Transition from child to adult services for young people with cerebral palsy in Ireland: Influencing factors at multiple ecological levels.

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ABSTRACT

Most young people with cerebral palsy (CP) survive into adulthood and will move from paediatric to adult services by the age of 18 years. Transition is more than the transfer of care to adult health services; it describes the process by which young people are prepared to take charge of their lives and their health in adulthood. Research examining the experience of transition among young people with CP often focuses on a single perspective, for example, parents or young people. Knowledge of subjective experiences of transition to adulthood from multiple perspectives may improve understanding of the factors that influence transition and the multi-level interactions between these factors, thereby facilitating planning and organisation of support and maximising the effectiveness of any transitional care intervention developed.

AIM

To describe experience of transition from the perspectives of young people with CP, their parents and health professionals and to explore multi-level, interactive factors between the young person and their environment that influence the transition to adult healthcare.

RESULTS

Twenty-one interviews were conducted with young people and parents (mean duration 67 minutes). Twenty-seven interviews were conducted with health professionals (mean duration: 66 minutes). Young people had a mean (SD) age of 18 (2.3) yr with 57% in GMFCS levels I-II and 47% pre-transfer. A majority of health professionals were physiotherapists, working in paediatrics, based in Dublin. Themes are mapped to an ecological framework, inspired by Bronfenbrenner’s (1979) model (Figure). At the individual level, limited awareness, preparation and access to information hindered successful transition. The microsystem included inter-personal interactions between young people and their parents or health professionals. Factors such as family knowledge, readiness, resilience and health professional expertise supported or hindered knowledge development and preparation. Mesosystem factors included provider-family interactions, inter-agency professional interactions, and inter-agency collaboration between child and adult services. Communication and coordination challenges between parents and health professionals, as well as among different services and agencies, impacted continuity. Ecosystem factors included limited adult service availability, referral constraints, and coordination deficiencies, resulting in access issues, unclear care paths, and care continuity disruptions. Policy gaps, staffing obstacles, time constraints, funding limitations, and disparities in service distribution had a significant impact on the transition process.

CONCLUSION

This study explores the transition experience of young people with CP, parents and health professionals in Ireland, and highlights interactions among personal and environmental factors at different ecological levels. Transition was influenced by diverse factors at multiple levels including interactions of families, health professionals, and larger systems factors such as policy and funding priorities. Understanding experiences of transition may facilitate planning and implementation of transitional care interventions. Enacting change across ecological levels is critical to a holistic approach to support transition and mitigate feelings of abandonment, loss, and uncertainty. The complexity of transition warrants a correspondingly sophisticated multi-level systemic response that involves all pertinent stakeholders.

REFERENCES


DIAGRAM

EXOSYSTEM

MESOSYSTEM

MICROSYSTEM

INDIVIDUAL

Geographical distribution of services

Budget and funding allocation

Provider-family interaction

Adult service characteristics

Lack of transition policy and implementation gaps

Salary, time and role constraints

Interagency collaboration and working

Parent knowledge, resilience and readiness

Service provider skill, expertise and commitment

Communication and coordination between paediatric & adult services

Parent, child & family preferences

Experiences of transition

Even lately, because of her vision impairment, she’s actually entitled to the blind allowance. But I had to by chance research it. And another Mummy in the same position, said “no one ever told me that”. I’d like to think there was somebody coming behind with a much younger child and that what I’ve gone through could be actually said “there you are. This is what you need to go and do. Watch out for this. Do this” (parent)

I didn’t even realise that a meeting was something that you did. I was being asked did I have any questions at this team meeting. I think it was just a bit of a shock to see them [paediatric health professionals]. Because I hadn’t seen them in a bit. I didn’t have time to think of any questions that I might have now (young person)

Like being discharged from the paediatric services and suddenly your GP is in control of everything...the GPs don’t always know the kids. Especially if they’ve been dealt with in services the whole time and they’ve had their paediatrician in the clinic looking after everything for them. And then you’re suddenly going back to a GP who goes “but I don’t actually know your child. I don’t really know how I’m supposed to help you here.” It’s been a learning curve for us. (parent)