

Delaktighet för personer med cerebral pares ur ett livscykelperspektiv

CPUP dagarna 7.10.2025

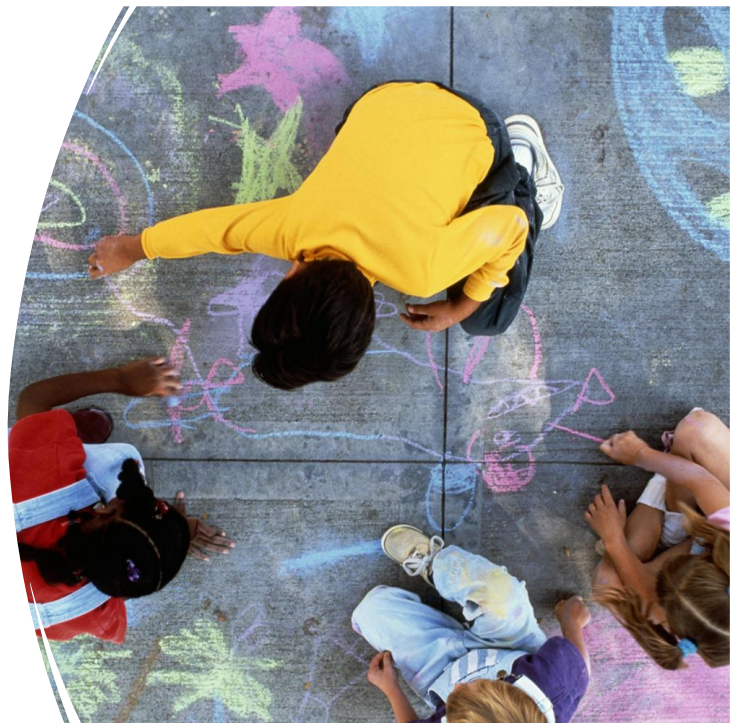
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Innehåll

- Delaktighet, inledning med teoretiska utgångspunkter
- Exempel på delaktighet i habiliteringen

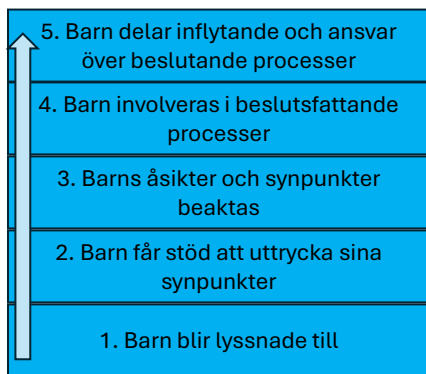


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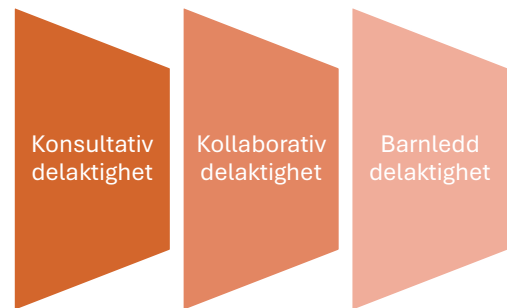
Varför delaktighet?

- De mänskliga rättigheterna (FN 1948)
- FN konventionen om barnets rättigheter (FN 1989)
- FN konvention om rättigheter för personer med funktionsnedsättning (2006)
- Agenda 2030 – globala målen för hållbar utveckling (FN 2015)
- Internationell klassifikation av funktionstillstånd, funktionshinder och hälsa, ICF (WHO 2001)

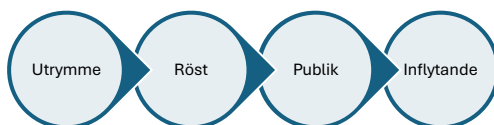
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Shier, 2001



Lansdown, 2009



Lundy, 2007



WHO, ICF, 2001

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The Family of Participation-related Construct Imms mfl. 2017

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY

REVIEW

Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability

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ABBREVIATIONS

IPRC Family of Participation-Related Constructs
ICF-CY International Classification of Functioning, Disability and Health for Children and Youth

This review outlines a conceptual approach to inform research and practice aimed at supporting children whose lives are complicated by impairment and/or chronic medical conditions, and their families. 'Participation' in meaningful life activities should be an essential intervention goal, to meet the challenges of healthy growth and development, and to provide opportunities to help ensure that young people with impairments reach their full potential across their lifespan. Intervention activities and research can focus on participation as either an independent or dependent variable. The proposed framework and associated hypotheses are applicable to children and young people with a wide variety of conditions, and to their families. In taking a fresh 'non-categorical' perspective to health for children and young people, asking new questions, and exploring issues in innovative ways, we expect to learn lessons and to develop creative solutions that will ultimately benefit children with a wide variety of impairments and challenges, and their families, everywhere.



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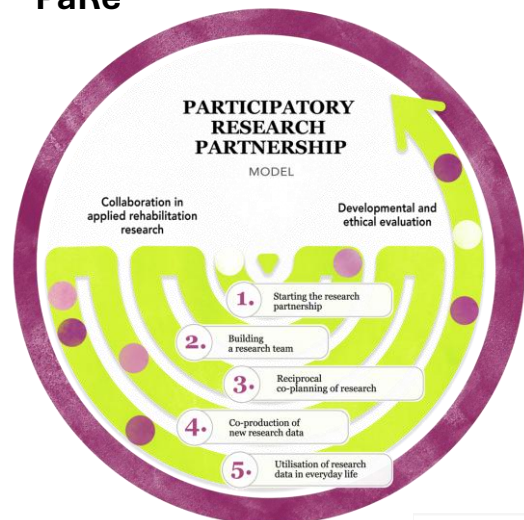


LOOK projektet (2014-2017) – Barnets rätt att
vara delaktig i sin habilitering



CMAP Book (barnets meningsfulla aktiviteter
och delaktighet (Sipari mfl. 2017; Vänskä mfl. 2022)

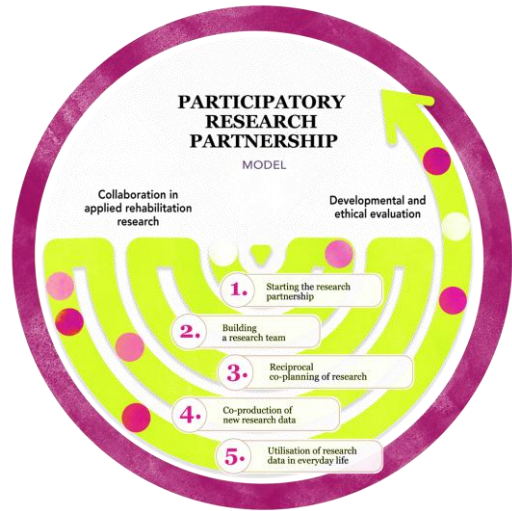
PaRe



Sipari mfl 2022

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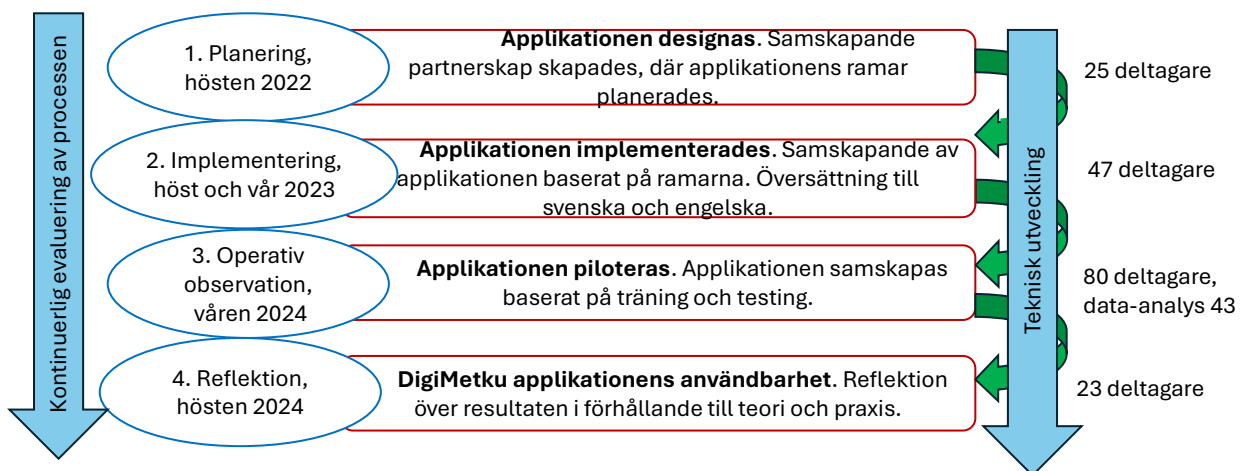
Syftet med detta projekt var att utveckla en digital applikation för att främja habilitering i vardagen för barn och ungdomar.



Sipari mfl 2022

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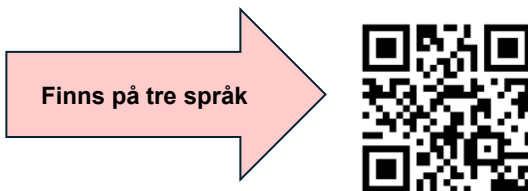
Den samskapande processen



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DigiMetku

<https://digimetku.fi>
<https://digimetku.fi/en>
<https://digimetku.fi/sv>



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Unga vuxnas perspektiv på övergången från barn- till vuxenhabiliteringen

Syftet: att utreda unga vuxnas perspektiv på övergången från barn- till vuxenhabiliteringen, hur de varit delaktiga i planeringen av övergången och hur de upplever planering av habilitering inom vuxenhabiliteringen.

- Fenomenografisk approach med individuell intervju som data-insamlingsmetod
- 14 unga vuxna gav sitt samtycke till intervju
- Medelålder 23,1 (19-26 år)
- GMFCS I-V
- Data-analys enligt Sjöström och Dahlgren (2002)




Article

The Perspectives of Young Adults with Cerebral Palsy on Transition to Adult's Health Care and Rehabilitation

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Abstract: The purpose of this study was to describe the perspectives of young adults with cerebral palsy on participating in the transition process when transitioning from children's health care to adults' health care and rehabilitation. A phenomenographic approach with data collected with semi-structured interviews was used. Fourteen young adults aged 19–26 with cerebral palsy participated. The analysis resulted in four categories: (1) need for comprehensive and participatory rehabilitation; (2) barriers in the rehabilitation system; (3) self-awareness, courage and activity are rewarded; and (4) a dream of an active role in society. To conclude, the young adults had both positive and negative experiences of the

<https://doi.org/10.3390/disabilities5010012>

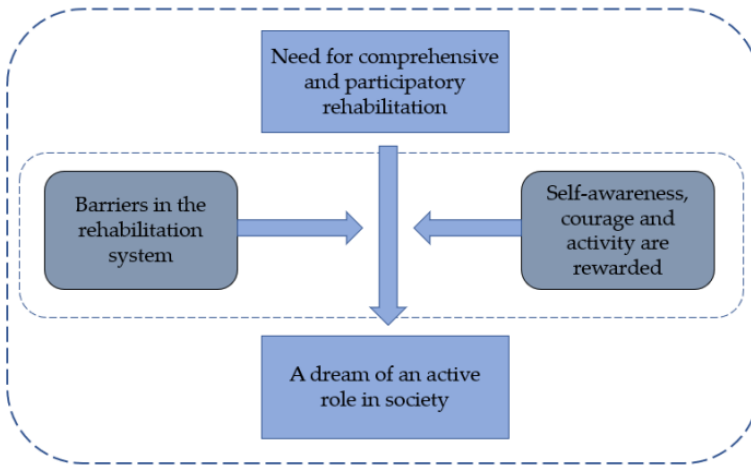
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The Participant's GMFCS * Level	Age	Housing	Study or Job Status
I	19	Living with parents	Studying at a university of applied sciences
V	19	Living with parents	Unemployed
V	19	Supported living	Basic education, no plans for future education or job
III	21	Living with parents	Had applied for studies at upper secondary school
I	22	Living with parents	Studying at university
III	23	Independent living, assistant	Unemployed
III	24	Independent living, assistant	Unemployed
I	24	Independent living	Paid job with employment support from Government Employment Service
III	25	Supported living	Vocational special education, no plans for job
V	25	Independent living, assistant	General upper secondary education, plan to apply for further studies
V	25	Living with parents, assistant	Unemployed
I	26	Supported living	Supported work once a week Mild intellectual disability
IV	26	Living with parents	Unemployed
IV	26	Independent living, assistant	Unemployed

* Gross Motor Function Classification Scale Expanded and Revised [23], assessed by the interviewer (an experienced physiotherapist).

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Resultat



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Konklusion

Inleda övergångsprocessen tidigt, med stark medverkan av ungdom och familj

Jämlik delaktighet i planering på vuxenhabiliteringen – jämför attendance och involvement

Tillräcklig tid för planering - interprofessionellt

Brett helhetsperspektiv -- Samarbete över sektorgränserna

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Sammanfattningsvis

- Rätten till delaktighet
- Förståelse för relationen mellan närvaro (attendance) och engagemang (involvement)
- Bedömningsinstrument huvudsakligen inom närvaro – hur bedöma engagemang?
- Att stöda intervention som fokuserar på attention (närvaro), ökar inte nödvändigtvis involvement (engagemang/involvering)
- Tänka helhetsmässigt och med framförhållning med tanke på vuxenålder – beakta kontext och omgivning

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Övriga källor (utan QR kod)

- Jeglinsky-Kankainen, I., Vänskä, N., Kinnunen, A., Sätälä, H., & Sipari, S. (2025). The Perspectives of Young Adults with Cerebral Palsy on Transition to Adult's Health Care and Rehabilitation. *Disabilities*, 5(1), 12. <https://doi.org/10.3390/disabilities5010012>
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