



Difficulty and Independence in Participation of Emerging Adults with Cerebral Palsy

Van Gorp M^{1,2}, Van Wely L^{1,2}, Dallmeijer AJ², De Groot V², Ketelaar M³, Roebroek M^{1,4} and the PERRIN-DECADE study group

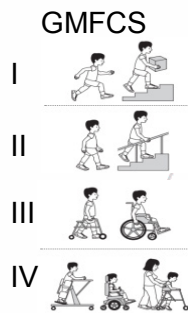
1 Erasmus MC University Medical Center, dept of Rehabilitation Medicine, Rotterdam, the Netherlands; 2 VU University Medical Center, dept of Rehabilitation Medicine, Amsterdam, the Netherlands; 3 Brain Center Rudolf Magnus and Center of Excellence for Rehabilitation Medicine, University Medical Center Utrecht and De Hoogstraat Rehabilitation, Utrecht, the Netherlands; 4 Rijndam Rehabilitation, Rotterdam, the Netherlands

Aim

To describe how difficulty and independence in participation of individuals with cerebral palsy (CP) without intellectual disability develop from adolescence into their late twenties and early thirties.

Participant characteristics

N (observations):	151 (379)
Age-range (yrs):	16-34
GMFCS: level I	71%
level II	11%
level III	7%
level IV	11%
Intellectual disability	none



Conclusions

- Many individuals with CP aged 16-34 experience difficulty in participation
- In individuals with CP, difficulty in participation increases in the mid- and late twenties

Methods

- Three biyearly measurements and 13-year follow-up
- Life Habits questionnaire, assessing difficulty and assistance in participation
- Participation domains: housing, education & employment, interpersonal relationships, recreation, community life, and responsibilities
- Domain scores (6-8 items) range 0-10:
 - Scores >8.88: no difficulty (dashed line)
 - Scores >5.55: no human assistance (dotted line)
- Multilevel linear regression analyses on domains scores by age and level of Gross Motor Function Classification System (GMFCS)

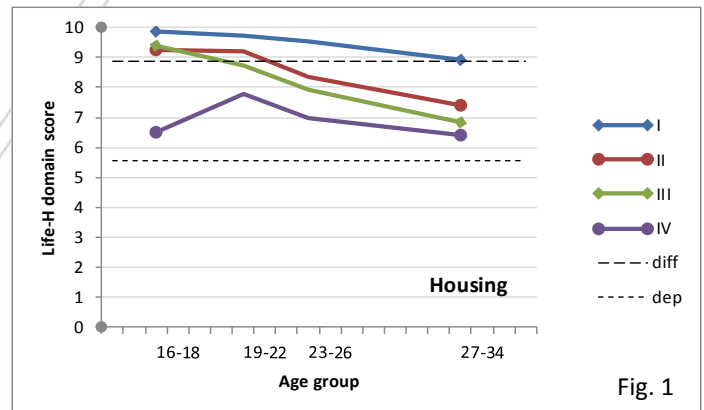


Fig. 1

Results

- On average, young adults with CP participated independently
- 41 to 95% experienced difficulty in any of the domains
- Difficulty in participation increased over age 23 in housing, education & employment, interpersonal relationships, recreation and community life
- For those in GMFCS III-IV, participation in recreation/community life increased before age 23



Fig. 2

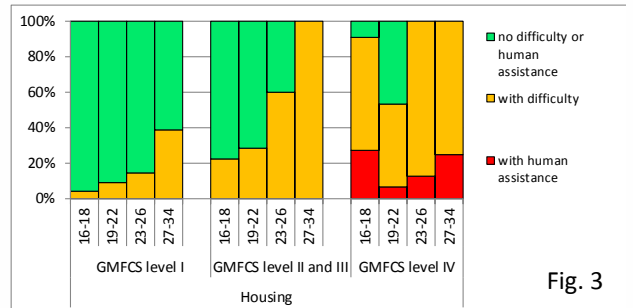


Fig. 3

Figures of exemplary housing domain: Fig. 1 Mean domain scores over ages 16-18, 19-22, 23-26 and 27-34 by GMFCS levels. Fig. 2 Pictures of items in housing domain. Fig. 3 Proportions of individuals with difficulty and human assistance

Clinical implications

- Clinicians should systematically screen for difficulties in participation and offer timely support to improve development of optimal participation

