

Young People with Cerebral Palsy in Transition from Paediatric to Adult Health Services – Best Practice Recommendations



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Cerebral palsy (CP) is the commonest cause of neurological disability in childhood and as many as 70% of children with CP survive into adult life.¹ Although the health and social care provision for these children is generally well organised and delivered by the paediatric services in the UK, there is a gap in the service provision of care for these individuals in their adolescent stage of development. This, and the need for the continuity of care, as well as the importance of the smooth transition from paediatric to adult services is now widely acknowledged.^{2,4}

Transfer from the care of the paediatric to the adult services is a major life event for young people with CP because of their unique and specific health, psychological, vocational and social needs. It requires close cooperation from the paediatric and adult medical teams in order to be seamless and successful.

This article aims to provide recommendations of best practice for achieving the transition of adolescents with CP from paediatric to adult care. The recommendations are based on published evidence and, where this is not available, on the clinical experiences of a panel of assembled experts (see appendix).

The policy context for transition from paediatric to adult services

The report 'Improving the life chances of disabled people'⁵ aims to promote planning and delivery of responsive, person-centred services, taking into account the needs and choices of individuals. It describes three key factors that are required for the effective support of young disabled people. These are:

- ▶ Planning for transition that focuses on the needs of the individual emphasising the role of the family and the need for it to be supported in a way that empowers disabled young people and their parents.
- ▶ Continuous service provision. It recom-

mends that the children and adult services should overlap to improve continuity of care.

- ▶ Access to more transparent and appropriate opportunities and choices.

Definition of transition

Transition, as defined by Blum et al.⁶ is 'the purposeful, planned movement of adolescents and young adults with chronic physical and mental conditions from child-centred to adult-orientated health care systems.' It is a process, not an event, and requires careful planning and timing.

Patient management in the paediatric and adult services differ greatly in their approach as to the issues of growth, development and involvement of the family. Consequently, a simple transfer to adult clinicians or allowing young people to 'drop out' of medical care is not acceptable and should be prevented.

Timing of transition

There is no 'right time' for transition and a flexible approach is crucial. Generally, the timing of transition should depend on the developmental readiness of the young adult as well as the capabilities of the adult providers.⁶ It has been suggested⁷ that transition should not occur until young adults have completed the developmental tasks of adolescence and have acquired the necessary skills and education to manage their condition largely independently of their parents.

Transfer of care from the paediatric to the adult service

The Panel (see Appendix) recommends that the transfer of care should be flexible and gradual and, ideally, coordinated by a community paediatrician. The process of transfer is best achieved through a joint transition clinic with members of both the adult and paediatric team which would see the young adult for up to two

Service provision	Minimum requirement	Ideal situation
Staff		
Training for the paediatric and adult medical teams in the management, care and transition of young people with cerebral palsy	✓	
Training of staff in disability diversity and communication skills	✓	
A 'key' person to be nominated e.g nurse, rehabilitation specialist, community paediatrician, to coordinate the transition from the paediatric to the adult service and be the intermediary for all medical and social needs	✓	
Specialist 'key' transition nurse or therapist in neurorehabilitation as part of both the paediatric and adult service		✓
Access to psychological support services – in paediatric liaison or community mental health		✓
Services		
Available information for young people with cerebral palsy, parents/carers regarding transition process	✓	
Good general information about treatment centres, available support services and resources	✓	
Dedicated out-patient room for young adults during clinic	–	✓
Young adult community services/out-patient services with resources tailored to their needs	✓	–
A national survey on the prevalence of cerebral palsy is required to enable better planning of services	✓	
Joint workings		
Integration and access to the key ancillary services e.g. social and therapy services and a further education advisor	✓	
Joint paediatric and adult CP transition clinics	✓	
Paediatric and adult neurorehabilitation services should be on the same hospital site		✓
Management of the young adult with CP should be based in the community. Services should be accessible in terms of location, access and service approach	✓	
Review of all equipment being used by the young person with CP prior to transfer to adult service, with a clear line of communication for future provision, repair and review	✓	

to three visits depending on their needs. Adequate and appropriate information on relevant health and social care and access to services should be provided to support young adults through the transition.

Summary of recommendations

The Panel felt that the following requirements (see Table) are necessary for a seamless transfer of care for the young adult. ♦

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