Living Arrangements, Occupation, and Use of Personal Assistance in Young Swedes with Cerebral Palsy

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BACKGROUND
- Most children living with cerebral palsy (CP) in Sweden are participating in CPUP - a nationwide multidisciplinary follow-up program and registry.
- There is a dearth of data on adults with CP after they leave the pediatric healthcare system.
- CPUP has recently started to enroll adults with CP.

OBJECTIVES
In this study, we investigated:
- type of living arrangements,
- occupation status,
- and use of personal assistance in young Swedish adults with CP.

METHODS
Study Design: Descriptive population based cross-sectional registry study.
Participants: N = 102 (63 males), median age 21 years (19-23), who were part of a pilot project to include adults with CP in CPUP Sweden. Assessments lasted 1.5 hrs and were performed by physio- and occupational therapists.

Data collection:
- Gross motor function (GMFCS levels)
- Hand function (MACS levels)
- Living arrangements ("independent living", "living with parents", "special service housing")
- Occupation status ("employed", "student", "daily activity", "unemployed")
- Use of personal assistance ("Yes", "No")

RESULTS
Living arrangements by GMFCS

- Living arrangements differed significantly among GMFCS levels (p<0.001).

Use of assistance by GMFCS

- Use of assistance correlated (p<0.001) with GMFCS (r=0.71) and MACS (r=0.70).

Occupation status by GMFCS

- Current study included a substantial proportion of individuals who functioned at a high level (GMFCS I = 37%; MACS I = 40%).
- Some young adults with CP and severe functional limitations are living independently. Many are still living with their parents.
- Many are students, quite a large number unemployed.
- It will be interesting to compare this group of young adults to young adults who do not have CP when they are a bit older.
- Adults with CP are now being recruited to participate in CPUP all over Sweden. Important to investigate whether there are regional differences in outcomes.

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