

# Fysisk aktivitet hos personer med cerebral parese – muligheder for forbedring af funktionsniveau hos unge

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# Bruger videnskab til at hjælpe børn og unge med tidlig hjerneskode



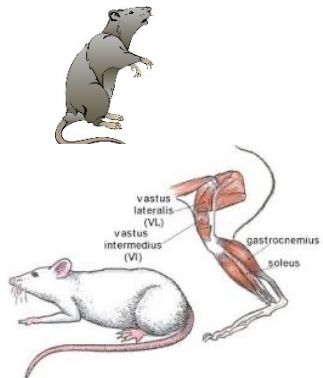
Basic science

Translational science

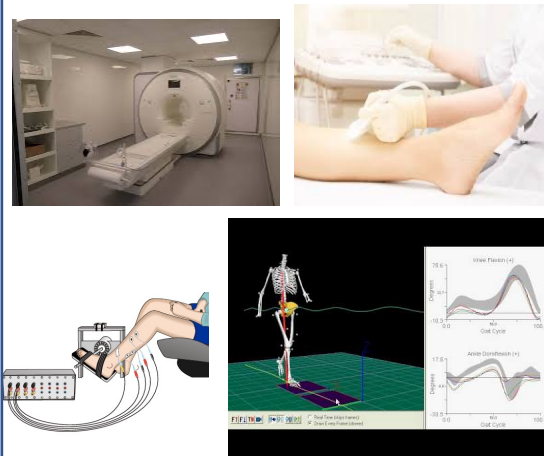
Clinically applied science



## Animal models



## Human models



## Developing new technologies for diagnosis and intervention



## RCT studies



# Transitionsklinik for børn og unge med cerebral parese på Rigshospitalet I København

Center for cerebral palsy



- 1) Opspore reduktion af funktionsniveau
- 2) Initiere og koordinere intervention

Interventioner I de unges egne hjem

Interventioner I kommunerne

Hospitalstilbud til voksne med CP

Børneafdelinger

CPOP

Praktiserende læger

Age 15-20 Years



- Konsultation
- Yderligere undersøgelser
- Interventions plan
- Etablering af netværk for unge
- Opfølgning

# Cerebral parese

- ca. 110 nye tilfælde pr år i Danmark (2/1000 levende fødte)

GMFCS I-III 70%



Larsen ML, Rackauskaite G, Greisen G, Laursen B, Uldall P, Krebs L, Hoei-Hansen CE. Continuing decline in the prevalence of cerebral palsy in Denmark for birth years 2008-2013. Eur J Paediatr Neurol. 2020 Oct 17

GMFCS IV-V 30%



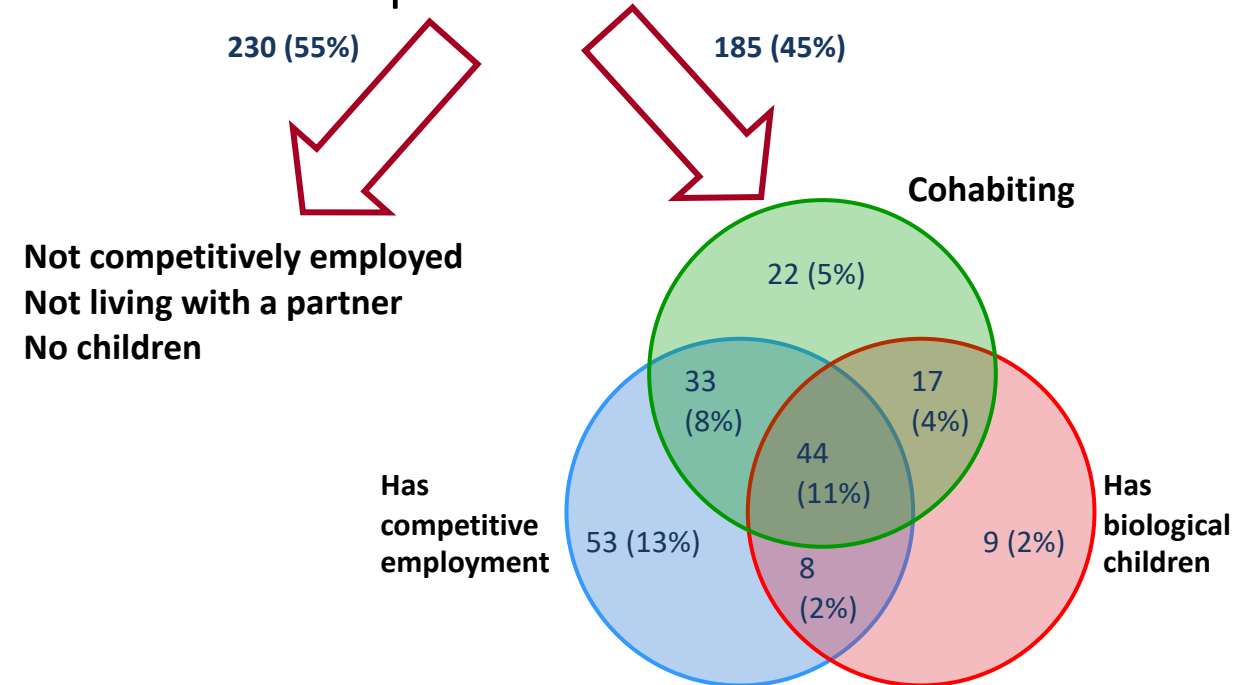
Hollung SJ, Hägglund G, Gaston MS, Seid AK, Lydersen S, Alriksson-Schmidt AI, Andersen GL. Point prevalence and motor function of children and adolescents with cerebral palsy in Scandinavia and Scotland: a CP-North study. Dev Med Child Neurol. 2021 Jun;63(6)

# Voksne med CP integreres ikke tilstrækkeligt I samfundet



## Social integration of adults with CP

Cohorte: 416 persons with CP born 1965 – 70

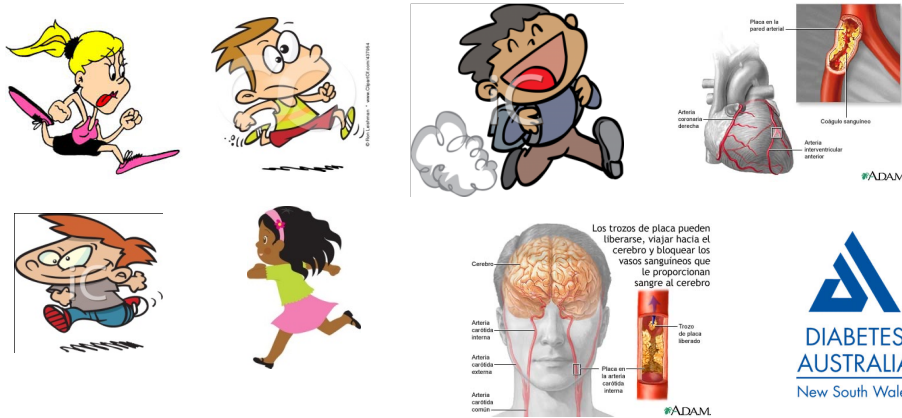


# Børn og unge med CP er mindre fysisk aktive

Children and young adults with CP (GMFCS I-II) are roughly only half as physically active as non-disabled peers.

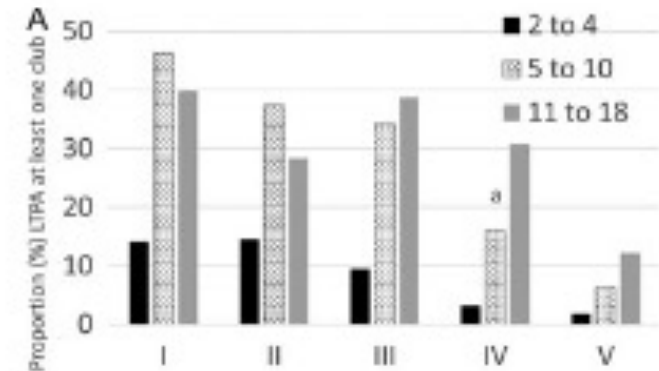
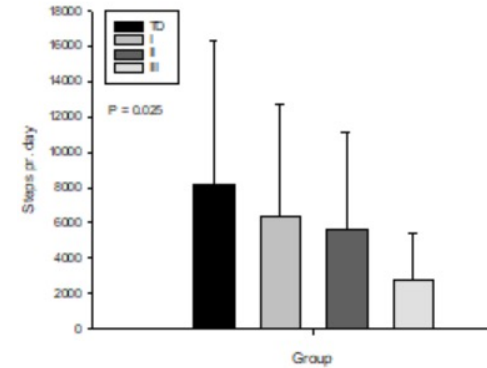


Review in progress



Nieuwenhuijsen et al.  
Inactive lifestyle in adults with bilateral spastic cerebral palsy. J Rehabil Med. 2009 Apr;41(5):375-81.

Damiano DL. Activity, activity, activity: rethinking our physical therapy approach to cerebral palsy. Phys Ther. 2006 Nov;86(11):1534-40.



van der Linden ML, Wordie SJ, Dufton BK, Jagadamma KC, Hunter C, Mercer TH, Gaston MS, Robb JE. Leisure Time Physical Activity in Children and Young People With Cerebral Palsy: A Population-Based Study. Pediatr Phys Ther. 2022 Apr 1;34(2):230-237.

# Reduktion af gangfunktion



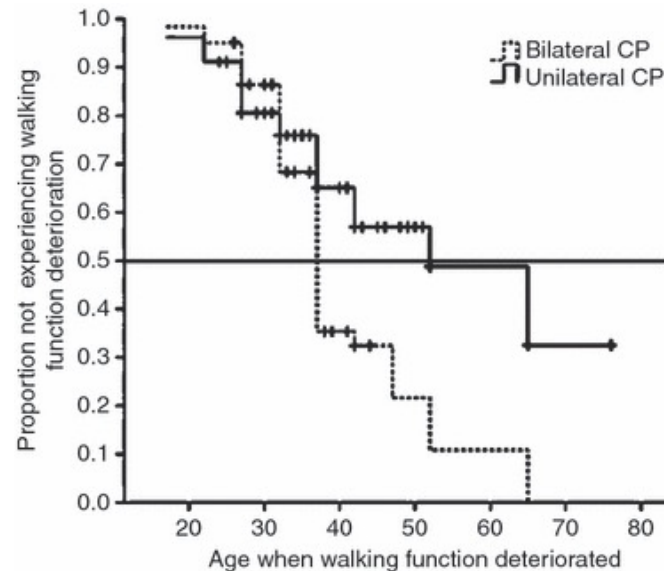
- Survey of 149 adults with CP 24-76 Years



- Survey of 221 adults with CP 20 -58 Years

52% reduced walking after onset

- Fatigue, pain and reduced balance



Opheim A, et al. Walking function, pain, and fatigue in adults with cerebral palsy: a 7-year follow-up study. Dev Med Child Neurol. 2009

35% decreased walking ability

9% stopped walking

- contractures (80%)

- daily pain (18%)

Stopped walking ( $n=20$ )

<14 years	10
15-24 year	5
25-34 year	3
35-44 year	0
>45 years	1
No answer	1
Total	20

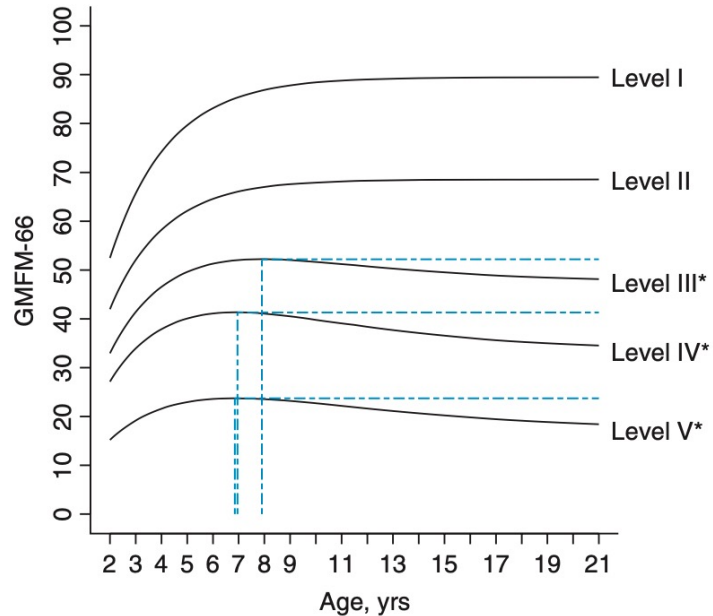
Age walking ability had decreased ( $n=49$ )

<14 years	2
15-24 years	12
25-34 years	17
35-44 years	13
>45 years	2
No answer	3
Total	49

Andersson C, Mattsson E. Adults with cerebral palsy: a survey describing problems, needs, and resources, with special emphasis on locomotion. Dev Med Child Neurol. 2001

# Reduktion I 'gross motor function'

657 children with CP (16 month – 21 Years)  
measured 3455 times with GMFM



Hanna SE et al.. Stability and decline in gross motor function among children and youth with cerebral palsy aged 2 to 21 years. Dev Med Child Neurol. 2009

Special period of opportunity?





# Hvad er problemet set fra 'brugernes' perspektiv?

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY

SYSTEMATIC REVIEW

## Health service use among adults with cerebral palsy: a mixed-methods systematic review

MANJULA MANIKANDAN<sup>1</sup>  | CLAIRE KERR<sup>2</sup>  | GRACE LAVELLE<sup>3</sup> | MICHAEL WALSH<sup>4</sup> | AISLING WALSH<sup>1,\*</sup> | JENNIFER M RYAN<sup>1,5,\*</sup> 

- Loss of trusted relationships – feeling of abandonment
- Not prepared for transition
- Challenges in finding appropriate/experienced service providers
- Lack of coordination between service providers
- Brief consultation



## Behovsundersøgelse

Overgangen fra barn til voksenliv

Hvor skal vi gå hen – hvordan får vi adgang til eksperterne?

Træthed



# Position statement: A call for action

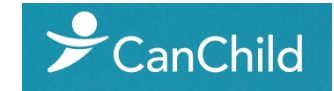


**Table 1. Four core components of successful transition**

Approach to each component should be youth-centred, strengths-based, and developmentally appropriate.	
1. Start transition planning early	Regularly assess transition readiness with both patient and caregivers. Ensure that adequate time is dedicated to coordinating successful transition. Understand each youth's potential and goals for activity, education, recreation, and vocation.
2. Create an individualized transition plan	Identify a transition 'champion'. Involve key multidisciplinary clinicians whenever possible, as well as primary care. Solicit input on care needs from youth and parents. Address gaps in youth preparedness, autonomy, and confidence.
3. Provide support before transition	Provide education and peer support for youth and caregivers. Support youth with a stepwise approach to increasing independence in care management. Create a comprehensive health transfer summary based on youth and caregiver priorities. Provide summary to youth and clinicians.
4. Ensure ongoing support after transition to adult care	Ensure youth attend appointments. Assess each youth's attachment to adult services. Continue to involve caregivers as per a youth's wishes, with gradual weaning over time. Measure outcomes routinely.



Jan Willem Gorter



A call for action: Recommendations to improve transition to adult care for youth with complex health care needs  
Alene Toulany, Jan Willem Gorter, Megan E. Harrison;  
Canadian Paediatric Society, [Adolescent Health Committee](#)  
April 2022

# Hvordan får vi tilpas meget fysisk aktivitet i personer med CPs liv?

Vi tilbyder kun 10 % af den træning som i dyrestudier har vist sig at være effektiv

10.000 timers reglen



600 'movements'  
Hver dag i 12 måneder.



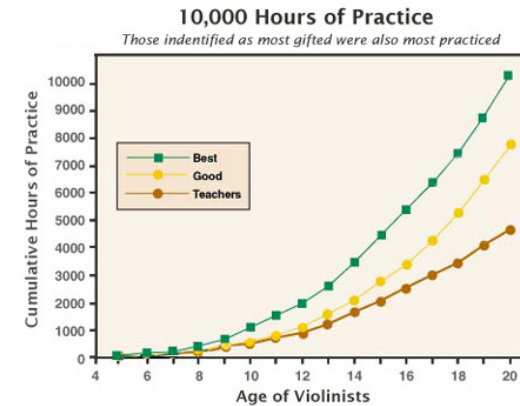
2000 skridt hver dag i 3-4 måneder.



30 'movements'  
per session 1-2 gange om ugen

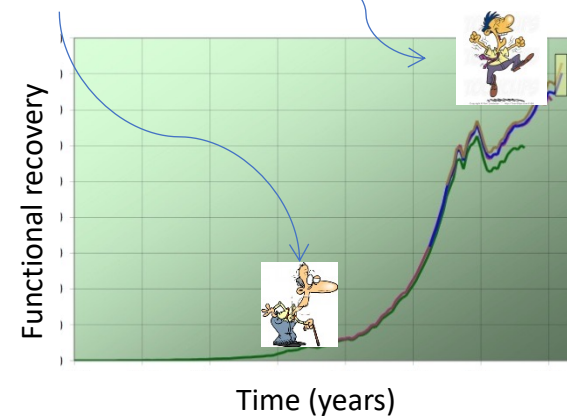


300 skridt 2-3 gange hver uge i 3-4 måneder.



Vi er her

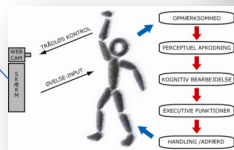
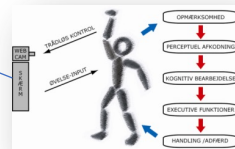
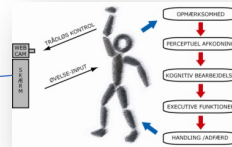
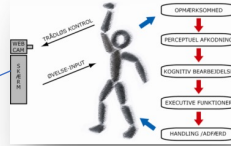
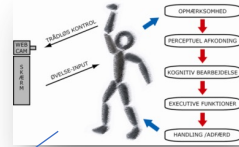
Måske kunne vi være her



Lang et al. (2009)  
Arch Phys Med Rehabil. 90(10):1692-8.

# Mulighed for stor mængde træning af mange personer

Din 'personlige' virtuelle coach



	Total duration	Physical activity
All (N=17)	02:32:42	01:45:32
CP (N=11)	02:33:38	01:45:27
TD (N=6)	02:31:00	01:45:40

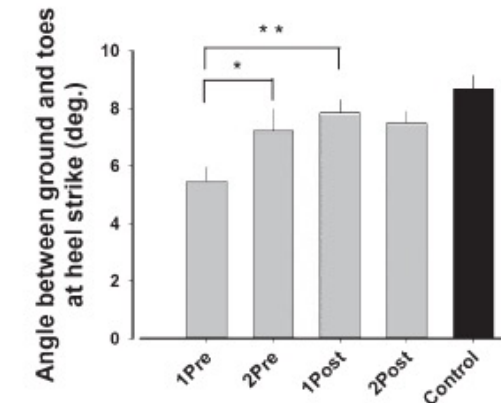


Schram Christensen et al. BMC Neurology (2017)

> NeuroRehabilitation. 2014;35(4):643-55. doi: 10.3233/NRE-141180.

## Gait training reduces ankle joint stiffness and facilitates heel strike in children with Cerebral Palsy

Maria Willerslev-Olsen <sup>1</sup>, Jakob Lorentzen <sup>1</sup>, Jens Bo Nielsen <sup>2</sup>



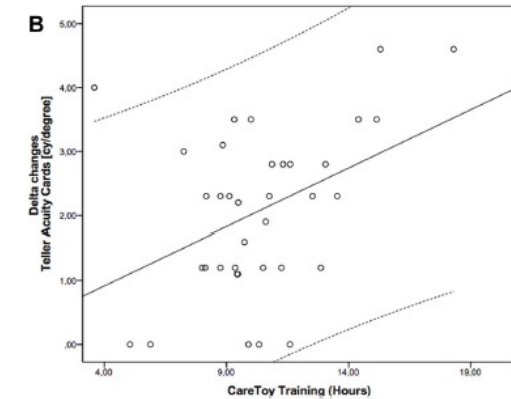
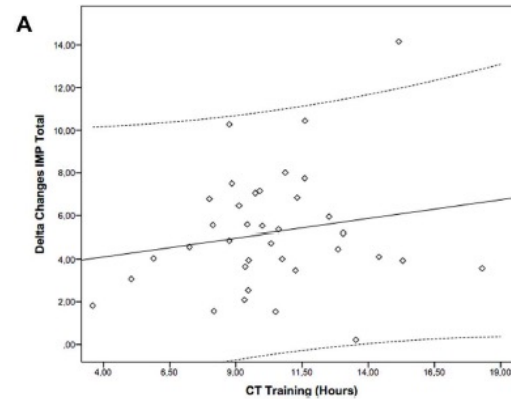
# Træning af babyer (Caretoy)



Table 3  
CareToy training in the 14 infants of the experimental group.

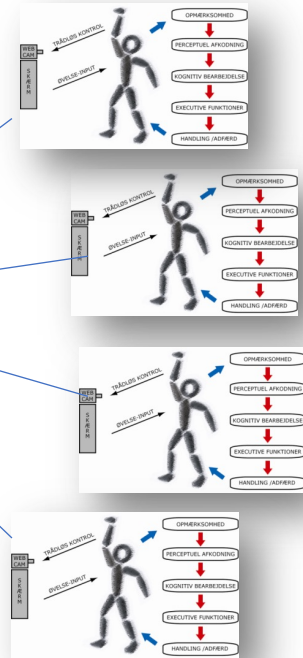
Subject	Corrected age at the beginning (months)	Mean daily planned training (minutes)	Mean daily executed training (minutes)	Training days	Total executed training (hours)
#1	3.60	16	13	17	4
#2	3.60	15	13	17	4
#3	3.00	31	8	8	2
#4	3.00	31	7	8	2
#5	4.30	19	18	28	9
#6	6.60	20	19	21	7
#7	5.53	27	21	13	5
#8	5.20	28	15	21	5
#9	4.47	29	20	23	8
#10	3.13	31	26	28	12
#11	4.37	28	26	28	12
#12	4.97	28	27	28	13
#13	3.10	31	28	28	13
#14	4.23	33	28	28	13

Sgandurra et al 2016  
Res Dev Disabil

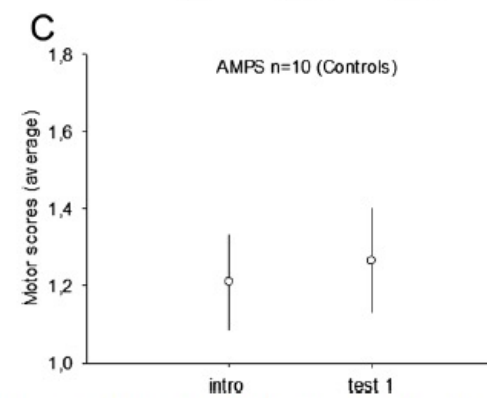
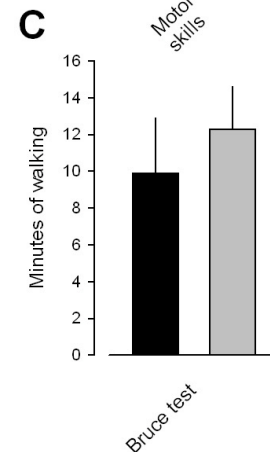
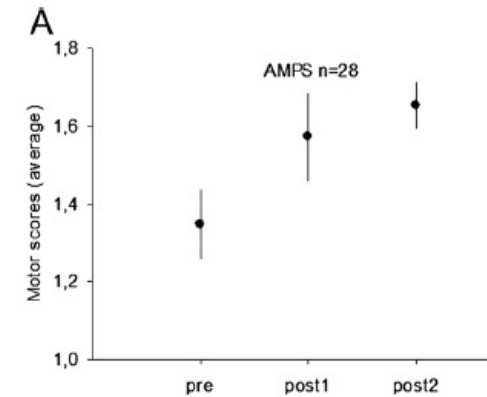
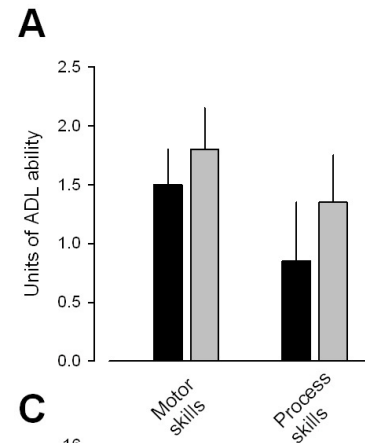


Sgandurra et al. 2017  
PloS ONE

# Træning af børn (Mitii)



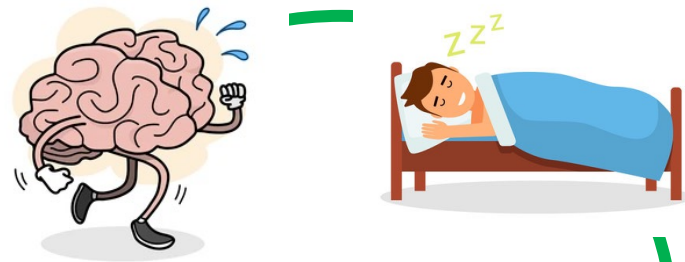
- 83 % of 45 children trained at least 30 mins every day in 20 weeks
- Average training time: 74 hours (3.7 hours/week)



Bilde et al. BMC Neurol. 2011

Lorentzen et al 2015. BMC Neurology

# Positiv påvirkning af personer med behov for neurorehabilitering



shutterstock.com · 460336855



## Neuroplasticity at home: Improving home-based motor learning technological solutions. A review

Christian Riis Forman\*, Jens Bo Nielsen and Jakob Lorentzen\*  
Mini Review, *Front. Rehabil. Sci. – Interventions for Rehabilitation*

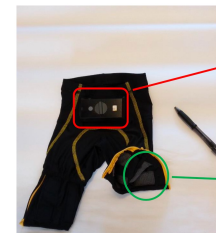


DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY

ORIGINAL ARTICLE

## Wearable electromyography recordings during daily life activities in children with cerebral palsy

JOSEPHINE S MICHELSEN<sup>1</sup> | MAI C LUND<sup>1,2</sup> | TINE ALKJÆR<sup>3</sup> | TAIJA FINNI<sup>4</sup> | JENS B NIELSEN<sup>1,2</sup> | JAKOB LORENTZEN<sup>1,2</sup>



Recording unit

EMG sensors

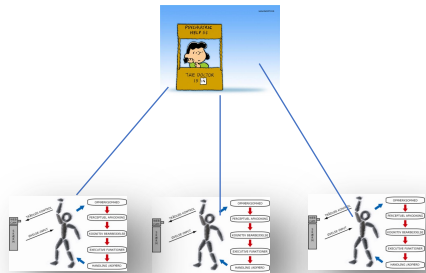
McPhee PG, Verschuren O, Peterson MD, Tang A, Gorter JW. *Ann Rehabil Med.* 2020 Aug;44(4):301-310.

# Positiv påvirkning af unge med behov for neurorehabilitering

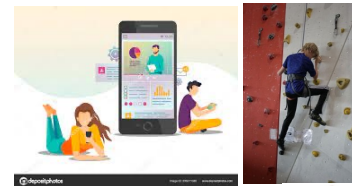
Identificer behov baseret på  
personlige præferencer



Feedback



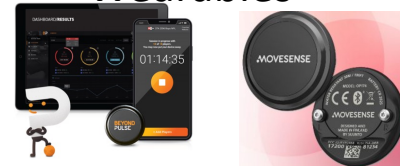
Planlæg hjemme-baseret  
intervention



Monitor intervention



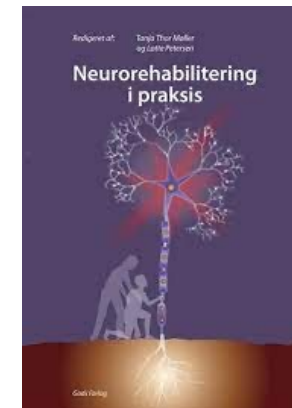
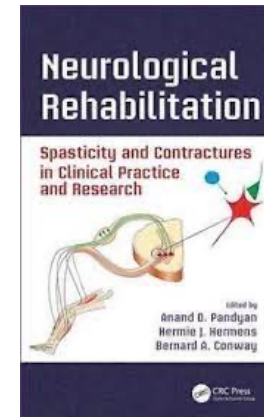
Wearables





# Neuroplasticitetsbaseret neurorehabilitation I hjemmet

- Continuous training (it takes 10.000 hours to be as good as possible)
- Motivation: Training should be challenging and if possible fun (but not all agree on what is challenging etc., so individualize)
- Attention and active participation.
- Experience of succes – i.e. Simple, (preferably) immediate and understandable reward!
- Consider possible interference effects
- Eat well.
- Sleep well



Journal of Motor Behavior, Vol. 47, No. 1, 2015  
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## REVIEW ARTICLE

### Science-Based Neurorehabilitation: Recommendations for Neurorehabilitation From Basic Science

Jens Bo Nielsen<sup>1</sup>, Maria Willerslev-Olsen<sup>1</sup>, Lasse Christiansen<sup>1</sup>, Jesper Lundbye-Jensen<sup>1</sup>, Jakob Lorentzen<sup>2</sup>



# Tak til alle mine gode kollegaer og samarbejdspartnere

## CP research group



## Staff and students

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- Monica Gorassini, **University of Alberta, Canada**
- Sampsa Vanhatalo, **University of Helsinki, Finland**
- Lee Barber, **University of Queensland, Australia**
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