service evaluation is a consequence of the misunderstanding that published national guidelines are based on evidence-based best practice (Allen *et al.* 2010).

Our findings emphasize the lack of information to guide service development and the urgent need for evaluation of transitional care. A recent review has also identified that there are no comprehensive validated measures of transition (McDonagh & Kelly 2010). Some measures are being developed in paediatric rheumatology (Shaw *et al.* 2007), CP (Donkervoort *et al.* 2009), paediatric liver transplant (Fredericks *et al.* 2010) and for more generic use (Sawicki *et al.* 2009; Williams *et al.* 2010). The lack of agreed process and outcome measures inevitably limits opportunities for comparing different service models.

Many of the reported service models emphasize that young people have different individual experiences of transitional care and recognize the need for flexibility when supporting transfer of clinical care. It is important to be able to record these experiences in a systematic way. Quality of life and participation (involvement in life situations) are crucial, personalized outcomes (World Health Organization 2001). Assessment of quality of life has been recommended as part of the World Health Organization standardized approach to service evaluation outcome studies. Several studies in our review described aspects of participation but none of the services formally evaluated participation and only one examined quality of life (Vidal *et al.* 2004). This study used the Diabetes Quality of Life measure which focuses on health related quality of life rather than being a measure of subjective wellbeing (Garratt *et al.* 2002).

Our review has highlighted the reliance on single transition champions to take forward the implementation of transitional care. Reliance on a single member of staff risks the future sustainability of a new service. This theme is echoed in Allen and colleagues (2010) report about transition procedures of paediatric to adult diabetes services in England. The authors found that approximately one-sixth of services attributed the service development to a particular member of staff.

A further aim of the scoping review was to evaluate condition specific models. This approach has the advantage of identifying shared outcome measures for particular disorders (e.g. glycosylated haemoglobin levels in diabetes) but it limits the opportunity for identifying similarities and shared experiences across chronic health conditions (Sawyer *et al.* 2007). A recent study of preferences for healthcare among Dutch adolescents highlighted the benefits of shared experiences of young people across CHN groups. Jedeloo and colleagues (2010) also reported that young people with a variety of chronic conditions share healthcare preferences and value a more generic approach. Rapley and Davidson (2010) argue that services should follow generic transition principles but have flexibility to address condition specific issues. Patel and colleagues (2007) contend that mental health services should be developed in a 'youth-focussed' way and incorporate other youth health and welfare issues to help remove the stigma of mental health problems, increase accessibility and ensure a comprehensive multi-agency approach.

Allen and Gregory (2009) recommended that assumptions in current guidance about transition in diabetes needed rethinking; some of these findings may be applicable to other conditions. Allen and colleagues (2010) restated this assertion 'Rather than asking how transition should be managed, we might ask how best to meet the needs of young people with diabetes at this stage of the life-course'. It is encouraging to note that the findings of our framework analysis reported here showed that most services have considered an individualized approach.

This scoping review had several limitations. First, evidence to inform best practice available from other medical conditions was not sought. Second, the search strategies may have inadvertently excluded some relevant publications or models of transitional care. Transition and transfer are not standardized Medical Subject Headings terms, making it more difficult to locate relevant material. Third, the reviewers could only rate the information included in the selected publications. It is likely that there is more to be learned about the reviewed models as authors may not have included all information relevant to the service model in the article. Finally, there are likely to be other transitional care models which have not as yet been presented or submitted for publication.

Conclusions

Evaluation of models of transitional care needs to take into account many different aspects of the service. NPT is a valuable tool when considering those elements of service delivery necessary for the successful integration of any proposed new practice into routine everyday healthcare. The literature identified in this scoping review, provided little information about service evaluation or sustainability, and rarely reported service users and providers' attitudes to the new service.

Critically, there is a paucity of evidence to inform best practice about transitional care and an urgent need for research to evaluate current transition practices for children with CHNs.

Key messages

- The scoping review identified no models of transitional care for young people with ASDs, either from electronic database searches or from UK professionals working in the field.
- Services lacked evaluation, with only a minority reporting consideration of sustainability of the service.
- Normalization Process Theory provided a structure to assess key elements required for successful implementation and integration of new practice into everyday healthcare.

Conflict of interests

The authors have no conflict of interests to declare.

Carl May is one of the original authors of Normalization Process Theory.

Acknowledgements

We would like to thank the members of the Newcastle University Transition research team for all of their help and advice.

Allan Colver, Mark Deverill, Gail Dovey-Pearce, Helen McConachie, Janet McDonagh, Christine Price and Tim Rapley. We also thank Fiona Beyer for her advice about systematic searching.

This article presents independent research commissioned by the National Institute for Health Research under its Programme Development Grants funding scheme (RP-DG-1108-10015). The views expressed in this article are those of the author(s) and

not necessarily those of the NHS, the National Institute of Health Research or the Department of Health.

References

Note: Papers marked with an asterisk (*) met scoping review inclusion criteria.

- Adolescent Health Committee & Canadian Paediatric Society (2007) Transition to adult care for youth with special health care needs. A position paper. *Paediatric Child Health*, 12, 785–788.
- All Party Parliamentary Group on Autism & Allard, A. (2009) *Transition to adulthood. Inquiry into transition to adulthood for young people with autism*.
- Allen, D. & Gregory, J. (2009) The transition from children's to adult diabetes services: understanding the 'problem'. *Diabetic Medicine*, 26, 162–166.
- Allen, D., Cohen, D., Robling, M., Hood, K., Atwell, C., Lane, C., Gregory, J., Lowes, L., Channon, S., Gillespie, D., Groves, S. & Harvey, J. (2010) *The transition from paediatric to adult diabetes services: what works, for whom and in what circumstances?* NIHR.
- American Academy of Pediatrics, American Academy of Family Physicians & American College of Physicians-American Society of Internal Medicine (2002) A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*, 110, 1304–1306.
- Arksey, H. & O'Malley, L. (2005) Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, 8, 19–32.
- Bax, M. C. O., Smyth, D. P. L. & Thomas, A. P. (1988) Health care of physically handicapped young adults. *British Medical Journal*, 296, 1153–1155.
- *Betz, C. L. & Redcay, G. (2003) Creating healthy futures: an innovative nurse-managed transition clinic for adolescents and young adults with special health care needs. *Paediatric Nursing*, 29, 25–30.
- Blum, R. W., Garell, D., Hodgman, C. H., Jorissen, T. W., Okinow, N. A., Orr, D. P. & Slap, G. B. (1993) Transition from child-centred to adult health-care systems for adolescents with chronic conditions. A position paper for the Society of Adolescent Medicine. *Journal of Adolescent Health*, 14, 570–576.
- Bowen, M. E., Henske, J. A. & Potter, A. (2010) Health care transition in adolescents and young adults with diabetes. *Clinical Diabetes*, 28, 99–106.
- Brien, S., Lorenzetti, D., Lewis, S., Kennedy, J. & Ghali, W. (2010) Overview of a formal scoping review on health system report cards. *Implementation Science*, 5, 2.
- *Cadario, F., Prodam, F., Bellone, S., Binotti, M., Trada, M., Allochis, G., Baldelli, R., Esposito, S., Bona, G. & Aimaretti, G. (2009) Transition process of patients with type 1 diabetes (T1DM) from paediatric to the adult health care service: a hospital-based approach. *Clinical Endocrinology*, 71, 346–350.
- Collis, F., Finger, E., Okerstrom, E. & Owens, K. (2008) *Review of transition of young adult clinics*. Prepared for the Department of Human Services, Australia.
- *Cuttell, K., Hilton, D. & Drew, J. (2005) Preparation for transition to adult diabetes services. *Paediatric Nursing*, 17, 28–30.
- Datta, J. (2003) *Moving up with Diabetes. The Transition from Paediatric to Adult Care*. The National Children's Bureau, London, UK.
- Department of Health (2001) *National service framework for diabetes: standards*.
- Department of Health (2004) *National service framework for children, young people and maternity services*.
- Department of Health (2007a) *Aiming high for disabled children: better support for families*.
- Department of Health (2007b) *You're welcome quality criteria*.
- Department of Health (2010a) *Implementing 'Fulfilling and rewarding lives'. Consultation for statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy*.
- Department of Health (2010b) *'Fulfilling and rewarding lives' The strategy for adults with autism in England*.
- Department of Health & Department for children schools and families (2007) *A transition guide for all services*.
- Department of Health & Department for children schools and families (2008a) *Children and young people in mind: the final report of the National CAMHS Review*.
- Department of Health & Department for children schools and families (2008b) *Transition: moving on well*.
- Department of Health & Department for education and skills (2006) *Transition: getting it right for young people*.
- Donkervoort, M., Wiegerink, D. J. H. G., Meeteren, J. V., Stam, H. J. & Roebroek, M. E. (2009) Transition to adulthood: validation of the Rotterdam Transition Profile for young adults with cerebral palsy and normal intelligence. *Developmental Medicine & Child Neurology*, 51, 53–62.
- Doug, M., Adi, Y., Williams, J., Paul, M., Kelly, D., Petchey, R. & Carter, Y. H. (2009) Transition to adult services for children and young people with palliative care needs: a systematic review. *Archives of Disease in Childhood*, 96, 78–84.
- Dovey-Pearce, G., Hurrell, R., May, C., Walker, C. & Doherty, Y. (2005) Young adults' (16–25 years) suggestions for providing developmentally appropriate diabetes services: a qualitative study. *Health & Social Care in the Community*, 13, 409–419.
- *Dunning, P. L., Best, J. D. & Alford, F. P. (1990) Comprehensive care programme for young adult with IDDM. *Practical Diabetes*, 7, 218–222.
- *Dyrløv, K., Povlsen, L., Sølvkær, L., Marinelli, K., Olsen, B. S., Hougaard, P. & Mortensen, H. B. (2000) Improving the outcome for children and adolescents with type 1 diabetes: results of a changing service in Copenhagen. *Practical Diabetes International*, 17, 217–225.
- Fredericks, E. M., Dore-Stites, D., Well, A., Magee, J. C., Freed, G. L., Shieck, V. & James Lopez, M. (2010) Assessment of transition readiness skills and adherence in pediatric liver transplant recipients. *Pediatric Transplantation*, 8, 944–953. doi: 10.1111/j.1399-3046.2010.01349.x.
- Garratt, A. M., Schmidt, L. & Fitzpatrick, R. (2002) Patient-assessed health outcome measures for diabetes: a structured review. *Diabetic Medicine*, 19, 1–11.

- Gask, L., Bower, P., Lovell, K., Escott, D., Archer, J., Gilbody, S., Lankshear, A., Simpson, A. & Richards, D. (2010) What work has to be done to implement collaborative care for depression? Process evaluation of a trial utilizing the normalization process model. *Implementation Science*, *5*, 15.
- *Gerber, B. S., Solomon, M. C., Shaffer, T. L., Quinn, M. T. & Lipton, R. B. (2007) Evaluation of an internet diabetes self-management training program for adolescents and young adults. *Diabetes Technology & Therapeutics*, *9*, 60–67.
- *Gholap, N., Pillai, M., Virmani, S., Lee, J. D., James, D., Morrissey, J., Datta, V. & Patel, V. (2006) The alphabet strategy and standards of care in young adults with type 1 diabetes. *British Journal of Diabetes and Vascular Disease*, *6*, 168–170.
- Gunn, J., Kokanovic, R., Palmer, V., Potiriadis, M., Johnson, C., Johnston Ata-Ata, K., Dowrick, C., Griffiths, F., Hegarty, K., Herrman, H., Gilchrist, G., Blashki, G. & May, C. (2009) *Re-organising the Care of Depression and other Related Disorders in the Australian Primary Health Care Setting*. Australian Primary Health Care Research Institute, Canberra, Australia Capital Territory, Australia.
- Higgins, J. P. T. & Green, S. (eds) (2009) *Cochrane Handbook for Systematic Reviews of Interventions Version 5.0.2* [Updated September 2009]. The Cochrane Collaboration, Chichester, UK.
- *Holmes-Walker, D. J., Llewellyn, A. C. & Farrell, K. (2007) A transition care programme which improves diabetes control and reduces hospital admission rates in young adults with Type 1 diabetes aged 15–25 years. *Diabetic Medicine*, *24*, 764–769.
- Jedelo, S., van Staa, A., Latour, J. M. & van Exel, N. J. A. (2010) Preferences for health care and self-management among Dutch adolescents with chronic conditions: a Q-methodological investigation. *International Journal of Nursing Studies*, *47*, 593–603.
- *Johnston, P., Bell, P. M., Tennet, H. & Carson, D. (2006) Audit of young people with type 1 diabetes transferring from paediatric to adult diabetic services. *Practical Diabetes International*, *23*, 106–108.
- Kennedy, I. (2010) *Getting it right for children and young people: overcoming cultural barriers in the NHS so as to meet their needs*.
- Kennedy, A., Chew-Graham, C., Blakeman, T., Bowen, A., Gardner, C., Protheroe, J., Rogers, A. & Gask, L. (2010) Delivering the WISE (Whole Systems Informing Self-Management Engagement) training package in primary care: learning from formative evaluation. *Implementation Science*, *5*, 7.
- *Linroth, R. (2009) Meeting the needs of young people and adults with childhood-onset conditions: Gillette lifetime specialty healthcare. *Developmental Medicine and Child Neurology*, *51*, 174–177.
- May, C. & Finch, T. (2009) Implementing, embedding, and integrating practices: an outline of normalization process theory. *Sociology*, *3*, 535–554.
- May, C., Finch, T., Mair, F., Ballini, L., Dowrick, C., Eccles, M., Gask, L., MacFarlane, A., Murray, E., Rapley, T., Rogers, A., Treweek, S., Wallace, P., Anderson, G., Burns, J. & Heaven, B. (2007) Understanding the implementation of complex interventions in healthcare: the normalization process model. *BMC Health Services Research*, *7*, 148.
- McDonagh, J. & Kelly, D. (2010) The challenges and opportunities for transitional care research. *Pediatric Transplant*, *14*, 688–700.
- Nakhla, M., Daneman, D., To, T., Paradis, G. & Guttmann, A. (2009) Transition to adult care for youths with diabetes mellitus: findings from a universal health care system. *Pediatrics*, *124*, e1134–e1141.
- *Orr, D. P., Fineberg, N. S. & Gray, D. L. (1996) Glycemic control and transfer of health care among adolescents with insulin dependent diabetes mellitus. *Journal of Adolescent Health*, *18*, 44–47.
- *Parfitt, G. (2008) Improving the young person's experience of transition: lessons from Wales. *Paediatric Nursing*, *20*, 27–30.
- Patel, V., Flisher, A. J., Hetrick, S. & McGorry, P. (2007) Mental health of young people: a global public-health challenge. *The Lancet*, *369*, 1302–1313.
- *Price, C., Corbett, S. & Dovey-Pearce, G. (2010) Barriers and facilitators to implementing a transition pathway for adolescents with diabetes; a health professionals perspective. *International Journal of Adolescent Health*, *3*, 489–498.
- Rapley, P. & Davidson, P. M. (2010) Enough of the problem: a review of time for health care transition solutions for young adults with a chronic illness. *Journal of Clinical Nursing*, *19*, 313–323.
- Ritchie, J. & Spencer, L. (1994) Qualitative data analysis for applied policy research. In: *Analyzing Qualitative Data* (eds A. Bryman & R. G. Burgess), pp. 173–194. Routledge, Abingdon, UK.
- Rosen, D. S., Blum, R. W., Britto, M., Sawyer, S. M. & Siegel, D. M. (2003) Transition to adult health care for adolescents and young adults with chronic conditions: position paper of the society for adolescent medicine. *Journal of Adolescent Health*, *33*, 309–311.
- Royal Australasian College of Physicians (2007) *Transition to adult health services for adolescents with chronic conditions*.
- Royal College of Nursing (2004) *Adolescent transition care. Guidance for nursing staff*.
- Royal College of Paediatrics and Child Health (2003) *Bridging the gaps: health care for adolescents*.
- Royal College of Physicians of Edinburgh (2008) *Think transition*.
- Sawicki, G. S., Lukens-Bull, K., Yin, X., Demars, N., Huang, I. C., Livingood, W., Reiss, J. & Wood, D. (2009) Measuring the transition readiness of youth with special healthcare needs: validation of the TRAQ transition readiness assessment questionnaire. *Journal of Pediatric Psychology*, *2*, 160–171.
- Sawyer, S. M., Drew, S., Yeo, M. S. & Britto, M. T. (2007) Adolescents with a chronic condition: challenges living, challenges treating. *The Lancet*, *369*, 1481–1489.
- Scott, L., Vallis, M., Charette, M., Murray, A. & Latta, R. (2005) Transition of care: researching the needs of young adults with type 1 diabetes. *Canadian Journal of Diabetes*, *29*, 203–210.
- Shaw, K. L., Southwood, T. R. & McDonagh, J. E. (2004) Transitional care for adolescents with juvenile idiopathic arthritis: a Delphi study. *Rheumatology*, *43*, 1000–1006.
- Shaw, K. L., Southwood, T. R., McDonagh, J. E. & the British Society of Paediatric and Adolescent Rheumatology (2007) Development

- and preliminary validation of the 'Mind the Gap' scale to assess satisfaction with transitional health care among adolescents with juvenile idiopathic arthritis. *Child: Care, Health and Development*, 33, 380–388.
- Singh, S. P., Paul, M., Ford, T., Kramer, T., Weaver, T., McLaren, S., Hovish, K., Islam, Z., Belling, R. & White, S. (2010) Process, outcome and experience of transition from child to adult mental healthcare: multiperspective study. *The British Journal of Psychiatry*, 197, 305–312.
- Sloper, P., Beecham, J., Clarke, S., Franklin, A., Moran, N. & Cusworth, L. (2010) *Models of Multi-Agency Services for Transition to Adult Services for Disabled Young People and Those with Complex Health Needs: Impact and Costs*. Social Policy Research Unit, University of York, York, UK.
- Stevenson, C. J., Pharoah, P. O. D. & Stevenson, R. (1997) Cerebral palsy -the transition from youth to adulthood. *Developmental Medicine & Child Neurology*, 39, 336–342.
- *Tan, M. J. & Kilmach, V. J. (2003) Portfolio of health advice for young people with disabilities transferring to adult care. *Child: Care, Health and Development*, 30, 291–296.
- Thomas, D. (2003) Qualitative data analysis: using a general inductive approach. *Website of the Health Research Methods Advisory Service*. Available at: <http://frankumstein.com/PDF/Psychology/Inductive%20Content%20Analysis.pdf> (accessed from 1 April 2010).
- UK Parliament (2005) *The Disability Discrimination Act*. The Stationary Office, London, UK.
- *Van Wallegghem, N., MacDonald, C. & Dean, H. (2006) Building connections for young adults with type 1 diabetes mellitus in Manitoba: feasibility and acceptability of a transition initiative. *Chronic Diseases in Canada*, 27, 130–134.
- *Van Wallegghem, N., MacDonald, C. & Dean, H. (2008) Evaluation of a systems navigator model for transition from pediatric to adult care for young adults with Type 1 diabetes. *Diabetes Care*, 31, 1529–1530.
- *Vanelli, M., Caronna, S., Adinolfi, B., Chiari, G., Gugliotta, M. & Arsenio, L. (2004) Effectiveness of an uninterrupted procedure to transfer adolescents with Type 1 diabetes from the Paediatric to the Adult Clinic held in the same hospital: eight-year experience with the Parma protocol. *Diabetes, Nutrition & Metabolism*, 17, 304–308.
- Vidal, M., Jansa, M., Anguita, C., Torres, M., Giménez, M., Esmatjes, E., Levy, I. & Conget, I. (2004) Impact of a special therapeutic education programme in patients transferred from a paediatric to an adult diabetes unit. *European Diabetes Nursing*, 1, 23–27.
- Watson, A. R. (2000) Non-compliance and transfer from paediatric to adult transplant unit. *Pediatric Nephrology*, 14, 469–472.
- Watson, A., Hilton, D. & Hackett, D. (2009) Therapeutic recreation camps to provide a residential experience for young people in transition to adult renal units. *Pediatric Nephrology*, 25, 787–788.
- While, A., Forbes, A., Ullman, R., Lewis, S., Mathes, L. & Griffiths, P. (2004) Good practices that address continuity during transition from child to adult care: synthesis of the evidence. *Child: Care, Health and Development*, 30, 439–452.
- Williams, T. S., Sherman, E. M. S., Mah, J. K., Blackman, M., Latter, J., Mohammed, I., Slick, D. J. & Thornton, N. (2010) Measurement of medical self-management and transition readiness among Canadian adolescents with special health care needs. *International Journal of Adolescent Health*, 3, 1–9.
- World Health Organization (2001) *International Classification of Functioning, Disability and Health (ICF)*. World Health Organization, Geneva, Switzerland.
- *Xenakis, N. & Goldberg, J. (2010) The Young Women's Program: a health and wellness model to empower adolescents with physical disabilities. *Disability and Health Journal*, 3, 125–129.

Appendix I

Definitions for 10 transition categories and sources of the recommendations

Transition category	Descriptions	Sources
Timing	Transition services should be delivered in a timely and co-ordinated manner.	Department of Health 2004, 2007a; Department of Health & Department for education and skills 2006; American Academy of Pediatrics <i>et al.</i> 2002; Collis <i>et al.</i> 2008
	Transfer should occur at the appropriate time for the individual rather than at a specific time point and requires a level of flexibility. Timing should take into account the complexity of need. Young people should not transfer fully to adult services until they have the necessary skills to function in an adult service.	Royal College of Paediatrics and Child Health 2003; Department of Health & Department for education and skills 2006; Department of Health 2007a; Collis <i>et al.</i> 2008; Department of Health & Department for children schools and families 2008b; Fredericks <i>et al.</i> 2010
	The transition process needs to be spread over a number of years.	Royal College of Nursing 2004; Adolescent health committee & Canadian Paediatric Society 2007; Department of Health 2007a; Royal College of Physicians of Edinburgh 2008; All Party Parliamentary Group on Autism & Allard 2009; Doug <i>et al.</i> 2009
Individual focus	The transition process should be individual to the needs and aspirations of the young person. Person centred and needs focused.	Rosen <i>et al.</i> 2003; Department of Health 2004, 2007a; Shaw <i>et al.</i> 2004; Department of Health & Department for education and skills 2006; Department of Health & Department for children schools and families 2007, 2008b; Royal Australasian College of Physicians 2007; Collis <i>et al.</i> 2008; All Party Parliamentary Group on Autism & Allard 2009
	Young people and their families should be in control of the design and delivery of their care package. They should be supported to shape services and be involved in the transition process.	Department of Health & Department for education and skills 2006; Department of Health 2007a,b; Collis <i>et al.</i> 2008; Doug <i>et al.</i> 2009
	Young person and family should input into the transition planning process.	Department of Health 2001, 2007a; Rosen <i>et al.</i> 2003; Department of Health & Department for education and skills 2006; Collis <i>et al.</i> 2008; Royal College of Physicians of Edinburgh 2008; All Party Parliamentary Group on Autism & Allard 2009
Considers other areas of transition	Transition should include lifestyle/psychosocial/ educational/vocational issues as well as medical issues.	Rosen <i>et al.</i> 2003; Royal College of Paediatrics and Child Health 2003; Shaw <i>et al.</i> 2004; Department of Health & Department for education and skills 2006; Adolescent health committee & Canadian Paediatric Society 2007; Department of Health & Department for children schools and families 2007, 2008b; Royal Australasian College of Physicians 2007; Collis <i>et al.</i> 2008; Royal College of Physicians of Edinburgh 2008; All Party Parliamentary Group on Autism & Allard 2009
Preparation for adult services	Families are provided with accurate and easy to understand information about local services and transition.	Department of Health 2007a,b
	Transparency in decision making.	Department of Health & Department for education and skills 2006; Department of Health 2007a
	Comprehensive information, advice, education and guidance for all young people.	Shaw <i>et al.</i> 2004; Adolescent health committee & Canadian Paediatric Society 2007; Department of Health 2007a; Department of Health & Department for children schools and families 2007; Collis <i>et al.</i> 2008; All Party Parliamentary Group on Autism & Allard 2009
	Opportunity for young people to make appointments and attend consultations on their own or be seen on their own for part of a consultation.	Shaw <i>et al.</i> 2004; Adolescent health committee & Canadian Paediatric Society 2007; Department of Health 2007b
Skills training	Transition should allow the young person to gain independence and take responsibility for their own healthcare choices.	Department of Health 2004, 2007a; Department of Health & Department for education and skills 2006; Adolescent health committee & Canadian Paediatric Society 2007; Department of Health & Department for children schools and families 2007, 2008b; Royal College of Physicians of Edinburgh 2008

Appendix I *Continued*

Transition category	Descriptions	Sources
Service delivery	Transition should develop the young person's knowledge, confidence, self-advocacy and self-management skills.	Department of Health & Department for education and skills 2006; Adolescent health committee & Canadian Paediatric Society 2007; Department of Health & Department for children schools and families 2008b; Doug <i>et al.</i> 2009; Fredericks <i>et al.</i> 2010
	Staff should be trained in working with young people and transition issues.	Rosen <i>et al.</i> 2003; Royal College of Paediatrics and Child Health 2003; Shaw <i>et al.</i> 2004; Department of Health & Department for education and skills 2006; Department of Health 2007b; Royal Australasian College of Physicians 2007; Department of Health & Department for children schools and families 2008b; All Party Parliamentary Group on Autism & Allard 2009
	Staff should have a clear understanding of their roles and responsibilities.	Department of Health 2007a,b; Department of Health & Department for children schools and families 2008b
	Every young person should have a transition review that leads to a comprehensive health transition plan developed with the family.	Royal College of Nursing 2004; Department of Health & Department for children schools and families 2007, 2008b
	Developing the transition plan should be a continuous process, including checklists for key areas.	American Academy of Pediatrics <i>et al.</i> 2002; Royal College of Nursing 2004; Department of Health & Department for children schools and families 2008b
Service development	Statutory year 9 review for young people with special educational needs, learning difficulties and disabilities.	Department of Health 2007a
	Primary care should be informed and able to contribute to transition planning if appropriate. A good relationship should be maintained with general practitioners and primary care throughout childhood and adolescence.	Department of Health & Department for education and skills 2006; Royal Australasian College of Physicians 2007
	Other relevant services should be either co-located within the service or the service provides information about local services available and is aware of the referral pathway.	You're Welcome criteria 2007
	Consistent multi-agency working to ensure that disabled young people are given a real choice about their future. Team work across and within agencies and effective information sharing.	American Academy of Pediatrics <i>et al.</i> 2002; Department of Health 2004, 2007a; Department of Health & Department for education and skills 2006; Department of Health & Department for children schools and families 2008b; Royal College of Physicians of Edinburgh 2008; All Party Parliamentary Group on Autism & Allard 2009
	Children and adult services need to communicate and work together effectively. Effective liaison between services.	American Academy of Pediatrics <i>et al.</i> 2002; Department of Health & Department for education and skills 2006; Department of Health 2007a; Royal Australasian College of Physicians 2007; Collis <i>et al.</i> 2008; Department of Health & Department for children schools and families 2008b; All Party Parliamentary Group on Autism & Allard 2009
Sustainability, outcome measures and evaluation	Multi-disciplinary teams to provide co-ordinated care.	Royal College of Paediatrics and Child Health 2003; Shaw <i>et al.</i> 2004; Adolescent health committee & Canadian Paediatric Society 2007; Department of Health & Department for children schools and families 2008b
	There should be measurable outcomes to ensure a value for money service. Services should be regularly reviewed and evaluated.	Royal College of Paediatrics and Child Health 2003; Royal College of Nursing 2004; Department of Health & Department for education and skills 2006; Department of Health 2007b; Department of Health & Department for children schools and families 2008b; Royal College of Physicians of Edinburgh 2008
	Easily accessible services that can be contacted outside school/college hours. Services should be easily accessible at key transition points in life.	Royal College of Paediatrics and Child Health 2003; Department of Health 2007a,b