

Participation of children and youth with cerebral palsy in rural Uganda: Activity attendance and involvement compared with peers without cerebral palsy

SND-ID: 2021-331-1. **Version:** 1. **DOI:** <https://doi.org/10.5878/febd-dx96>

Associated documentation

Picture_My_Participation_2019.pdf (850.27 KB)

Variable_list_PMP-I Andrews_et_al.pdf (74.91 KB)

Citation

Andrews, C., Kakooza-Mwesige, A., & Forssberg, H. (2022) Participation of children and youth with cerebral palsy in rural Uganda: Activity attendance and involvement compared with peers without cerebral palsy (Version 1) [Data set]. Karolinska Institutet. Available at: <https://doi.org/10.5878/febd-dx96>

Creator/Principal investigator(s)

[Carin Andrews](#) - Karolinska Institutet, Department of Women's and Children's Health

[Angelina Kakooza-Mwesige](#) - Makerere University, Kampala, Uganda, Department of Pediatrics and Child Health

[Hans Forssberg](#) - Karolinska Institutet, Department of Women's and Children's Health

Research principal

[Karolinska Institutet](#) - Department of Women's and Children's Health

Description

AIM: To compare participation attendance and involvement of children and youth (C&Y) with and without cerebral palsy (CP) in a low-income area of eastern Uganda.

METHOD: Eighty-two C&Y with CP aged 6–22 years and 81 age- and sex-matched C&Y without CP participated in the study. Data on attendance and involvement in 20 home and community activities were obtained using the instrument "Picture My Participation". Non-parametric statistical methods were used to assess between-group differences. Effect size estimates were calculated.

RESULTS: Pooled attendance across all activities was significantly lower in C&Y with CP than in C&Y without CP ($P<0.001$) and for each activity item ($P=0.004$ to $P<0.001$). Effect sizes for each activity were 0.2–0.7. Between-group differences were larger for community activities than for home activities. Pooled involvement across all activities was less in the CP group ($P<0.001$) and for each activity ($P=0.014$ to $P<0.001$). Effect sizes for each activity were 0.2–0.5. C&Y at GMFCS level I–II had higher attendance ($P<0.001$) and involvement ($P=0.023$) than those at GMFCS III–V.

INTERPRETATION: Participation attendance and involvement of young people living with CP in Uganda were restricted, especially for community activities. There is a need to identify context-specific participation barriers and develop strategies to overcome them.

Eighty-two children and youth with cerebral palsy aged 6–22 years and 81 age- and sex-matched children and youth without CP participated. Motor function, self-care skills, and social functions were assessed, and caregivers were interviewed on behalf of their children using Picture My Participation (PMP). PMP measures participation in 20 home and community activities, and was developed for use

in low and middle-income countries. The instrument consists of four sections measuring attendance, involvement, importance, and facilitators/barriers:

<https://ju.se/en/research/research-groups/child/projects/picture-my-participation.html>

We used the first two sections in this study. The interviews were conducted by a social worker living in the area and familiar with the culture and language.

The dataset consists of three (3) files:

- Data_set_PMP-I_Andrews_et_al.xlsx
- Variable_list_PMP-I_Andrews_et_al.pdf
- Picture_My_Participation_2019.pdf (the survey used)

Data contains personal data

Yes

Sensitive personal data

Yes

Type of personal data

Pseudonymised health data

Code key exists

Yes

Language

[English](#)

Unit of analysis

[Individual/Patient](#)

Population

Eighty-two children and youth with cerebral palsy aged 6–22 years, and 81 age- and sex-matched children and youth without cerebral palsy.

Study design

Observational study

Description of study design

A population-based cross-sectional study of children and youth with and without cerebral palsy.

Sampling procedure

[Total universe/Complete enumeration](#)

The participants were 82 children with cerebral palsy identified in a three-stage population-based screening in 2015 of all children living in a specific geographic area in eastern Uganda, as well as 81 age and sex-matched peers without cerebral palsy living in the same area.

Time period(s) investigated

2019-05-03 – 2019-12-20

Variables

46

Number of individuals/objects

163

Response rate/participation rate

100%

All children identified with cerebral palsy were possible to follow up and were willing to participate in the study

Data format / data structure

[Numeric](#)

[Text](#)

Data collection 1

- Mode of collection: Interview
- Time period(s) for data collection: 2019-05-03 – 2019-12-20
- Data collector: Makerere University
- Instrument: Picture my Participation - PMP measures participation in 20 home and community activities, and was developed for use in low and middle-income countries. It consists of four sections measuring attendance, involvement, importance, and facilitators/barriers.
- Instrument: Gross Motor Function Classification System - The Gross Motor Function Classification System is used to classify gross motor function such as sitting, standing, crawling and walking and the need for assistive devices and assistance.
- Sample: Children and youth with cerebral palsy and their caregivers
82 children and youth with cerebral palsy were classified using Gross Motor Function Classification System and their caregivers were interviewed on behalf of their children using Picture My Participation
- Sample: Children and youth with cerebral palsy and their caregivers
Caregivers of 81 children and youth without cerebral palsy were interviewed on behalf of their children using Picture My Participation
- Sample size: 163
- Number of responses: 163
- Source of the data: Population group

Geographic spread

Geographic location: [Uganda](#), [Sub-Saharan Africa](#)

Geographic description: This study was performed in the Iganga Mayuge Health and Demographic Surveillance System, which includes more than 80,000 inhabitants in 65 villages in rural eastern Uganda.

Lowest geographic unit

Parish

Highest geographic unit

Town district

Responsible department/unit

Department of Women's and Children's Health

Funding 1

- Funding agency: Swedish Research Council

Funding 2

- Funding agency: Promobilia Foundation

Funding 3

- Funding agency: Folke Bernadotte Foundation

Funding 4

- Funding agency: Stiftelsen Sunnerdahls Handikappfond

Funding 5

- Funding agency: Sällskapet Barnavård

Funding 6

- Funding agency: Stiftelsen Frimurare Barnhuset

Ethics Review

Other - Ref. HS 1734

Higher Degrees Research and Ethics Committee of the School of Public Health, College of Health Sciences, Makerere University, and the Uganda National Council for Science and Technology

Research area

[Medical and health sciences](#) (Standard för svensk indelning av forskningsämnen 2011)

[Neurology](#) (Standard för svensk indelning av forskningsämnen 2011)

[Pediatrics](#) (Standard för svensk indelning av forskningsämnen 2011)

[Public health, global health, social medicine and epidemiology](#) (Standard för svensk indelning av forskningsämnen 2011)

Keywords

[Children](#), [Youth](#), [Cerebral palsy](#), [Uganda](#), [Disabled children](#), [Low-income country](#), [Participation](#)

Publications

Andrews, C., Kakooza-Mwesige, A., Almeida, R., Swartling Peterson, S., Wabwire-Mangen, F., Eliasson, A.-C., Forssberg, H., Peterson, S., Forssberg, H., Peterson, S., Andrews, C., Eliasson, A., Kakooza-Mwesige, A., Wabwire-Mangen, F., & Almeida, R. (2020). Impairments, functional limitations, and access to services and education for children with cerebral palsy in Uganda : a population-based study. In *Developmental Medicine & Child Neurology* (Vol. 62, Issue 4, pp. 454-462).

<https://doi.org/10.1111/dmcn.14401>

DOI: <https://doi.org/10.1111/dmcn.14401>

Kakooza-Mwesige, A., Andrews, C., Peterson, S., Wabwire Mangen, F., Eliasson, A.-C., Forssberg, H., Forssberg, H., Andrews, C., Mangen, F., Peterson, S., Kakooza-Mwesige, A., & Eliasson, A. (2017).

Prevalence of cerebral palsy in Uganda : a population-based study. In The Lancet Global Health (No. S2214-109X(17)30374-1; Vol. 5, Issue 12, pp. e1275–e1282).

[https://doi.org/10.1016/S2214-109X\(17\)30374-1](https://doi.org/10.1016/S2214-109X(17)30374-1)

DOI: [https://doi.org/10.1016/S2214-109X\(17\)30374-1](https://doi.org/10.1016/S2214-109X(17)30374-1)

Namaganda, L. H., Almeida, R., Kajungu, D., Wabwire-Mangen, F., Peterson, S., Andrews, C., Eliasson, A. C., Kakooza-Mwesige, A., Forssberg, H., Namaganda, L. H., Forssberg, H., Eliasson, A., Namaganda, L., Wabwire-Mangen, F., Almeida, R., Kajungu, D., Kakooza-Mwesige, A., Andrews, C., & Peterson, S. (2020). Excessive premature mortality among children with cerebral palsy in rural Uganda : A longitudinal, population-based study. In PLOS ONE (No. e0243948; Vol. 15, Issue 12).

<https://doi.org/10.1371/journal.pone.0243948>

DOI: <https://doi.org/10.1371/journal.pone.0243948>

Andrews, C., Namaganda, L., Eliasson, A., Kakooza-Mwesige, A., & Forssberg, H. (2021). Functional development in children with cerebral palsy in Uganda: population-based longitudinal cohort study. In Developmental medicine and child neurology. <https://doi.org/10.1111/dmcn.14996>

DOI: <https://doi.org/10.1111/dmcn.14996>

SwePub: <oai:prod.swepub.kib.ki.se:147233668>

Andrews C, Namaganda LH, Imms C, Eliasson A-C, Asige E, Wanjala G, et al. Participation of children and young people with cerebral palsy in activities of daily living in rural Uganda. Dev Med Child Neurol. 2022;00:1–11. <https://doi.org/10.1111/dmcn.15323>

DOI: <https://doi.org/10.1111/dmcn.15323>

If you have published anything based on these data, [please notify us](#) with a reference to your publication(s). If you are responsible for the catalogue entry, you can update the metadata/data description in DORIS.

Accessibility level

Access to data through SND

Access to data is restricted

Use of data

[Things to consider when using data shared through SND](#)

Versions

Version 1. 2022-06-29

Contact for questions about the data

Carin Andrews

carin.andrews@ki.se

Related research data in SND's catalogue

[Excessive premature mortality among children with cerebral palsy in rural Uganda: a longitudinal, population-based study](#)

[Functional development in children and youth with cerebral palsy in Uganda](#)

Download metadata

[DataCite](#)

[DDI 2.5](#)

[DDI 3.3](#)

[DCAT-AP-SE 2.0](#)

[JSON-LD](#)

[PDF](#)

[Citation \(CLS\)](#)

Published: 2022-06-29