

Title: Social Participation and Quality of life in disabled young adults.

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Named PhD candidate:

Aim: To understand the interrelationship between an individual's life with impairments and their broader social context and how this shapes their social participation and quality of life (QoL) in adulthood.

Research questions:

1. What are the specific ways that disability leads to differences in disabled young adults' social participation across key domains of employment, education, leisure, housing and romantic relationships, in comparison to non-disabled young people?
2. Which environmental and social factors have positive or negative impacts on the social participation and QoL of disabled young adults?
3. How do impairments and environments interact to shape modes of social participation and QoL?
4. How do social participation and QoL change from childhood, through the transitions of adolescence and into early adulthood in the UK?
5. To what extent can we predict the social participation and QoL of disabled young adults and its impact on transitions to adulthood in the UK and other regions of Europe?

SPARCLE Research Programme

This project links to a broader research programme across nine European regions called SPARCLE (Study of Participation of Children with Cerebral Palsy Living in Europe), which has examined the QoL and social participation of a cohort of young people with cerebral palsy (CP) over time (Colver et al. 2015; Dang et al. 2015; Michelsen et al. 2009). SPARCLE focuses on CP because it is a well-established diagnostic category, which nevertheless represents a continuum, capturing a range of impairments (e.g. cognition, movement, perception, language) and severities. Cerebral palsy is therefore a useful 'exemplar' through which to explore restrictions in body function and changes that occur as an individual matures.

Combining the new quantitative data this project will generate, with those from the previous SPARCLE UK research, enables a life-course approach to examine influences on social participation and QoL for disabled young adults. In addition, there is potential through collaboration with SPARCLE European partners to generate longitudinal and cross-sectional analysis that will enable examination of factors influencing participation and QoL from childhood to adulthood, in varied European policy and socio-economic contexts. This will ensure greater consideration of the impact of the environment on participation and QoL.

Quality of life, Health and Wellbeing

Key international policy statements acknowledge the relationship between health, QoL, disability and the environment in which a person lives (United Nations 2007; WHO 1948; WHO 1986). These policy definitions of QoL and health are useful for stressing the social and cultural factors that constitute them, providing a strong justification for examining the specificity of the relationship between them and social participation in different socio-economic and cultural contexts. What enables us to do this is the methodology detailed below and the location of the project within a broader ongoing European research programme, which has been studying young adults with CP since childhood.

Methodological Design

This project will gather new cross-sectional data which will contribute to existing and longitudinal data from a prospective cohort of disabled young adults. As in previous SPARCLE studies, we will use quantitative surveys to measure individuals' personal characteristics, family and community environments, social participation and QoL. The same surveys are being used across our European network. The data will enable the development of statistical models showing the influence of individual (e.g. impairment level, family support), community (work/education environment) and regional (European regions) level factors on social participation and QoL.

We believe it is important that our research practice is informed by dialogue with disabled young people through an advisory group. They have already fed into design of the study and will continue to advise on project management, analysis of results and dissemination of findings to ensure our interpretations are meaningful, recommendations are acceptable, and findings are publicised appropriately.

Participants

SPARCLE recruited a representative sample of children with CP born between 31/07/1991 and 01/04/1997 across Europe. This project will collect data from participants in NI who will now be aged between 22 and 28 years. This is an appropriate age range to work with, in the context of research showing that disabled transitions to adulthood are extended (Hästbacka et al. 2016) and that adult transitions generally are being more elongated (Arnett 2004). We will be recruiting participants who gave consent at the end of the previous SPARCLE projects to be contacted again about future research studies. Our aim is to recruit approximately 95 young adults with CP from NI who participated in SPARCLE studies in childhood and adolescence. For each participant with CP, we will recruit one participant without a neurodisability matched on area of residence (GP practice), sex and age.

We will collect quantitative data on social participation, QoL and personal factors using several well-recognised, validated measures. The majority of measures we will use are the same or are age appropriate versions used in SPARCLE 1&2. Using these measures will allow us to make comparisons across geographical areas and over time in the interactions among functioning, social participation and QoL. We estimate that the questionnaires will take between 90-120 minutes to complete per participant.

Independent Variables:

1. *Personal factors*: year of birth, sex, academic year in which young people attended school year 11, postcode (to be transformed into deprivation score using multiple index of deprivation), highest educational qualification, current employment status and residential status.
2. *Body function* (people with CP only): type and distribution of CP; intensity and impact of pain (using the Short Form 36 Bodily Pain scale), motor function (using Gross Motor Function Classification System (Palisano et al. 1997) and Manual Ability Classification System (Eliasson et al. 2006)): eating and drinking (using Eating and Drinking Classification System (Sellers et al. 2014): communication (using the Viking Speech Scale (Pennington et al. 2013) and Communication Function Classification System (Hidecker et al. 2011).
3. *Environment* (people with CP only): We will use an adapted version of the European Child Environment Questionnaire (Dickinson et al. 2011) to assess environmental factors that enable social participation.
4. *Stage in transition to adult role*. We will use the Rotterdam Transition Profile (Donkervoort et al. 2009) to capture participants' stage of transition in terms of participation in education and employment, finances, housing, romantic relationships, transportation, leisure (social activities) and health care: care demands, services and aids, rehabilitation services.
5. *Use of services*: The Youth Health Care-Satisfaction, Utilisation and Needs questions (Schmidt et al. 2007) will be used to capture participants' engagement with different services.

Dependent Variables:

1. *Social participation*: The Questionnaire on Young People's Participation (QYPP) (Tuffrey et al. 2013) captures frequency of participation across seven domains: home life, getting on with other people, education, work and finance, community and political life, recreation and leisure, preparing for the future.
2. *Quality of life*: We will use WHOQOL-BREF to measure general QoL.

Analysis

We will use multivariable regression models (a combination of linear, logistic and ordinal logistic, depending on the outcome variable being analysed) to examine current and longitudinal associations between people's personal characteristics, environmental factors, stage in transition, use of services and their social participation and QoL. We will use structural equation modelling to examine pathways between predictor variables and social participation and QoL, incorporating factors from across the life course that our regression models suggest may mediate the pathway.

Expected Outputs

(1) a quantitative dataset on the health, QoL and participation of young adults with and without CP; (2) set of recommendations to promote the health of disabled young adults aimed at policy makers, healthcare providers and professional bodies; (3) key publications in journals across disciplinary perspectives, examples include: Social Science and Medicine, Sociology of Health and Illness, Youth Studies, Disability and Society, Archives of Physical Medicine and Rehabilitation; Disability and Rehabilitation; (4) summaries and reports of new knowledge to stakeholders including: participants, policy makers and NGOs.