Preparing for the future: how does the participation of adolescents with cerebral palsy compare to the general population?

C Tuffrey, BJ Bateman, K Parkinson and AC Colver
North Tyneside General Hospital and University of Newcastle Upon Tyne
Background

• Universal features of Adolescence (Steinberg)
  – Puberty
  – Emergence of advanced thinking skills
  – Transition to adult roles
Transitions in Adolescence

- Domestic/Housing transition
- Educational/employment transition
- Economic transition
- Changing relationships
Research evidence from young adults with cerebral palsy

• Significantly less likely to live independently compared to general population

• Intellectual disability, epilepsy and severity of motor impairment significant predictors of not achieving independent living.


Employment for young adults with disabilities

- Adolescents with spinal injury and with CP less likely to have had paid employment than controls

- Barriers to employment include time needed to manage personal care and benefits system


Relationships

- Adolescents with CP (and no severe LD) less likely to be in a romantic relationship than peers

- Highly significant differences between young adults with CP and general population in rates of cohabitation, marriage and having children


This study

• Part of a larger study undertaken to evaluate a new instrument to measure frequency of Participation in adolescents with CP – the Questionnaire of Young People’s Participation (QYPP)

• Undertaken in Northern England in 2009-2010

• Data collected using the QYPP from
  – 107 young people with CP
  – 540 young people from general population
QYPP

• Underlying concepts based on International Classification of Functioning, Disability and Health

• Developed following qualitative work with young people with and without CP

• Draft instrument had 7 domains
  – Home life
  – **Getting on with people**
  – Education
  – **Work and finances**
  – Community and political life
  – Recreation and leisure
  – **Preparing for the future**
QYPP

• Additional domain *Preparing for the future*
  – Sleepovers
  – Work experience
  – Planning for leaving home and employment
CP sample

- 68 of the sample without severe LD

- Aged 13.2 years to 21.3 years (median 16.1 years)

- 53% male
General population sample

- Collected as part of SPARCLE 2 study

- From 2 secondary schools in North East England

- Aged 13 years to 17.9 years (median 14.6 years)

- 49% male
Results

- Participation was less frequent in the CP group for
  - having an informal part-time job (9% vs 36% p<0.001)
  - formal paid work (4% vs 20%, p<0.005)

- Participation in work experience and having written a c.v. was more common in the CP group

- Discussing careers was similar for the two groups
• Participation was less frequent in the CP group for
  - discussing leaving home
    (52% vs 66%, p<0.05)
  - sleeping over at friends’ houses
    (45% vs 91%, p<0.001)
  - spending time alone with a girl or boyfriend
    (21% vs 52%, p<0.001)
Limitations of the study

• Not a matched control group – general population sample had lower median age

• Relatively small CP sample
Conclusions - Work

• Young people with CP had lower Participation in paid employment compared to general population
  – Causes for this likely to be multifactorial

• Many young people gain experience of employment whilst in adolescence

• More research is needed to look at preparation for employment in adolescents with disability
Conclusions – Leaving home

• Young people with CP less likely to discuss independent living
  – Barriers may include reduced expectations

• Young people with CP have less experience of staying away at friends’ houses
  – Barriers may include issues around access, attitudes and expectations, social relationships
Conclusions - Relationships

• Young people with CP have less opportunity to form intimate relationships
  – Barriers may include practical concerns, financial issues, adult attitudes
  – This has implications for a number of aspects of adolescent development
Take home messages for clinicians

• Ask about these areas of Participation when seeing adolescents with disabilities

• Explore barriers including parental and young person’s expectations

• Challenge expectations of other professionals

• More research is needed into facilitators and barriers
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