

## **Abstract**

Transition from paediatric to adult health care services has been characterised as a being poorly planned and co-ordinated, resulting in a reduction in services and may be distressing for families.

**Aim:** This study aimed to establish what provisions are currently available for transition in Scotland for young people with cerebral palsy and what some clinicians believe future provisions should involve.

**Methods:** Semi-structured interviews were conducted with 13 community paediatricians (or equivalents in Health Boards without community paediatricians) from 12 different Scottish Health Boards. Interviews were audio recorded, transcribed and analysed thematically using framework analysis.

**Results:** Both current transition provision and the areas that the clinicians felt needed improvement varied greatly between Health Boards. Key areas in need of improvement were co-ordination and communication within health services and also between health services and educational, social services and adult health services to which young people were transitioning.

**Interpretation:** Transition remains problematic and variable. For transition to be improved further research is needed to explore what effect this variation is having on young people and their families.

**Key Words:** Care pathways, Cerebral palsy, Child health, Transition

## **Transition from paediatric to adult health services for young people with cerebral palsy in Scotland**

### **Introduction**

The improved survival rate and the continuing medical needs of young people with cerebral palsy (CP), as well as other childhood onset disabilities and illnesses, has resulted in an increasing focus on the period of transition between services for children and those for adults (Beresford, 2004, Chamberlain and Kent, 2005). Transition involves multiple agencies and co-ordination between clinicians in both paediatric and adult services, and between medical and non-medical services such as education and social services.

Several reports suggest that current transition arrangements are uncoordinated, young people may not always be involved in the process and suitable adult services are not always available (Ko and McEnergy, 2004, Kirk, 2008). The community paediatrician provides a point of contact in children's services and input from the different professionals is normally well co-ordinated (Chamberlain and Kent, 2005, Schwartz et al., 2011). However, there is currently no equivalent role to that of the community paediatrician within adult services (Chamberlain and Kent, 2005, Fiorentino et al., 1998a) and the responsibility for managing and co-ordinating health input for some young people may be discharged to their general practitioner (GP) (Ko and McEnergy, 2004, Fiorentino et al., 1998a, Fiorentino et al., 1998b).

Transition has also been characterised as a difficult time for young people and their parents (Kirk, 2008, Lugasi et al., 2011) particularly as the latter may become increasingly

aware of their own mortality and potential future difficulties in looking after their child as they age (Hallum, 1995).

Scotland has a separate National Health Service (NHS) to the rest of the UK and separate health policies (Stalker, 2002) but no research has been conducted recently on transition for young people with CP in Scotland. This study therefore aimed to investigate community paediatricians' perceptions of current services for transition from paediatric to adult health care for young people with CP and how these might be improved.

## **Methods**

### *Participants*

Nine consultant community paediatricians, two associate specialist community paediatricians, one GP and one physiotherapist, were purposively sampled from 12 Scottish Health Boards. The initial criterion used for selection was that participants should be community paediatricians routinely involved with young people with CP during transition. However, it was discovered that Scotland's three most remote and rural Health Boards did not have a consultant community paediatrician at the time of the study and so the most appropriate alternative clinician was chosen. All participants were approached by email following \*\*s attendance at a national working group for community paediatricians. One remote and rural, and one mainland Health Board did not respond when contacted and were

therefore not included. Furthermore, one Health Board nominated two community paediatricians who were both included giving a total of 13 clinicians from 12 Health Boards.

### *Interviews*

Semi-structured interviews were conducted by \*\*, either in person at the participants place of work or via video conferencing. The first part of the interview comprised five open questions asking the clinician to describe the transition process, what they thought worked well, what did not work well and what they would like to see improved. The second part of the interview contained 11 questions about the transition process and two about adult services to which young people transition.

Ethical approval for this study was granted by the \*\*\*\* Research Ethics Committee and all participants were fully informed about the research before taking part and provided written consent. The interviews were audio recorded and transcribed *verbatim* and any information identifying a respondent or Health Board was removed.

All of the interviews were analysed thematically using the framework method of data management and analysis described by Ritchie et al (Ritchie et al., 2003) which involved four main stages:-

1. a thematic index was created following familiarization of the researcher with the transcripts
2. the index was then systematically applied to the transcripts using NVivo 9 (QSR International Pty Ltd)

3. thematic matrices were created using NVivo 9 and participants' responses concerning each sub-theme were summarised and entered into the relevant matrices
4. the participants' responses for a specific sub-theme were then systematically reviewed to detect categories which showed the range of data classed as belonging to that sub-theme.

All analysis was conducted by \*\* with regular discussion with \*\* and \*\* who also checked the construction and application of the thematic matrices and interpretation to avoid bias.

## **Results**

The interviews lasted a mean of 52 minutes (range 29 – 101 minutes). Nine main themes were identified, three of which related to the transition process, three related to the adult services, one to the impact of transition on young people and their families and one to service level consideration. The final theme, healthcare provision in paediatrics, will not be discussed here as it was not directly relevant to the specific aims of this study. There was wide variation within all themes as to what provisions were currently available for transition and how clinicians thought transition could be improved.

### *Transition planning and processes*

Three themes were identified which related to the transition process: services and specialities involved in transition, professionals involved in transition and health transition processes. The majority of participants reported that transition in health did not occur as a co-ordinated package but as multiple separate transitions between different specialist areas, for example neurology or physiotherapy. Co-ordination between health, education and social services during transition varied from 'very good' to 'none'. Where participants reported good co-ordination, a key method was multi-professional education-led meetings.

*CP 03: 'there are in fact transition processes ... happening in education and in social work ... families find it very hard to understand transition as a concept because it's actually happening in three different areas of work at the same time and not always in a synchronised way'*

When clinicians were asked who was responsible for transition in health, eight reported that it was the community paediatrician, with other answers including the clinical team, parents, and the GP. The majority of community paediatricians also reported that, although responsible for transition, they felt that they did not have control over the process and did not have feedback as to whether transition went well.

*CP10: 'a lot of the time when you're referring through to therapists or whatever we're not gonna have that feedback and there's nothing that we can do about that once they're out of the service if that hasn't worked that well'*

The majority of community paediatricians were involved in aspects of transition outside of health (e.g. supporting families around day placements). Furthermore, participants highlighted that transition could be difficult for the staff involved who had been caring for patients for a long time and had limited powers to improve their care. Tables 1 and 2 summarise transition planning in health as described by participants.

#### *Adult Health Services*

Three themes were identified which related to services for adults with CP: structure of adult services, role of doctors in adult services and input from nurses and allied health professionals (AHPs) in adult services. After transition, young people with CP can either be referred to an adult Learning Disability Team (LDT), a rehabilitation service or discharged back to their GP. The referral pathways are summarised in Figure 1. Criteria for access to adult LDTs (where available) varied and included the educational setting of the young person, the complexity of their needs, and a having a formal diagnosis of a Learning Disability (LD). Transition was characterised as working well in two areas that followed pathway A and in one of the areas that followed pathway B (Figure 1), as all young people with significant needs had a service to which they could transition.

Although the input from adult LDT was normally multi-disciplinary and well-coordinated, general health care for adults with CP was described as being more uncoordinated than in paediatrics. Participants reported that this was, in part, due to no

longer having a school to bring health care professionals together. Furthermore, health care in adult services was often provided as required for specific problems rather than the adult receiving regular general review unless there was a specific medical reason for review.

*CP01: 'you'll have individuals in silos you know, you'll have the neurologist and the other thing is that you know unless your problem is active ... You know physicians will not take you on as a ... review situation they will only deal with an active problem and discharge'*

Three medical specialties were identified as taking over the medical care of the young people – LD consultants, rehabilitation consultants and GPs. There was considerable variation between Health Boards around the role and availability of each specialist. LD consultants are psychiatrists and were generally reported as only being involved in young people's behavioural and mental health needs rather than complex physical needs. Two Health Boards were reported as not having LD consultants at the time of interview

Only five participants reported that rehabilitation consultants were available for referrals. Of those, one reported that the rehabilitation consultant would provide long-term follow-up and have a role similar to a community paediatrician, one reported that it was only a short-term assessment service and three either did not know or did not provide details about the adult service provided.

In all Health Boards, GPs played a greater role in the medical care of young people after transfer but there was considerable debate by respondents about GPs taking over the

management and co-ordination of health care for adults with CP. In adult services, both nurses and AHPs, in particular physiotherapists, often played a key role in the care of adults with CP. Within the LD team, nurses or physiotherapists would often provide either a co-ordinating or supportive role for families. It was also reported that there were more services available within the LD team compared to those in other services.

#### *Young people and their families during transition*

Participants described a variety of concerns reported by young people and their parents about transition in health, including no longer receiving regular consultant review, reduced therapy and young people with a LD being seen by a psychiatrist when they had previously seen a community paediatrician. In the majority of cases, it was reported that families were more concerned about transition in education and social work than transition in health. Although all participants reported that young people were involved in transition, most reported that there were very few decisions to make or choices. Currently the information available to families about transition was either only verbal or *ad hoc* leaflets.

*CP09: 'yeh most times that's the bigger issue ... at the end of the day health happens ... they can go to their GP or they'll ring me up even if they're 19 and say help ... But if a parent's sitting at home with a very disabled kid and there's nothing in place that's appallingly difficult'*

#### *Improving transition*

For all themes participants suggested improvements to transition (Table 3), which varied depending both on which services were currently available in their Health Board and what participants thought the healthcare needs of young adults with CP were. Opinions varied as to whether young people with cerebral palsy needed input from a generalist doctor after transition who would take over the community paediatrician's role. Some participants highlighted the need to review to proactively detect orthopaedic problems. In contrast, others stated that, after growth had ended, the young person should be medically stable. Amongst those who argued for further services, some argued that it should be provided by a rehabilitation consultant. Others suggested that there was a need for separate adult training to fill this gap. Furthermore, one theme 'service level considerations' was identified which related specifically to improving transition. Difficulties with funding and staffing were reported by the majority of participants who also felt that national level implementation was needed.

*CP10: 'these conditions the ... neurodisabling conditions you know (pause) you've got lots of different professionals involved and you need to have a clear pathway'*

## **Discussion**

This study provides some insight into perspectives and experiences of 13 clinicians responsible for co-ordinating transition of young people with CP into adult services. This is

based on framework analysis specifically developed for use in social policy research (Ritchie and Spencer, 2004). The advantages of using framework analysis include: it is driven by the original data allowing the data supporting any conclusion to be easily retrieved; it allows for the systematic and comprehensive analysis of the data collected by treating all the data in the same way; and the analytical process can be easily understood and replicated by other researchers (Ritchie and Spencer, 1994).

The main finding across all the themes identified is that transition was highly variable between and possibly within Health Boards. This was most likely not reported in previous studies because they focused on limited geographical areas.

Transition was characterised by most participants as a series of separate transitions happening within health, education and social work, and different areas within health often with only limited co-ordination between them. This lack of co-ordination between transitions within different services has also been reported by Fiorentino *et al.* (1998b). Contrary to previous findings by Kirk (2008) and Fiorentino *et al.* (1998b), all respondents reported that young people would be fully informed about, and involved in, transition. However, the extent of involvement of young people and their carers could be limited by the absence of formal transition planning and that most communication was verbal.

Many participants believed that transition could not be improved without major changes to adult services but there was variation as to what services they thought should be available in the future. In the majority of Health Boards, the adult services to which the young person

would transition would depend on whether or not they had a LD, which supports previous findings (Fiorentino et al., 1998a, Fiorentino et al., 1998b).

It was generally felt that, in areas without a rehabilitation service willing to take on young people without LD, this service would be beneficial, or where this service was available it worked well. Bent *et al.* (2002) found that young adult teams which were led by rehabilitation consultants for young people with physical disabilities but without a LD increased participation in society. However, some of the participants who, in principle, supported the idea of rehabilitation-led services for those without a LD, highlighted that these were unlikely to be funded without evidence of their economic benefit. In contrast to this, Bent *et al.* (2002) found that young adult teams did not require any additional resources compared to normal ad hoc service provision. However, this conclusion was based on the assumption that rehabilitation consultants are part of normal services for adults with CP, something which is not the case in the majority of Health Boards in Scotland.

Additionally it was reported that for those young people referred to the adult LD team, there was a need for generalist medical input to continue the co-ordination and management of young people's physical needs. Although these young adults would receive a multi-disciplinary team-based service and may receive regular review by a nurse or a physiotherapist, the majority were not reported to receive regular review by a consultant to manage their medical needs. Instead responsibility for their overall medical needs would be taken over by their GP. Some participants highlighted that routine consultant-led services may not be necessary as adults with CP should be medically stable after cessation of growth.

However, there is evidence that adults with CP report a decline in mobility and an increase in pain and fatigue (Andren and Grimby, 2004, Hilberink et al., 2007) although these studies do not demonstrate if regular medical review is beneficial and can prevent or reduce the impact of this decline.

There was also considerable debate as to whether GPs were in a position to take over the co-ordination of the medical needs of young people with CP. Although there is no evidence in the literature about this, Fiorentino *et al.* (1998a) found that young people and their carers did not feel confident going to their GP for issues associated with their disability. This may be partly due to young people receiving the majority of their care as children from hospital based practitioners rather than their GP (Andren and Grimby, 2004). Participants also suggested that transition may be less stressful if young people have a good relationship with their GP.

It was notable that the majority of participants reported that any therapy required by a young person would be available after transition, particularly for those referred to adult LD teams. This is contrary to findings by Ko and McEnery (2004) but may be due to differences in provisions between regions or in perceptions as to what is required. However, the current study did support the finding by Ko and McEnery (2004) that medical specialists were available in adult services if needed.

Limitations of this study are the small number of participants and that they only represent one group of clinicians. In the future attitudes to transition should be sought from clinicians in adult services and GPs. It is also important that before future services are developed the opinions of young people transitioning and their families/carers are explored. It is not possible

to know from the present study what effect the current variation in transition provision is having on young people with CP and their families. It is possible, although unlikely, that the varying different transition arrangements identified in this study are all providing the necessary support for young people with CP. These variations suggests a need for a co-ordinated mechanism to develop comprehensive guidelines and pathways to ensure that all young people receive a well-co-ordinated and planned transition about which they are fully informed, and in which they are fully involved.

## References

- Andren, E. & Grimby, G. 2004. Dependence in daily activities and life satisfaction in adult subjects with cerebral palsy or spina bifida: a follow-up study. *Disability and Rehabilitation*, 26, 528-36.
- Bent, N., Tennant, A., Swift, T., et al. 2002. Team approach versus ad hoc health services for young people with physical disabilities: a retrospective cohort study. *Lancet*, 360, 1280-1286.
- Beresford, B. 2004. On the road to nowhere? Young disabled people and transition. *Child: Care, Health and Development*, 30, 581-587.
- Chamberlain, M. A. & Kent, R. M. 2005. The needs of young people with disabilities in transition from paediatric to adult services. *Europa medicophysica*, 41, 111-23.
- Fiorentino, L., Datta, D., Gentle, S., et al. 1998a. Transition from school to adult life for physically disabled young people. *Archives of Disease in Childhood*, 79, 306-311.
- Fiorentino, L., Phillips, D., Walker, A., et al. 1998b. Leaving paediatrics: the experience of service transition for young disabled people and their family carers. *Health & Social Care in the Community*, 6, 260-270.
- Hallum, A. 1995. Disability and the transition to adulthood: Issues for the disabled child, the family, and the pediatrician. *Current Problems in Pediatrics*, 25, 12-50.
- Hilberink, S. R., Roebroek, M. E., Nieuwstraten, W., et al. 2007. Health issues in young adults with cerebral palsy: towards a life-span perspective. *Journal of Rehabilitation Medicine*, 39, 605-11.

- Kirk, S. 2008. Transitions in the lives of young people with complex healthcare needs. *Child: Care, Health and Development*, 34, 567-75.
- Ko, B. & Mcenery, G. 2004. The needs of physically disabled young people during transition to adult services. *Child: Care, Health and Development*, 30, 317-323.
- Lugasi, T., Achille, M. & Stevenson, M. 2011. Patients' perspective on factors that facilitate transition from child-centered to adult-centered health care: a theory integrated metasummary of quantitative and qualitative studies. *Journal of Adolescent Health*, 48, 429-40.
- Ritchie, J. & Spencer, L. 1994. Qualitative data analysis for applied policy research. *In:* BRYMAN, A. & BURGESS, R. G. (eds.) *Analyzing qualitative data*. London: Routledge.
- Ritchie, J. & Spencer, L. 2004. Qualitative data analysis: the call for transparency. *Building Research Capacity* 7, 2-4.
- Ritchie, J., Spencer, L. & O'connor, W. 2003. Carrying out qualitative analysis *In:* RITCHIE, J. & LEWIS, J. (eds.) *Qualitative research practice: a guide for social science students and researchers* London Sage Publications Ltd
- Schwartz, L. A., Tuchman, L. K., Hobbie, W. L., et al. 2011. A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child: Care, Health and Development*, 37, 883-95.
- Stalker, K. 2002. Young disabled people moving into adulthood in Scotland. York: Joseph Rowntree Foundation.

