Experienced Problems of Young Adults With Cerebral Palsy: Targets for Rehabilitation Care

Channah Nieuwenhuijsen, MSc, Mireille Donkervoort, PhD, Wilbert Nieuwstraten, MD, Henk J. Stam, MD, PhD, FRCP, Marij E. Roebroeck, PhD; and the Transition Research Group South West Netherlands

ABSTRACT. Nieuwenhuijsen C, Donkervoort M, Nieuwstraten W, Stam HJ, Roebroeck ME; and the Transition Research Group South West Netherlands. Experienced problems of young adults with cerebral palsy: targets for rehabilitation care. Arch Phys Med Rehabil 2009;90:1891-7.

Objective: To determine the problems experienced by young adults with cerebral palsy (CP) and the relationship between those problems and personal and CP-related characteristics.

Design: Cross-sectional study.

Setting: Rehabilitation centers in the southwest Netherlands. **Participants:** Young adults (N=87; aged 18-22y) with CP and normal intelligence (roughly corresponding to an intelligence quotient >70, excluding participants who attended schools for those with learning disabilities).

Interventions: Not applicable.

Main Outcome Measures: We used the Canadian Occupational Performance Measure in a semistructured interview to assess participants for experienced problems. We further categorized experienced problems according to the domains of the *International Classification of Functioning, Disability and Health* and assessed the relationship between those problems and personal and CP-related characteristics (eg, age, sex, level of gross motor functioning, manual ability, level of education) using appropriate correlation coefficients.

Results: Approximately 70% of participants experienced problems in daily life, addressing the areas of self-care (59%), productivity (52%), and leisure activities (37%). More specifically, problems were most prevalent in recreation and leisure (30%), preparing meals (29%), housework (14%), and dressing (14%). Problems in functional mobility, paid or unpaid work, and socialization were considered as most important (represented by the highest mean importance score). Mobility problems were associated with lower levels of gross motor functioning (Spearman ρ =.39), and problems with self-care were associated with lower levels of manual ability (Spearman ρ =.40).

Conclusions: Although frequently addressed during pediatric rehabilitation care, problems with mobility and self-care still prevail in young adults with CP. In addition, during the transition into adulthood, young adults with CP may experience

problems regarding domestic life and work, which they consider important.

Key Words: Activities of daily living; Cerebral palsy; Health transition; Rehabilitation.

© 2009 by the American Congress of Rehabilitation Medicine

Cring medical conditions of childhood.¹⁻³ In the Netherlands, 1.51 per 1000 inhabitants have CP, and epidemiologic data suggest that this prevalence has not decreased over time.⁴ Children with CP account for approximately 50% of pediatric rehabilitation patients in the Netherlands, and this population has received much attention in pediatric rehabilitation medicine regarding the provision of health care services.⁵ However, as they enter adulthood, attention for young adults with CP seriously declines, despite the physical, social, and emotional changes that may occur during this transition.⁶

There has been a recent increased awareness about the need for lifelong care of persons with CP. ^{7,8} It is recognized that young adults with childhood disability might encounter difficulties during their transition into adulthood that require treatment and care. ⁹⁻¹¹ The lack of coordinated services for these young adults with CP has prompted several researchers to propose a multidisciplinary approach to care. ^{6,12-15} In the United Kingdom, specialized young adult teams were designed to improve the transition from child to adult care; evaluations of these interventions show that they lead to improved participation in society for young adults with CP. ^{6,7} Young adult teams are also available in Sweden, ¹⁶ and the first Dutch young adult team started in 2007. ^{17,18}

Although the number of lifespan care initiatives is growing, we have limited systematic knowledge of specific problems encountered by young adults with CP during the transition to adulthood. In a previous study¹⁹ with young adults with CP, we demonstrated several unmet needs, primarily involving information, mobility, and health services. Although young adults with low levels of gross motor functioning reported the most unmet needs, those with higher functioning also reported several unmet needs.¹⁹ Donkervoort et al²⁰ reported that 20% to 30% of young adults with CP encountered difficulties in performing daily activities and social participation. They experienced difficulties mainly in mobility, self-care, nutrition, em-

0003-9993/09/9011-00266\$36.00/0 doi:10.1016/j.apmr.2009.06.014

List of Abbreviations

COPM	Canadian Occupational Performance Measure
CP	cerebral palsy
GMFCS	Gross Motor Functioning Classification System
ICF	International Classification of Functioning,
	Disability and Health
MACS	Manual Ability Classification System

From the Department of Rehabilitation Medicine, Erasmus Medical Centre, Rotterdam, The Netherlands (Nieuwenhuijsen, Donkervoort, Stam, Roebroeck); and Sophia Rehabilitation, The Hague, The Netherlands (Nieuwstraten).

Supported by the Kinder Fonds Adriaanstichting and Johanna Kinder Fonds (grant no. 2003/0047-063).

No commercial party having a direct financial interest in the results of the research supporting this article has or will confer a benefit on the authors or on any organization with which the authors are associated.

Reprint requests to Marij E. Roebroeck, MSc, Erasmus MC, Dept of Rehabilitation Medicine, PO Box 2040, 3000 CA Rotterdam, The Netherlands, e-mail: m.roebroeck@erasmusmc.nl.