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Improving transition for young people with cerebral palsy in Scotland.

Wright, A.E., Robb, J. and Shearer, M.C. 2016. Transition from paediatric to adult health services in Scotland for young people with cerebral palsy. *Journal of Child Health Care*. **20**(2), pp.205-213.

Aim: To explore the perceptions of community paediatricians' in Scotland of current services for young people with cerebral palsy moving from paediatric to adult services and identify how care could be improved.

Methods: Semi-structured interviews were conducted with consultant community paediatricians (n=9), associate specialist community paediatricians (n=2), GP (n=1) and physiotherapist (n=1) from across 12 Scottish health boards. Interviewees were asked to describe the process of transition for young people with cerebral palsy, identify strengths and areas in need of improvement. Interviews were recorded and transcribed verbatim before Framework was used to conduct the analysis.

Findings : Nine themes were identified – eight of which are described in the paper. In summary, themes focused on the transition process, adult services and impact on young people and their families. Transition services were not synchronised between services (young people with cerebral palsy may be under the care of multiple specialities), in some cases transition was well co-ordinated but the differences in health care between paediatric and adult care created concern for families. Families concerns, as reported by the health care professionals in this study mainly focused on; inconsistency in consultant led reviews, reduced therapy and reviews led by a psychiatrist rather than a community paediatrician for those with a learning disability. Co-ordination and communication between all agencies, a transition nurse linking professionals, transition clinics and increased awareness in adult services of the needs of young adults were some of the aspects identified as needing improvement.

Conclusion: This study demonstrated that there was wide variation in transition services between and within the 12 health boards. Multiple and separate transition services were experienced by families across health, education and social care agencies with very limited sharing of information and co-ordination. The study recommends that any improvements in transition were dependant on major changes to adult services.

Young people with complex needs need co-ordinated and individualised transition planning

Delivery of effective transition services for all young people with a long-term condition is key to them learning to self-care and partnership with health care professionals to develop and maintain healthy behaviours into adulthood (Viner, 2008). For young people with cerebral palsy or learning

disability, who may be more dependant on their families for care and require multiple specialist services, transition can be more complicated. Despite extensive knowledge of the importance of co-ordinated transition pathways that involve young people and families this study is yet another that highlights challenges and deficiencies.

This study raises our awareness of transitional issues for young people with cerebral palsy from the perspective of care professionals' with by proxy reports of families concerns. However, research has been conducted with this patient population describing their experiences of transition that complements this study (Racine et al., 2014; Larivière-Bastien et al., 2013; Davies et al., 2011). Young people with cerebral palsy have expressed fear and apprehension caused by the loss of their close and accessible relationship with paediatric care. Other concerns mirror those of health professionals in this study and describe a lack of communication between providers of care and information in preparation for transition (Larivière-Bastien et al., 2013). Parents and young people describe feelings of abandonment at the time of transition and a lack of knowledge regarding their condition by adult services (Davies et al., 2011; Larivière-Bastien et al., 2013). The diversity in transitional services and separate transitions across health, education and social work for young people with complex needs, apparent in Wright et al's (2016) study, can only add to their anxieties.

Variation in transitional pathways across providers is almost inevitable with local adaptations of transition models available to inform services, differing knowledge and experience of health care professionals and the availability of funding. As Wright et al (2016) highlight we need to know what impact this variation has on young people with cerebral palsy into adulthood. However, it seems clear that this variation in transition across the range of professions involved in the care of young people with complex needs should be a priority for improvement. Individualised transition planning for young people with cerebral palsy led by a key professional who is responsible for co-ordination of transition across and within services might improve the consistency of care.

It remains to be seen whether the NICE (NICE, 2016) guidelines for transition to adult services will have an impact on increasing the quality and consistency of transitional services particularly for young people with complex needs.

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