

Patterns of participation within domestic life and peer relations - Youths own experiences

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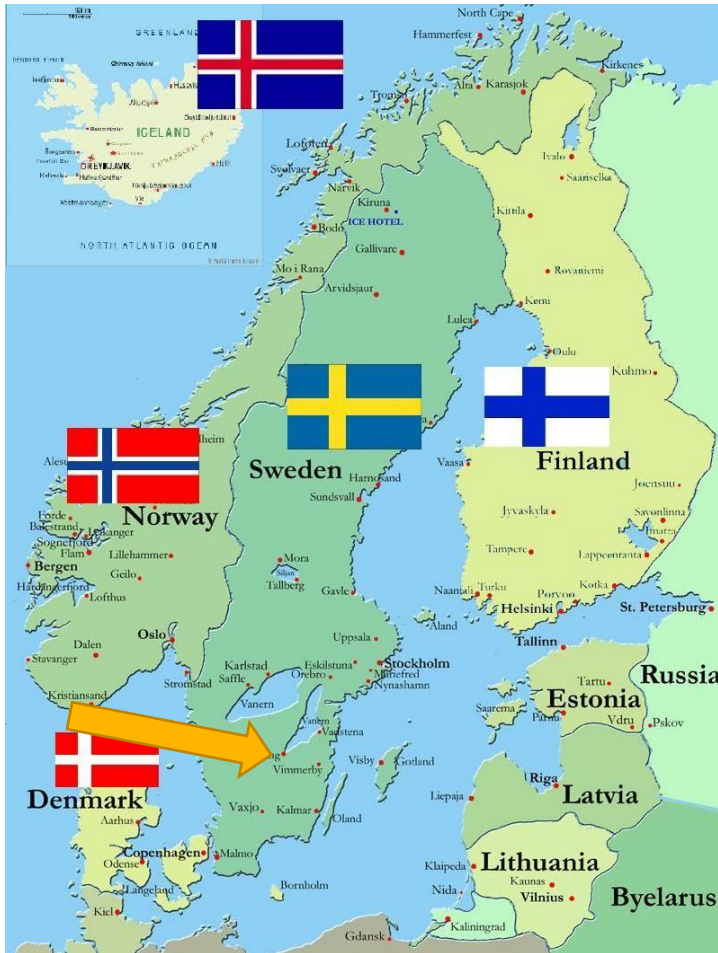
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LoRDIA -Longitudinal Research on Development in
Adolescence



Sweden



Population: Approx. 10 million

Coastal islands-inland lakes, forests

Democracy

Tax: 30-35 % (School, health care, police services and transportation etc.)

Free public hospitals

Parental insurance

School is mandatory for all children

Syllabus for children with intellectual disabilities

Presentation Outline

Rationale

Aim

The research program LoRDIA

Methodological implications including youths with intellectual disabilities

Methods

Key Findings

Conclusion

Implications

Rationale

- Participation in domestic life activities and peer relations is vital for children and youths opportunities to learn skills and acquire meaningful relationships with others (WHO,2007).
- Adolescents with impairments and – or long-term health conditions are often excluded in longitudinal research due to methodological reasons (Alderson & Morrow, 2011)
- Self-ratings of participation are needed to capture the subjective dimension of the participation concept (Arvidsson, 2013).
- Self-ratings from adolescents corresponds to the UN Convention on the Rights of the Child (UNICEF,1989)

Aim

To identify how individual factors (related to body function and activity performance) and factors within the family environment relates to self-reported participation cluster profiles in domestic life and peer relations) as defined by the International Classification of Functioning, Disability and Health, Children and Youth version (ICF-CY).

Longitudinal Research on Development in Adolescence (LoRDIA)

www.lordia.se



Prospective longitudinal study design

Paper-based Questionnaires

Total population

- 2108 adolescents age 12-13 at base line (1st wave)
- 4 municipalities
- Response rate 89 %

Data collection

- compulsory schools
- compulsory schools for students with intellectual disabilities

Ethical approval for the LoRDIA research program, including consent and data collection procedure was approved by the Regional Research Review Board in Gothenburg, Sweden (No. 362-13; 2013-09-25).



Content of the questionnaire to adolescents

Part I

- Identity of the person
- Socio-demographic data and family structure
- Perceptions of family economy
- Perceptions of self-body and puberty
- Free time activities
- Peer network and quality of peer relations

Part II

- Family relations and parenting models
- Sibling relations
- School behaviors and relations to teachers
- Everyday functioning and experience of long-term health condition and disability

Part III

- Experiences of harassments
- Personality and self-perception
- Use of tobacco, alcohol and drugs,
- Criminal behavior
- Family coherence and support

374 items

25 scales



Practical and ethical concerns

Adapting questionnaire (content)

- Less abstract language
- Reduced number of response options

Adapting the data collection procedure

- Interview when needed
- Questions of sensitive nature
- Confidentiality in answers

Development of manual

- To ensure that data was collected in the same way as far as possible
(128 classes in 33 schools)

Design and data analysis

A bio-psycho-social approach to human functioning and health

Cross-sectional design

International Classification of Functioning, Disability and Health, Children and Youth Version (ICF-CY)

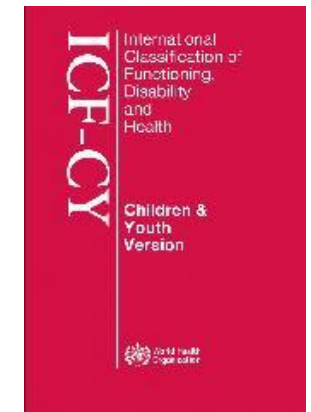
- Model and classification

Participation

- Frequency of attendance and perceived importance
- Participation in adolescence

Person-oriented approach: Cluster analysis

Variable-oriented approach: Anova



Cluster analysis

Dependent variables defining
the cluster analysis



**Frequency of
attendance
Domestic life and
peer relations**

**Perceived
importance,
domestic life and
peer relations**



**Nine clusters
were identified**

Cluster analysis

Dependent variables defining the cluster analysis

Frequency of attendance
Domestic life and peer relations

Perceived importance, domestic life and peer relations

Nine clusters were identified

Anova

Independent variables

Body functions

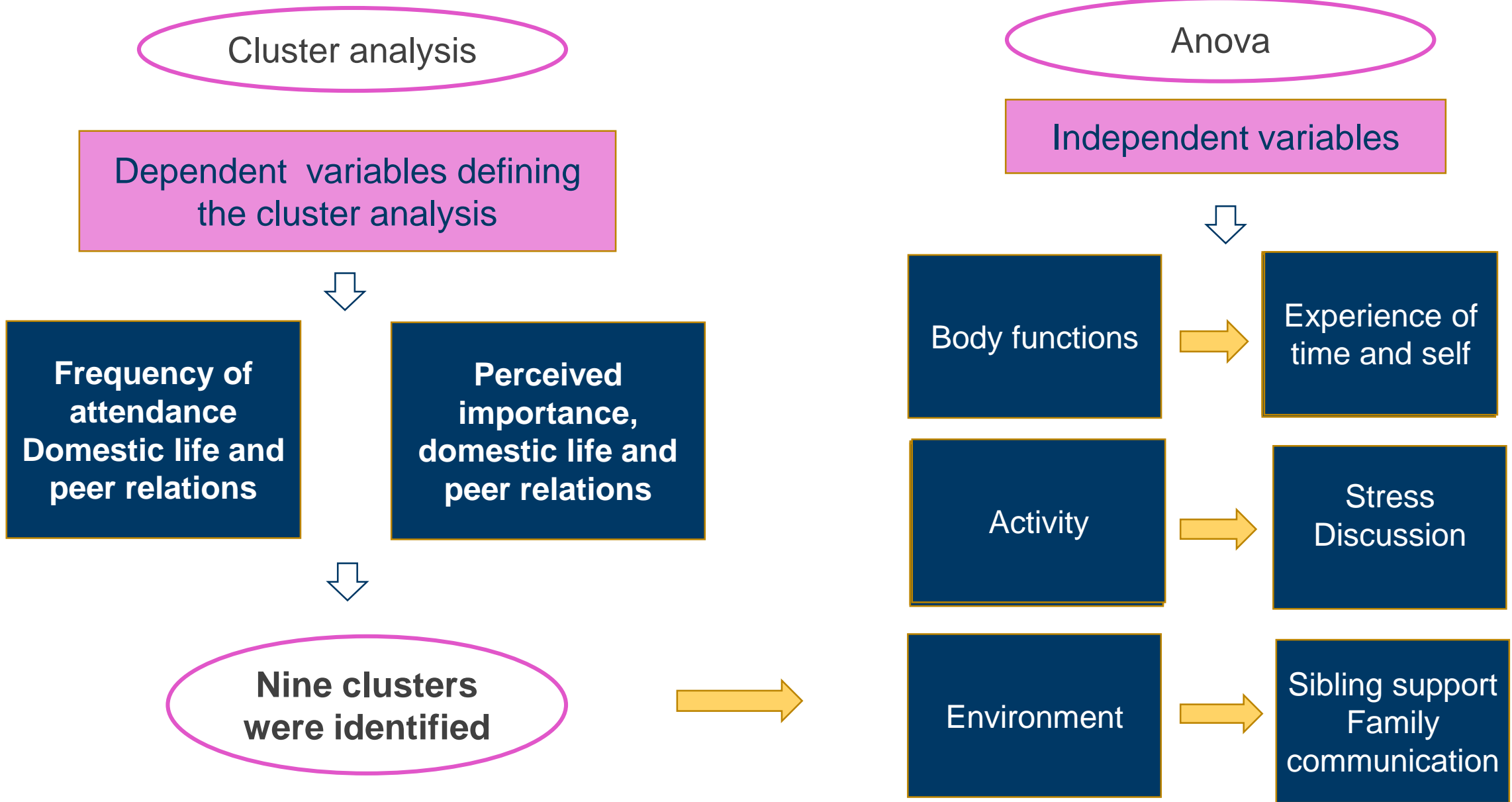
Experience of time and self

Activity

Stress Discussion

Environment

Sibling support
Family communication



Results

**Nine clusters
were identified**

- Adolescents with impairments and long-term health conditions were represented in all clusters
- Perceived importance ratings were higher for peer relations than for domestic life
- Frequency of dialogue participation and family environment affected the participation profiles more than factors related to body functions
- Handling stress and psychological demands did not have any significant effects on any of the cluster profiles/groups

Conclusions

Type of impairment or long-term health condition does not predict cluster membership in relation to participation in domestic life and peer relations.

Attendance and importance of peer relations were related to high ratings of discussion, sibling support and family atmosphere

Taking part in dialogue/discussions and the perceived atmosphere in the family seems to affect the self-reported participation profile.




Implications

Interventions aiming at enhancing participation should not only focus on the health problem or impairment.

Family and peer influence on participation for adolescents with and without disabilities need to be considered.

Both the frequency of attendance and the perceived importance (i.e. the involvement dimension) should be included in measuring participation.

Including children with intellectual disabilities in longitudinal  studies is possible!

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