Velkommen til
CP-KONFERANSEN
21–22 MARS 2024

Cheated of feature by dissembling nature
Deformed, unfinish'd, sent before my time
Into this breathing world, scarce half made up
And that so lamely and unfashionable
That dogs bark at me as I halt by them

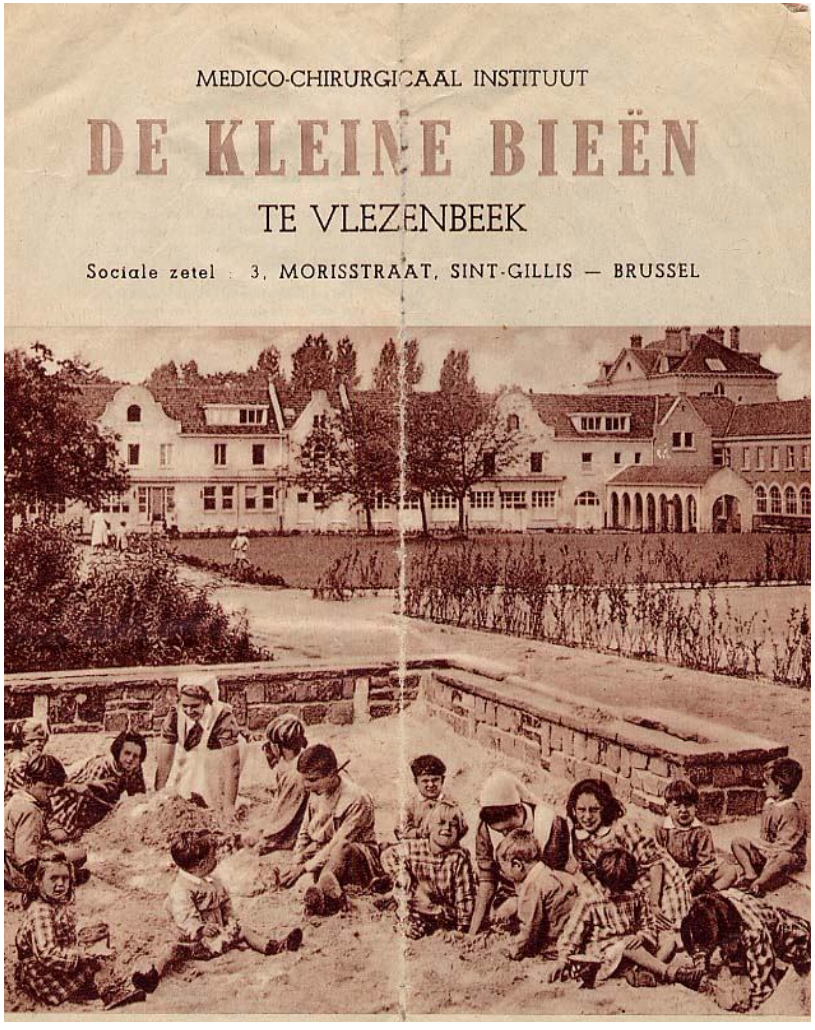
Shakespeare, King Richard III (I, 1)

Cerebral Parese-foreningen NorCP SYKEHUSET I VESTFOLD

- Should cerebral palsy (CP) be called CP?
- Is it a disorder or a condition?
- Is it appropriate and useful to regard CP as a spectrum?
- How operational can or should a definition be?
- Can we better delineate timing and non-progressiveness?
- How do we describe motor and non-motor features?
- Should we emphasize the lifelong course, the impact on participation?
- How do we account for medical, social, political, and personal dimensions?

Horton

welfare
poverty
tuberculosis
polio



DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY

The metaphysical model of disability: is this a just world?

Dan DMCN 2021

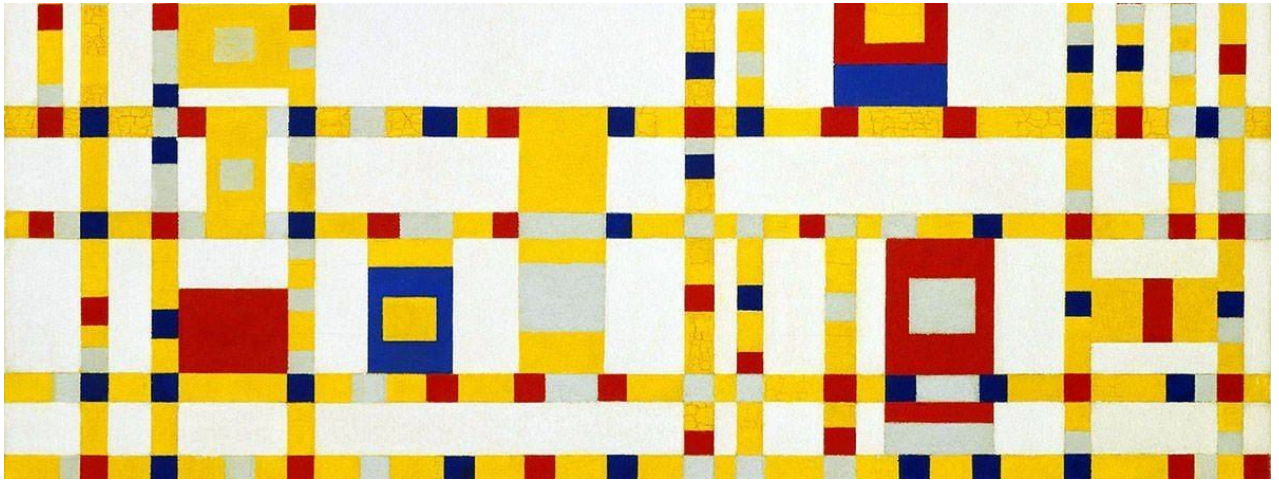
Throughout history, disability has been understood in many cultures as the manifestation of a higher power, whether as divine punishment and/or penance.[1] With variations in belief systems, this metaphysical view suggests that people endure physical suffering for their sins (or the sins of others). With progress in medical knowledge and also a considerable degree of secularization (particularly in the last 200 years), disability is now primarily viewed in medical terms, as the consequence of biological factors. In this biomedical model, health experts identify a person's impairments and limitations, and then take appropriate action to improve them.

It is noteworthy that both the metaphysical and medical models focus on the disabled person as the source of their problems. By contrast, the social model considers that disability results from environmental conditions preventing disabled persons from realizing their full potential and par-

studies has documented a widespread c
whereby one gets what one deserves or deser
gets.[3] This reflects a belief in some sort of u
that restores moral balance, which has beer
just-world fallacy. This belief is thought to en
ple to engage in long-term goals.[3] However,
research has concentrated on negative implic
tendency to rationalize people's suffering, the
victims of misfortune for their own fate. As a
people with health problems, for example, of
grated, and higher levels of derogation have
for those with more severe conditions.[4] Peop
world beliefs tend to have more negative viev
abled people and experience more discomfo
with them.[5] Just-world beliefs thus enhance
disenfranchisement of disabled individuals.

We can, on the contrary, transform our

- rehabilitation
- multidisciplinarity
- special education
- reference centres



habilitation vs rehabilitation

THE LANCET
Neurology

Towards improving outcomes in motor disorders associated with cerebral palsy

Saranda Bekteshi, Elegast Monbaliu, Sarah McIntyre, Gillian Saloojee, Sander R Hilberink, Nana Tatishvili, Bernard Dan

Neuroscience underlying rehabilitation: what is neuroplasticity?

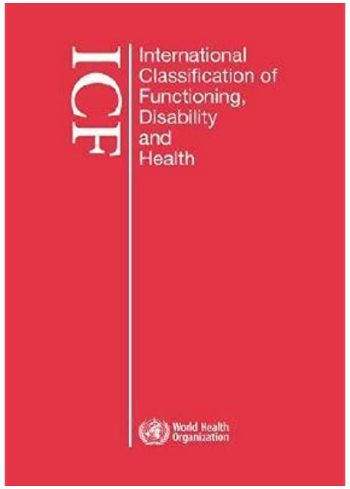
Dan DMCN 2019

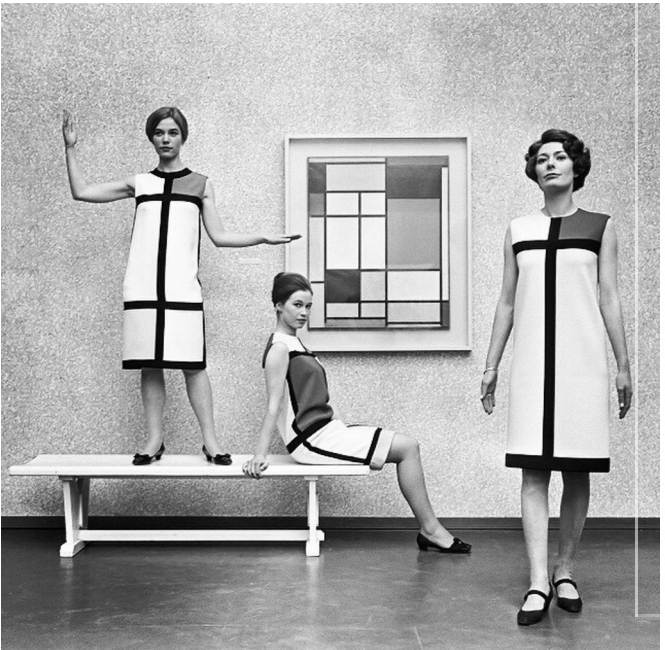
Neuroplasticity generally refers to the capaci
neural networks to change their connections
response to experience. However, can thera
plasticity? And does neuroplasticity contribut
tal rehabilitation? Affirmative answers to the
become the tenets of therapy and rehabilit
they provide a mechanistic understanding,
work, and thereby, growing evidence base
specific practices. Various behavioural, ne
On a wider scale, structural neuroplasticity involves regional
lume changes or the formation of new neural pathways,
rough synaptogenesis, axonal or dendritic sprouting, changes
myelin, or production of new neurons. The latter was long
ld to be impossible in the human brain beyond infancy (in
ntrast to other mammals), but the generation of neurons,
ose function remains to be further clarified, has now been
cumented in several parts of the adult human brain.[4]
Yet, more relevant mechanisms to neurodevelopmental

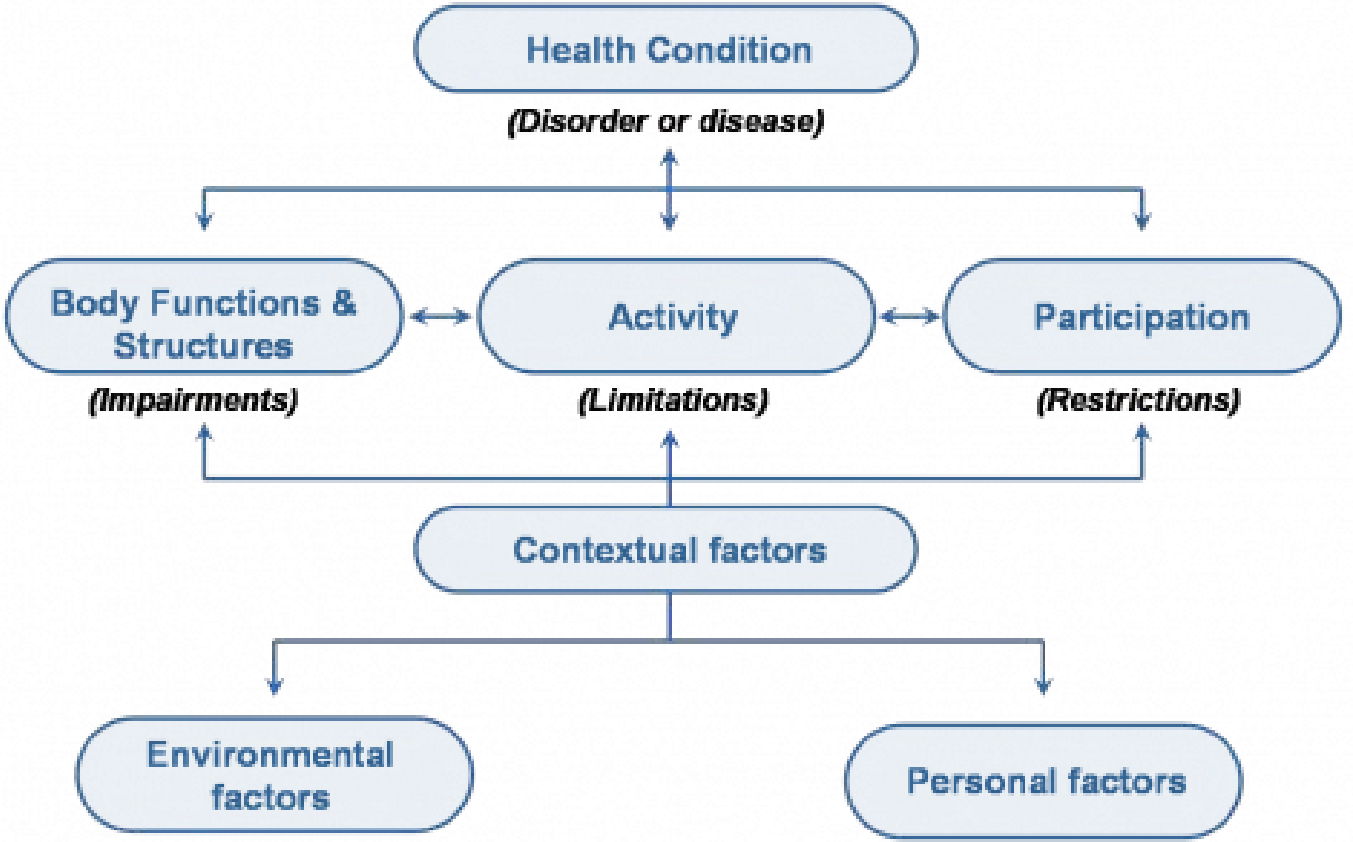
Intensive repetitive motor training: how does it work in children with cerebral palsy?

Dan DMCN 2021

Intervention approaches for neurodevelopmental
draw from the knowledge, experience, and id
from rehabilitation of adults with acquired brain
those interventions, intensive repetitive motor tra
successfully adapted, particularly in managemen
for children with cerebral palsy (CP). Furthe
include spinal circuits and deep brain
n target appears to be the cortex, with
rophysiological and neuroimaging stud-
sociated with intensive motor training in
mpairment show some inconsistencies,
to increased markers of connectivity







Cieza & Kostansjek. The International Classification of Functioning, Disability and Health: the first 20 years. DMCN. 2021

The F-words for child development: functioning, family, fitness, fun, friends, and future

Freedom: An F-word for functioning, disability, and health

Dev Med Child Neurol. 2023;65:298.

Health condition

Freedom

Body Structure and Function

Everyone needs to stay fit and healthy, including me! Help me find ways to keep fit.

Fitness

Activity

I might do things differently but I CAN do them. How I do it is not important. Please let me try!

Function

Participation

Having friends is important. Please give me opportunities to make friends with my peers.

Friends

Environmental Factors

They know me best and I trust them to do what's best for me. Listen to them. Talk to them. Hear them. Respect them.

Family

Personal Factors

Life is about having fun. Please help me do the activities that I find the most fun.

Fun

Nam June Paik

CanChild

Future

I will grow up one day, so please find ways for me to develop independence and be included in my community.

Rosenbaum. The F-words for child development: functioning, family, fitness, fun, friends, and future. DMCN 2022

Current perspective on health conditions

Caharija

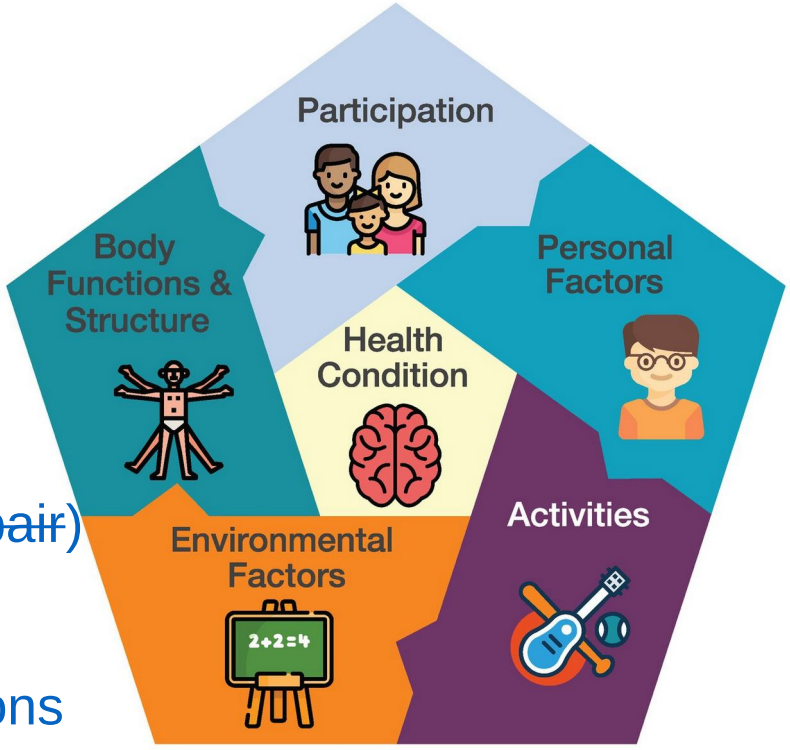
Enhance functioning

Social and cultural conditions

Person-driven goal setting (~~repair~~)

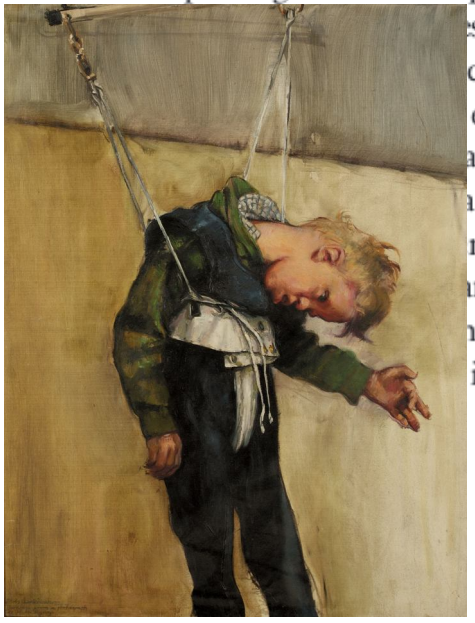
Relevance to themselves

Aspirations rather than limitations



Human enhancement: from disability to superability

Advances in technology increasingly allow people to improve selected aspects of their body structure and function. At work, in sports and leisure activities, and at home, a host of drugs and devices are increasingly available to expand body and mind, while research and industry are continually exploring and developing more substances, apparatus, and



Lenkiewicz

se developments is meant to serve the current philosophers tend to consider endeavours to ameliorate the human acterize the project as human enhance- ttempt – temporary or permanent – to nt limitations of the human body rtificial means (https://ieet.org/index. hancement).

is also an apt general description of proposed for people with impair- normalcy and presumed fixed boundaries to typical human functioning. Management ultimately aims to optimize participation and quality of life. When facilitating functioning of individuals with impairments, even using technologies that are emblematic of human enhancement (e.g. intelligent prosthetics, neural-control interface devices, and brain stimulation techniques), the target

but to provide people with

body parts that enhance fun

embodied through use-dep

connectivity.[3] This is no dif

It may prove useful to inc

focusing on an imagined co

ration between disability m

ment. Emerging function-e

have a great impact on pe

Pearlstein

Rehabilitative and therapeutic neuroarchitecture

Dan DMCN 2016

When assessing people's functioning and health we are increasingly taking account of the potential or actual influences of the physical attributes of their direct environments. In the current framework of the International Classification of Functioning, Disability and Health (ICF), such contextual factors are regarded as either facilitators of, or barriers to, a person's functioning. This development mirrors recent interest within the field of architecture and design in the effect of man-made structures on the human central nervous system. The ambition of neuroarchitecture as a field has been to promote the study of the perception of, and response to, architectural stimuli in order to provide a strong evidence base for designing places and spaces that provide a positive context for human experiences.[1]

Several functions have been the focus of investigation, including sensation and perception, movement, navigation, decision-making, learning and memory, and emotion. Data emerging from these studies may be used when designing private or public structures for general purpose. It may effectiveness, and staff retention, following environmental arrangements such as appropriate lighting, direct access to daylight, noise reduction, or provision of respite areas.[2]

To date, the principles of therapeutic architecture have been purposefully used in only a limited number of buildings, mostly general hospitals and departments or institutions of geriatrics, psychiatry, or rehabilitation, with generic objectives such as 'enhancing well-being'. The facilities may also feature specific landmarks supporting sensory and cognitive processing, social interaction, or motor cognition, though there has been little objective evaluation of these effects.

In contrast, therapeutic gardens have been very popular.[4] They are now quite common in children's hospitals; oncology, mental and behavioural health or dementia care facilities; homes for the elderly; and other settings in the community. There is a growing body of evidence on the benefits of therapeutic gardens to the health of patients, staff, and visitors.[4] Yet, many of the designated therapeutic

Postmodern family-centred care for disability

Dan DMCN 2021

Family-centred care has emerged over the last few decades as an aspirational standard for good clinical practice. It has been promoted for planning, delivering health services in individuals and their unique partnership between providers, family members. The approach typic strengths rather than deficits, and empha well-being and their involvement in decisi ily-centred care was originally conceptual based on the recognition of the impo dynamics and relationships in all aspec functioning and experiences. The family constant in the child's life, providing k child's specific needs and abilities. Fa therefore posits the family rather than t for health services. By extension, organi and around the whole family is increasing evant for almost all patient groups regardless of age.

Studies have documented a variety of practices, observed

Rather, they focus on cultural meaning, role in social forms and processes, and systems of interpersonal relation-

mily dissociates biological continuation of social rela- psychosocial than biologi- g with the fact that the eterosexual married couple n is now in the minority in here have been profound e family. There are now t exist previously (or were ccessive shifts and spread gh relationship breakdown milies that seem to have the y differently.

? In order not to overlook wider, meaningful social connections when providing family-centred care, it is important not to focus solely on a

Setting goals in rehabilitation: Children usually know what they want to achieve

Sršen DMCN 2023

Within the biopsychosocial model of the International Classificati of Functioning, Disability and Health (ICF), the goals tion can t impr tor- ing a r of a re n joint in- con i parents? men s f re. Slowly, normaliz tioning to th ization and ion of existing functional abilities, activities, and participation.

The ICF model of participation includes a dynamic interaction between individual characteristics (child, family, and environment) and dimensions (physical, social, and personality). Several factors influence the participation of children with

Direct
children to goal setting

Elicit
goal topics & priorities

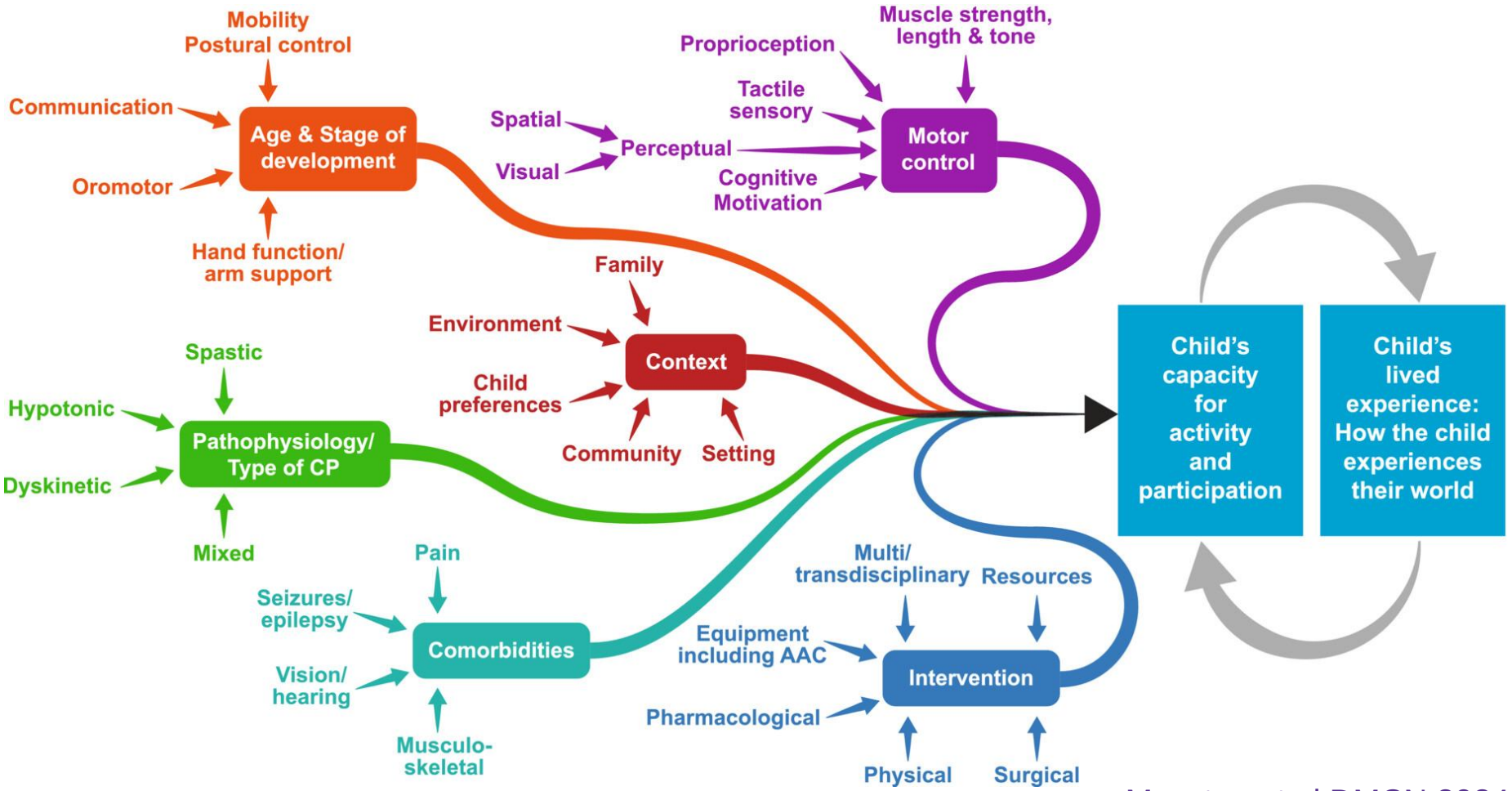
Construct
a goal statement

Indicate
baseline goal performance

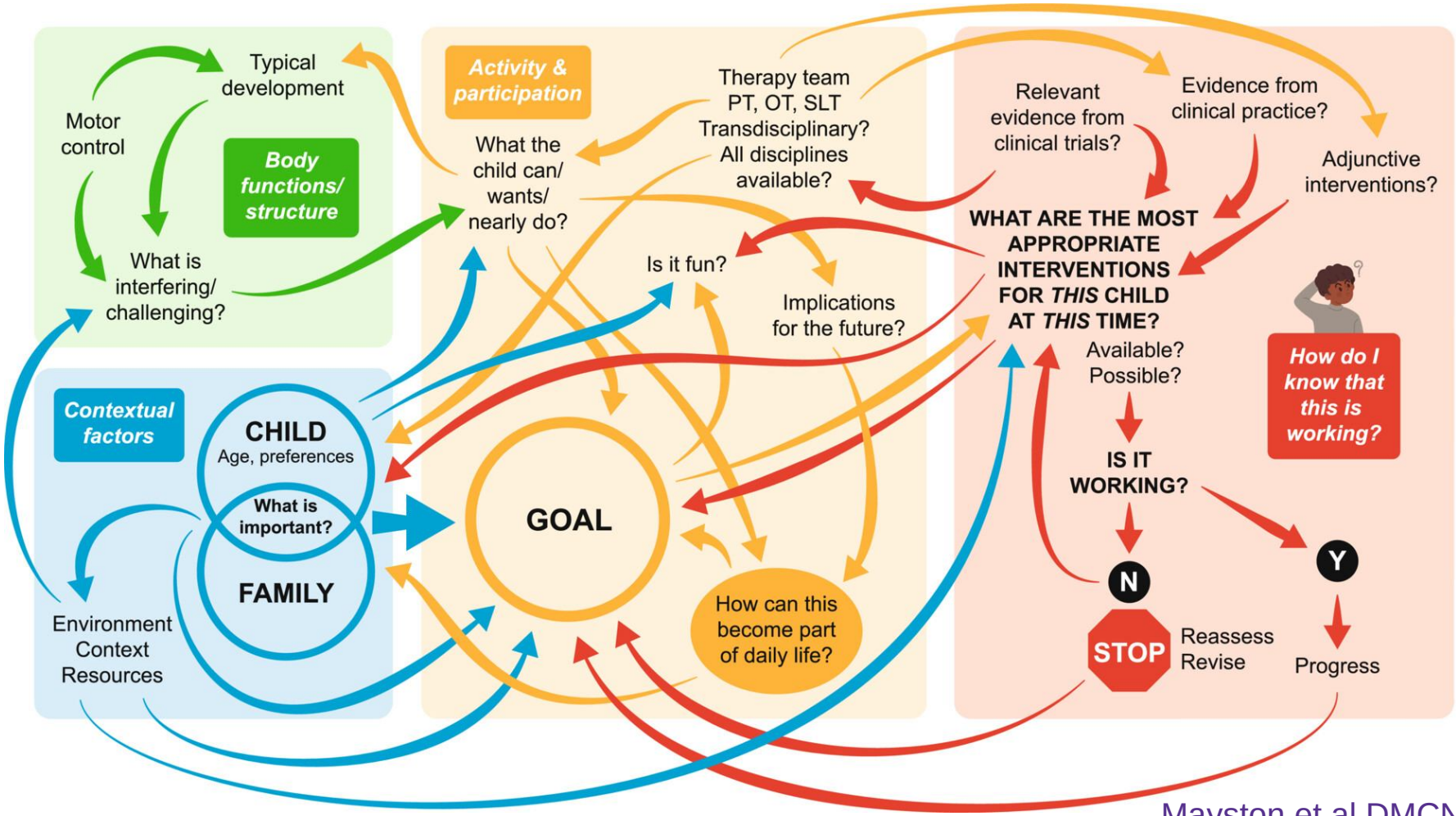
Develop
action plan to address goal

Evaluate
goal progress after intervention

Effective listening and communication to establish common goal re strategies that a considered funda ntal components ful rehab what i to achieve r support joint in- l parents? re. Slowly, d move in th tion of transd iary teamwork, with members that have developed sufficient trust and accord, to engage in goal setting, teaching, and learning across disciplines. Such work offers the opportunity to increase the practical experience and knowledge of both patients and team members.



Mayston et al DMCN 2024

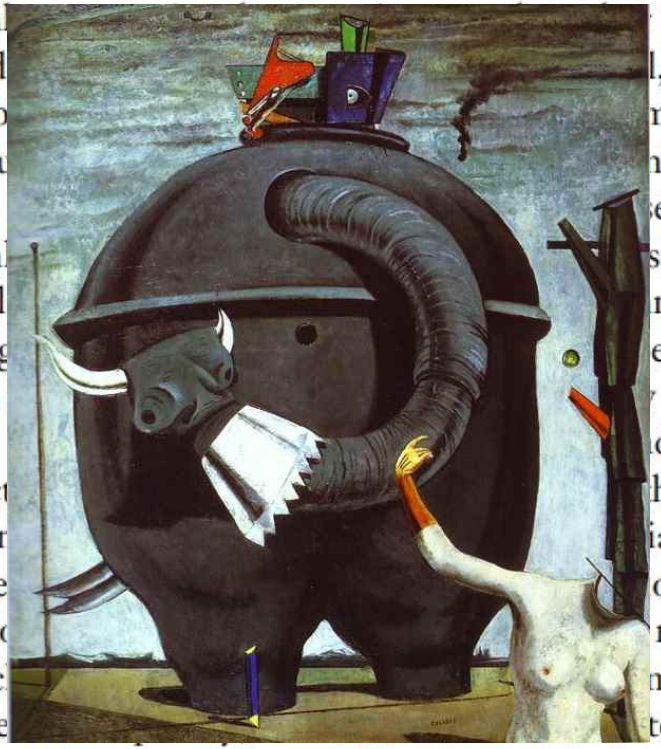


Mayston et al DMCN 2024

Complex developmental disability: a case of 'simplexity'?

Dan DMCN 2021

Clinical complexity is common in developmental medicine. It involves diagnosis, management, and a challenges in carrying out procedures and interventions. Diagnosis may be hampered b recognizing and interpreting symptoms, su psychological manifestations, as well as aspects. Making diagnoses may also be cha the framework of current nosology, due to l tion between generic and more specific diag vexed question of whether comorbidity is independent or related conditions.



The medical aspects are used to charact with medical complexity'.[1] These childre medical frailty and difficult-to-meet care nee a multisystem disease, a neurological conditi functional impairment, or dependence on tec port. Additional important factors contribute including developmental, psychological, cultural, and social

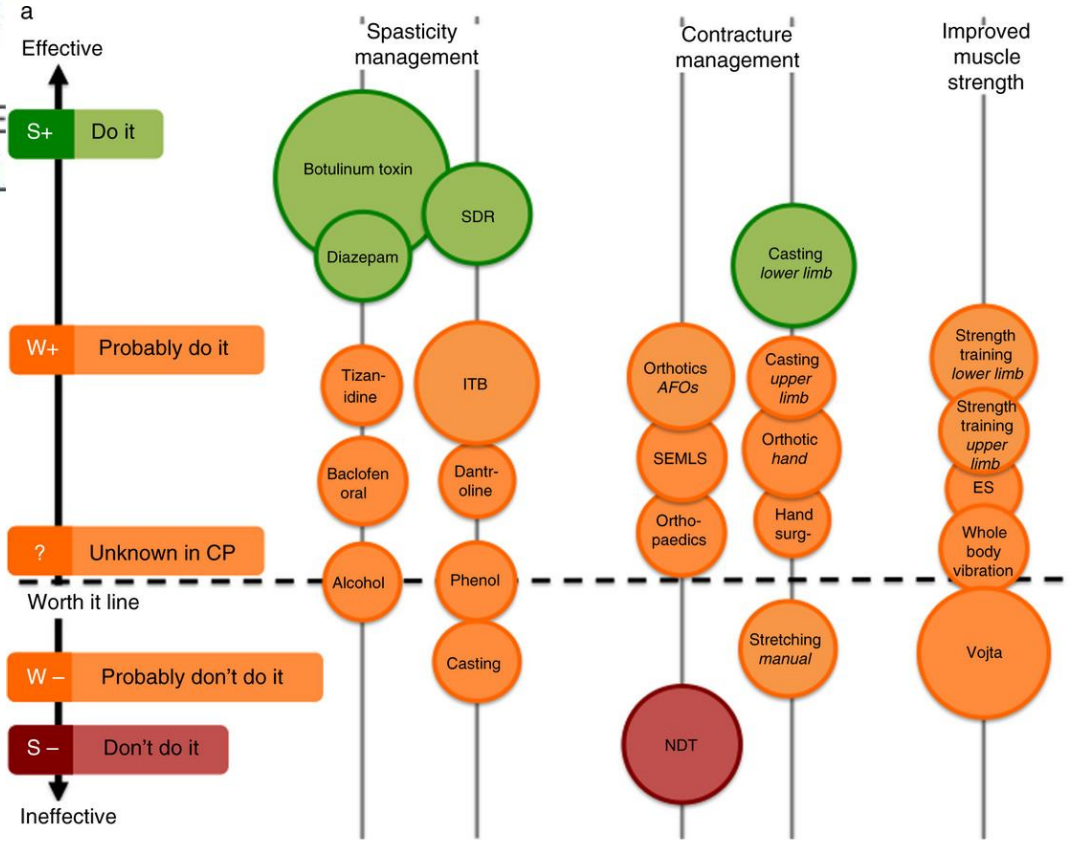
for certain activities), plan interactions (e.g. within the judgments and decisions (e.g. about l, when approaching complex develop- might be possible not to require the nents potentially provided by clinical essment tools. These might actually sent irrelevant information that is ill- mental uncertainty of situations and e offered. Instead, clinical situations fostering links between organizing, deed storytelling.[3] Solutions to that he context of 'simplexity', understood iate complexity of thought with neces- on. Such solutions would be 'neither nor summaries', but 'new ways of ask- mes at the cost of occasional detours, ter, more effective actions'.[4]

What is required to find 'simplex' solutions to improve

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY REVIEW

A systematic review of interventions for children with cerebral palsy: state of the evidence

IONA NOVAK[1,2] | SARAH MCINTYRE[1,2] | CATHE
NATALIE MORTON[1] | ELISE STUMBLES[1] | SALL

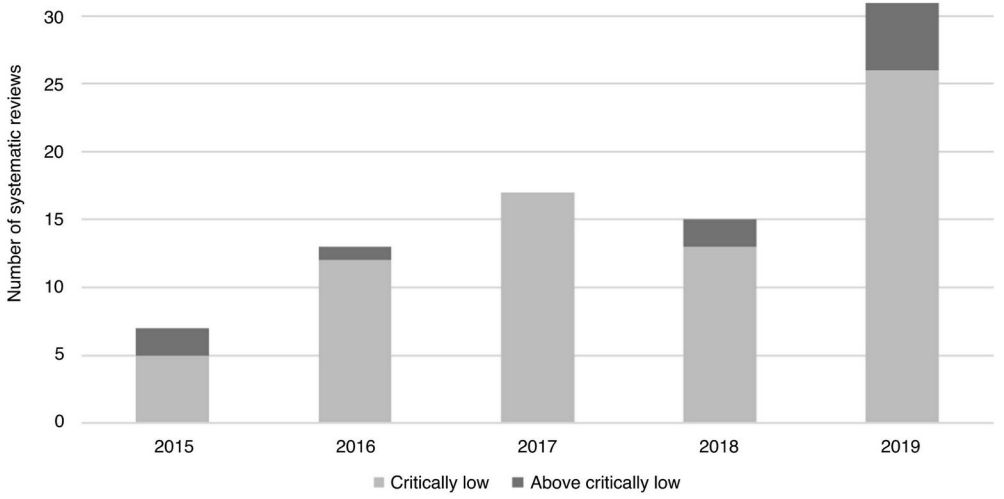


DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY ORIGINAL ARTICLE

Editor's Choice

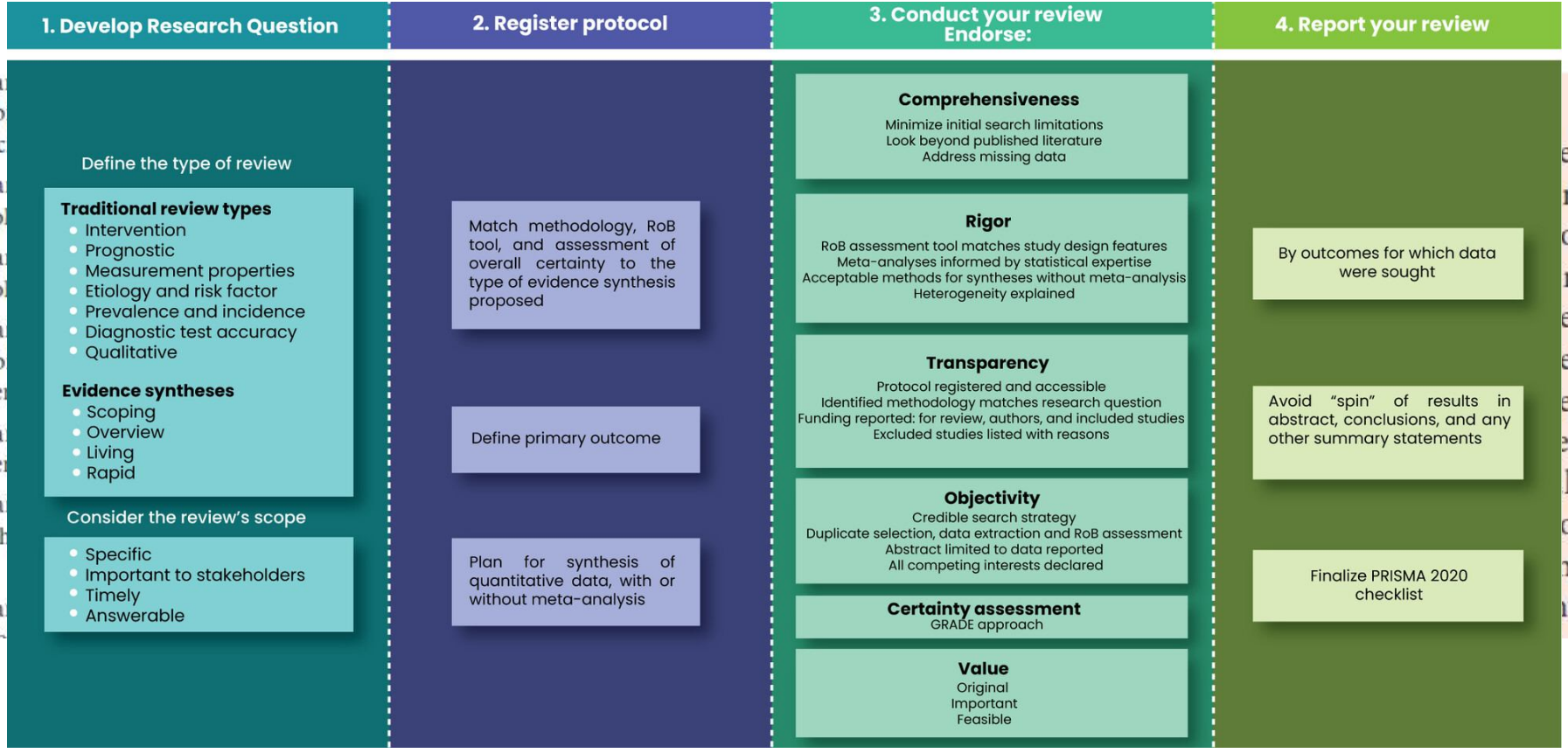
Quality appraisal of systematic reviews of interventions for children with cerebral palsy reveals critically low confidence

KAT KOLASKI[1,2] | LYNNE ROMEISER LOGAN[3] | KATHERINE D GOSS[3] | CHARLENE BUTLER[4]



Principles for good scholarship in systematic reviews

Kat Kolaski[1,2,3] | Lynne Romeiser Logan[4] | John P. A. Ioannidis[5,6,7,8]



GUIDE-Rehab (GUideline of Interventions DEscription in Rehabilitation) reporting guideline

GUIDE-rehab is a reporting guideline developed to report in all due details interventions to optimize functioning performed in the field of rehabilitation. GUIDE-Rehab is grounded on the many years of methodological work by Cochrane Rehabilitation and the Rehabilitation Treatment Specification System working group of the Amrican Congress of Rehabilitation Medicine (ACRM).

for all details about why and how the GUIDE-Rehab reporting guideline was produced, refer to the l paper.

Cochrane Rehabilitation

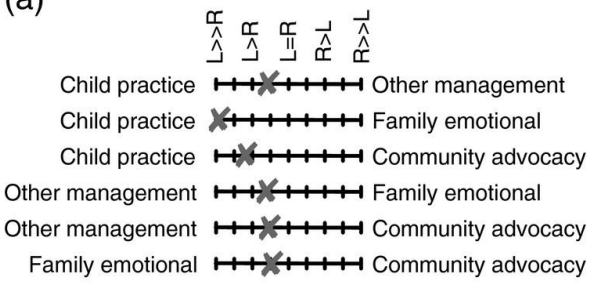
DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY ORIGINAL ARTICLE

Editor's Choice

Paediatric Rehabilitation Ingredients Measure: a new tool for identifying paediatric neurorehabilitation content

ROB FORSYTH[1,2] | DAVID YOUNG[3] | GEMMA KELLY[4] | KATHY DAVIS[4] | CAROLYN DUNFORD[4] | ANDREW GOLIGHTLY[5] | LINDSAY MARSHALL[6] | LORNA WALES[4]

(a)

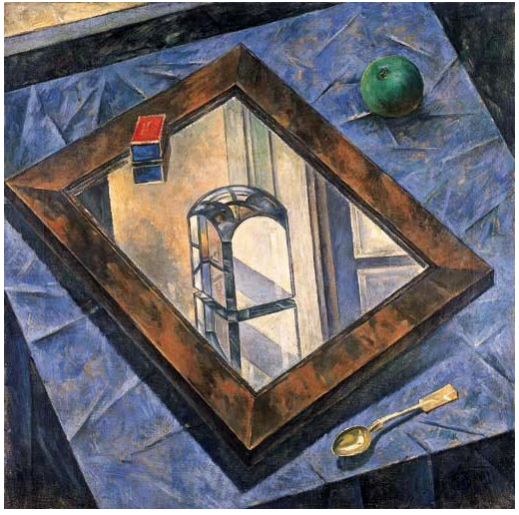


(b)

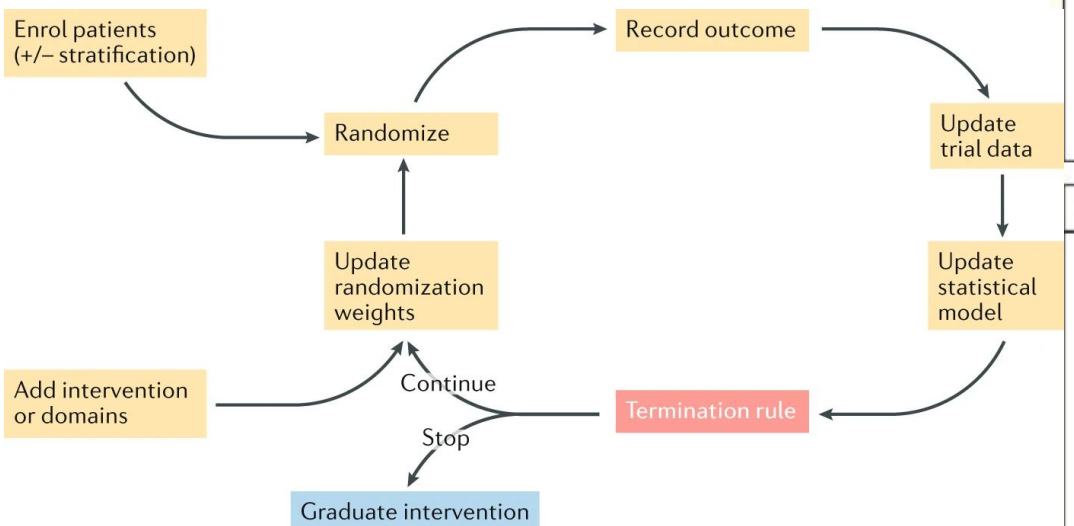
	Practice	Management	Family	Advocacy
Practice	1	3	9	5
Management	0.33	1	3	2
Family	0.11	0.33	1	2
Advocacy	0.2	0.5	0.5	1

(c)

Practice	61%
Management	21%
Family	10%
Advocacy	8%

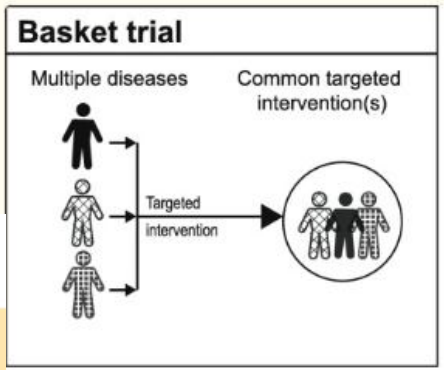


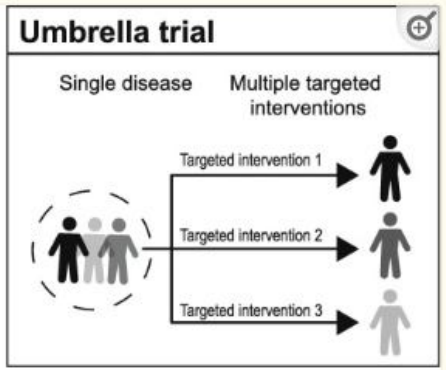
What research methodologies could make a difference in disability?

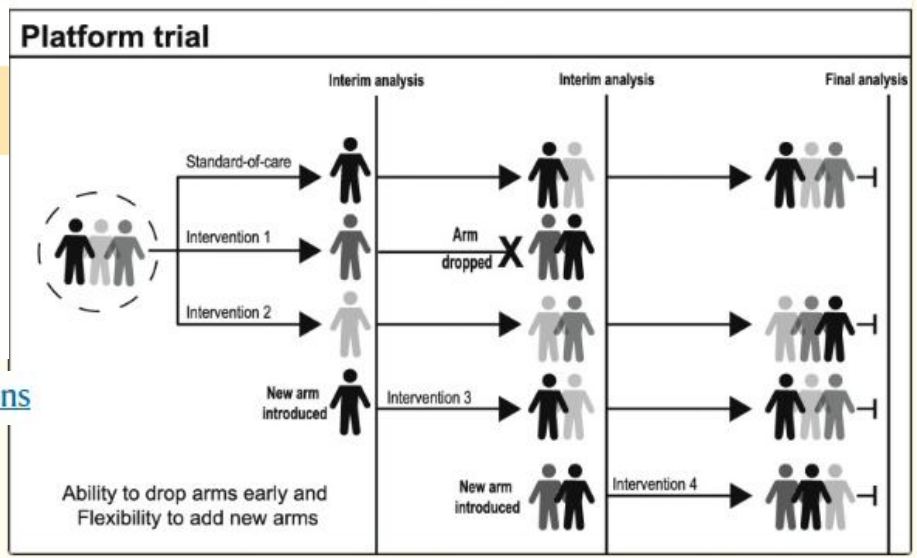


Adaptive platform trials: definition, design, conduct and reporting considerations

nature reviews drug discovery







Park *et al. Trials* (2019) 20:572

Individuals with lived experience of disability should participate in every stage of research

Individuals with impairments involved in disability research have historically been treated as passive subjects; thei
ers.
pro
but
The
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r

including research and scientific publishing.[4] It may be unclear, however, who the 'Us' refers to. In other words,

Relational ethics, informed consent, and informed assent in participatory research with children with complex communication needs

Leni Van Goidsenhoven[1] | **Elisabeth De Schauwer**[2]

[1]Department of Philosophy, University of Antwerp, Antwerp, Belgium

[2]Department of Special Needs Education/ Disability Studies, Ghent University, Ghent, Belgium

Abstract

There is a need for qualitative participatory research involving children with intellectual disability and complex communication needs (CCNs), but procedural ethics

Ableism's pervasive impact in healthcare: A time for action

Kristie Patten

New York University, Office of the President, New York, NY, USA

The study by Ames et al.[1] highlights the pervasiveness of sys and impairments to temic ableism in healthcare systems. Disability-related dis practices.[4] Lawrence crim pref to bi is th and Heal vide lens perp to cc livec

Impact of disability-based discrimination in healthcare on parents of children with medical complexity

Stefanie G. Ames[1] | Rebecca K. Delaney[2] | Claudia Delgado-Corcoran[1] | Amy J. Houtrow[3] | Justin Alvey[1] | Melissa H. Watt[2] | Nancy Murphy[1]

[1]Department of Pediatrics, University of Utah School of Medicine, Salt Lake City, UT, USA

[2]Department of Population Health Sciences,

Abstract

Aim: To qualitatively assess the impact of disability-based discrimination in health

From paediatrics to geriatrics: ageing with a neurodevelopmental disability

Dan DMCN 2018

Like everyone else, people with neurodevelopmental disorders experience continuous, complex anatomical changes in the developing nervous system and other body systems, with substantive implications for clinical expression, outcomes, and management. Compared to early childhood, t
change are dramatically reduced in adulthood
ous complications may occur, including mo
disorders. Some progressive problems are a
related to chronic disuse, such as hip dysplasia
sis in cerebral palsy. Adults with neurodevelop
ments require specific expertise and there is an
promote this expertise among a variety of he
als.[1] Paraphrasing the paediatric motto 'childr
adults', adults with neurodevelopmental impa
big children with developmental impairments.

Changes in adults' lives have been reporte
with advancing age, e.g. increasing fatigue.[2]

of childhood disability.[4] Non-specific clinical presentations of incurring diseases are also common from early childhood; so too are issues related to multiple medications (polypharmacy) with increased risk of drug interactions or adverse effects taking
liver functions, necessi-
-called 'geriatric giants'
lity, instability, inconti-
) as well as the 'modern'
anorexia, and cognitive
in neurodevelopmental
wever, be identified and
italization, institutional-
, ageing need not be an

basic science evidence
eurodevelopmental dis-
young adults and the

Childhood-onset disability: Lifelong realities require lifespan training

Dan DMCN 2024

'Children are not small adults!' This aphorism guides much of the thinking, clinical practice, and research in our field. The corollary is that 'adults with neurodevelopmental impairments are not big children with neurodevelopmental impairments'. This idea should serve as an equally strong principle to provide specialized appropriate care to 'former children', as their needs and challenges differ significantly, and require a tailored approach that considers the complexities of chronic disorders that persist into adulthood. However, young people transitioning to adulthood often face a major gap in expertise within health disciplines and service organization to address those unique needs.[1] For want of more suitable options, a small proportion of these adults continue to be followed by their paediatric specialists; more often the necessary multidisciplinary experience and

Building on a few successful initiatives, specific teaching pr ed; so nte- gra mes ca dult sp pe- cia in- div ntly en we re col- lea ap- pr be bo tice

- Goal-setting – Child/family-centred
- Intervention ingredients/Methodologies/Clinician
- New categories – AI
- Functioning/Context/Prevention
- Lifelong – Worldwide
- Social identity – ableism

@ProfBernardDan

www.eacd2024.org

European Academy of
Childhood Disability

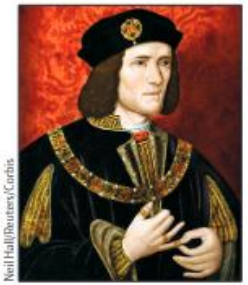
@ProfBernardDan

Cheated of feature by dissembling nature
Deformed, unfinish'd, sent before my time
Into this breathing world, scarce half made up
And that so lamely and unfashionable
That dogs bark at me as I halt by them

Shakespeare, King Richard III (I, 1)

The scoliosis of Richard III, last Plantagenet King of England: diagnosis and clinical significance

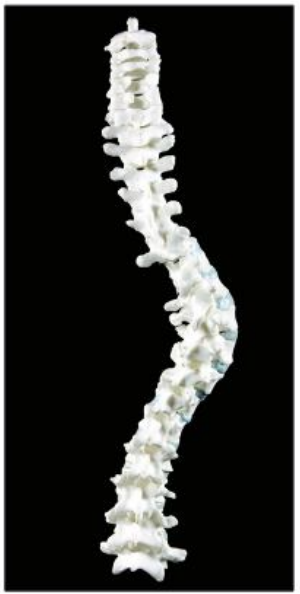
Jo Appleby, Piers D Mitchell, Claire Robinson, Alison Brough, Guy Rutty, Russell A Harris, David Thompson, Bruno Morgan



Neil Hall/Reuters/Corbis

Lancet 2014; 383: 1944

Richard III was king of England from 1483 to 1485, after declaring his nephew, Edward V, illegitimate. On Aug 20, 1485, Richard was killed in battle with the rebel udor at Bosworth. His body nd buried in the Greyfriars ned until its excavation in e a severe scoliosis.[1] escribed Richard III as ous play of 1593. There has reement whether this invention of his enemies



3D model of spine with replica polymer vertebrae created by laser sintering

structure, muscle markings, and cortical thickness of the legs and hips, compatible with a normal weight-bearing gait. Skeletal changes associated with syndromes such as Marfan's (eg, high arched palate and tall stature) were not present, and a normal foramen magnum makes a Chiari malformation unlikely. The subtle nature of the changes in vertebral anatomy suggest onset in the last few years of growth, which is compatible with adolescent onset idiopathic scoliosis, probably starting after 10 years of age.

The physical disfigurement from Richard's scoliosis

PERINATAL LESSONS FROM THE PAST

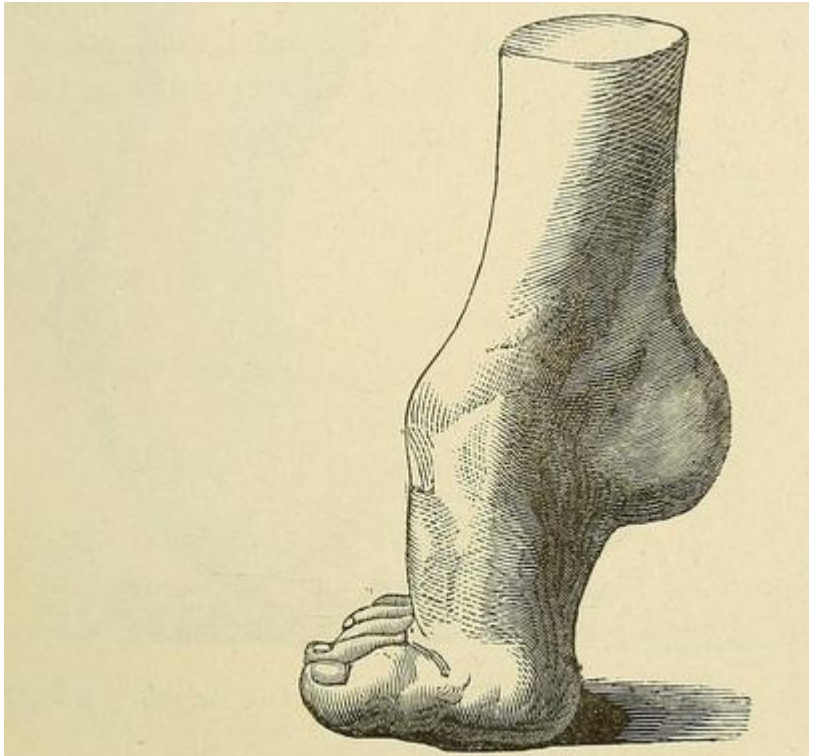


FIG. II.—*Non-congenital Talipes equinus in a youth aged* 11.

Dr William Little (1810–1894) of London and cerebral palsy

Peter M Dunn

William Little was born in 1810 in Whitechapel where his father kept the Red Lion Inn. He was educated at a school near Dover and at the Jesuit College of St Omer in France. A left club-foot following poliomyelitis prevented sporting activities but he excelled academically, especially in languages.

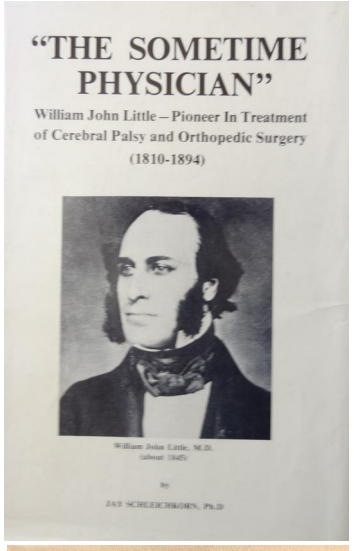
In 1825 he was apprenticed to an apothecary, after which he studied medicine at the London Hospital, qualifying at the age of 20 and then entering general practice in London. However, after attending lectures at Guy's Hospital and University College, he decided to become a physician, visited Leyden, Leipzig, and Dresden and studied in Berlin, graduating MD in 1937. While in Germany, Stromeyer of Hanover had in 1836 successfully corrected his club-foot using subcutaneous tenotomy, and on returning to London, Little introduced this new technique, operating on a 15 year old boy in February 1837. Thus the treatment of deformities was brought into the province of surgery. Little was elected to the staff of the London Hospital in 1839 and the same year published a treatise on club-foot.[1] In 1840 he founded the Orthopaedic Institution which through amalgamation became the Royal National Orthopaedic Hospital in Great Portland Street. He also had appointments to the Royal Orphan Asylum, Wanstead, the Asylum of Idiots, Reigate, and the Royal Hospital for Incurables.

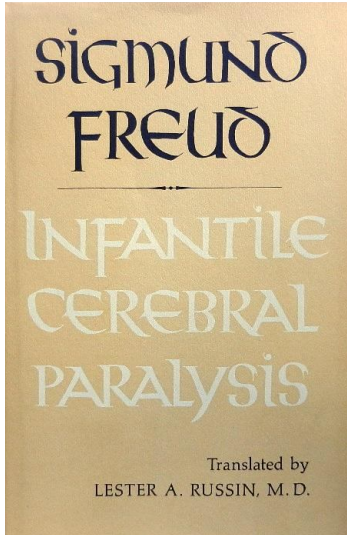
Dr William Little, 1810–1894.

Little was a good all-round physician and

or malformation of organ exists. These may be termed congenital malformations.'

Another extract from the same text illus-



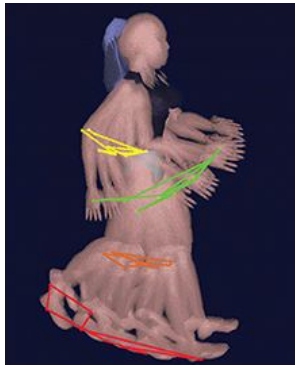


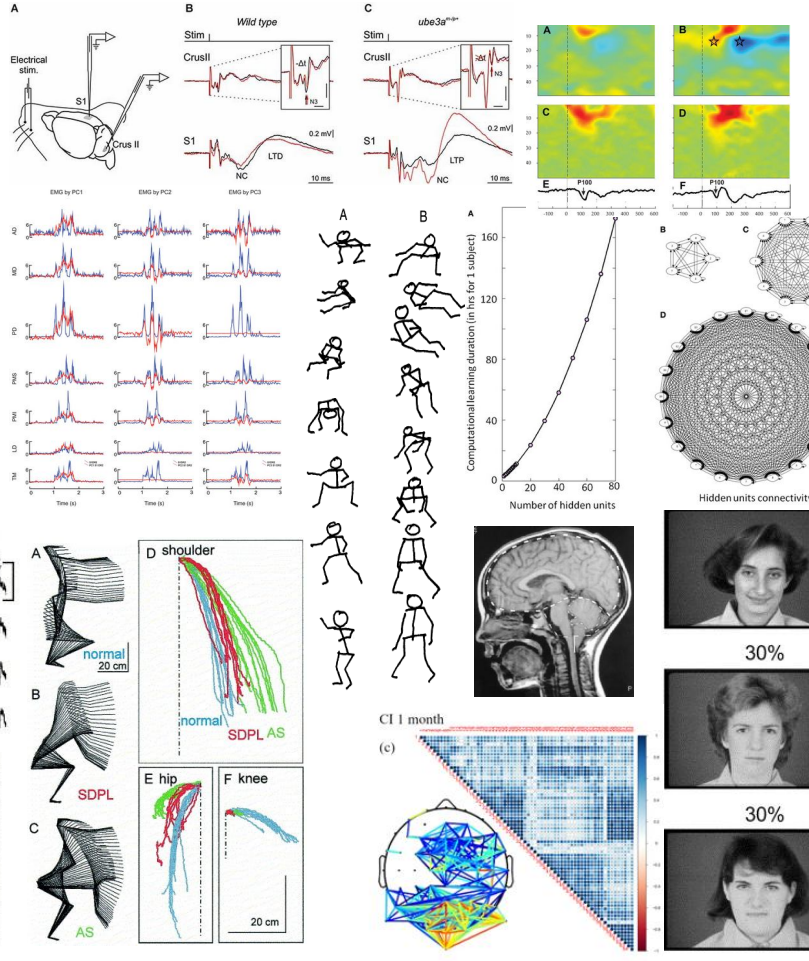
- Little, 1862 "Forstyrrelse som ser ut til å ramme barn i løpet av det første leveåret, og som påvirker progresjonen i utviklingsmessige ferdigheter og ikke bedres med tiden"
- Freud, 1868 "Infantil cerebral parese ville dermed bli definert som det generelle begrepet for alle hjernesykdommer i spedbarnsalderen forårsaket av en direkte effekt av en direkte effekt av cerebral parese på hjernen. cerebral parese i spedbarnsalder forårsaket av en direkte effekt av tilfeldig etiologi, enten i fosterlivet eller etter fødselen, og som påvirker enten ett eller flere nervesystemer"

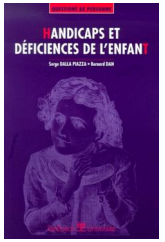
Perlstein, 1952 "Cerebral parese kan defineres som en tilstand som kjennetegnes av lammelse, parese, inkoordinasjon, dyskinesi eller en hvilken som helst avvikende motorisk funksjon som skyldes at hjernens motoriske kontrollsentre er involvert. motoriske kontrollsentre i hjernen"

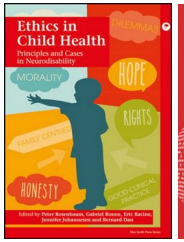
- Little's Club, 1957 "Vedvarende, men uforanderlig, forstyrrelse av bevegelse og kroppsholdning, som opptrer i de første leveårene, og som skyldes en ikke-progressiv forstyrrelse i hjernen som fører til forstyrrelser under utviklingen"
- Bax, 1964 "Cerebral parese er en forstyrrelse av bevegelse og holdning som skyldes en defekt eller lesjon i den umodne hjernen"

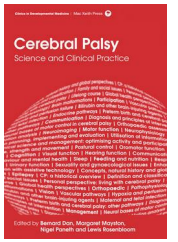
- Mutch et al, 1992 "Cerebral parese er en samlebetegnelse for en gruppe ikke-progressive, men ofte skiftende, motoriske funksjonsnedsettelser som skyldes lesjoner eller abnormiteter i hjernen som oppstår tidlig i utviklingen".
- SCPE, 2000 "Cerebral parese er en gruppe lidelser, dvs. det er et generelt paraplybegrep; det er permanent, men ikke uforanderlig; det innebærer en forstyrrelse av bevegelse og/eller holdning og motorisk funksjon; det skyldes en ikke-progressiv forstyrrelse/skade/avvik; denne forstyrrelsen/skaden/avviket oppstår i den utviklede/umodne hjernen".











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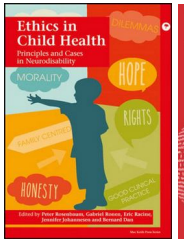
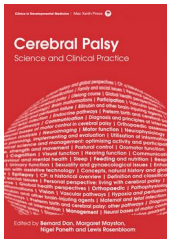
Journal of Pediatric Neurology 2004; 2(2): 57-64
www.jpneurology.org

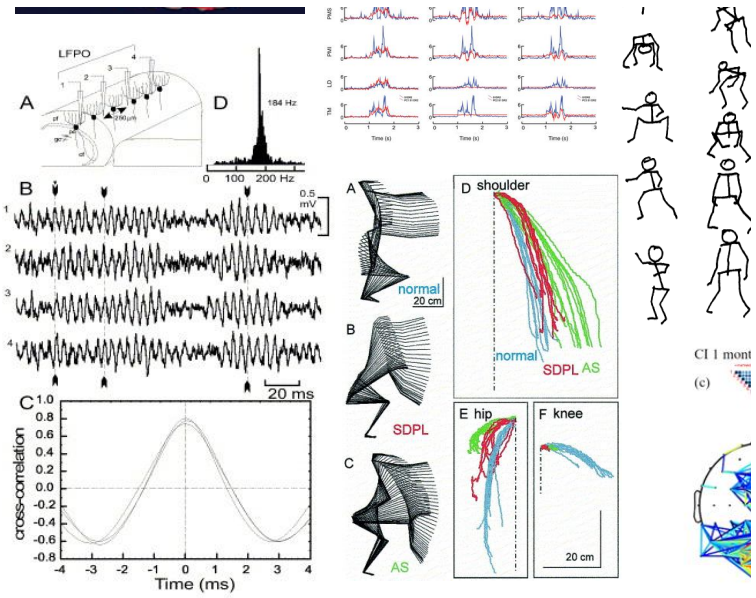




REVIEW ARTICLE

Reconstructing cerebral palsy

Bernard Dan



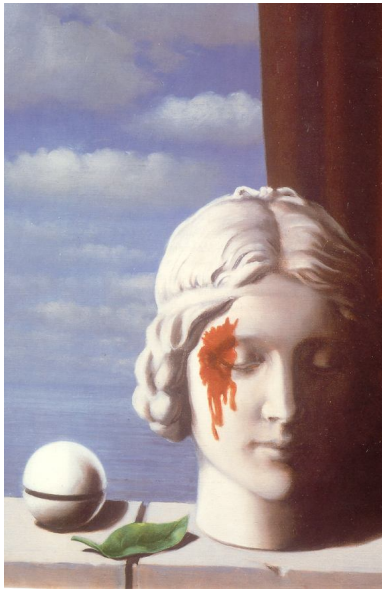
@ProfBernardDan

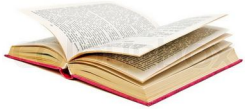
Perhaps individuals who are now diagnosed as having CP are different from individuals to whom this term has been applied over the course of the last 40 years. This might be due in part to epidemiological reasons, that have been termed the 'changing panorama' of CP (51). In addition, it might be because of the theories held about these individuals and the remedies that have been put in place around their abnormal behaviors, leading to the emergence of so-called 'classical' and 'modern' forms (52). Conversely, the resulting changes in the individuals have significantly contributed to the evolution of ideas about physiological and pathological motor development.

National Institute of Neurological Disorders and Stroke

Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, behaviour, epilepsy, and by secondary musculoskeletal problems.

Rosenbaum et al DMCN 2007



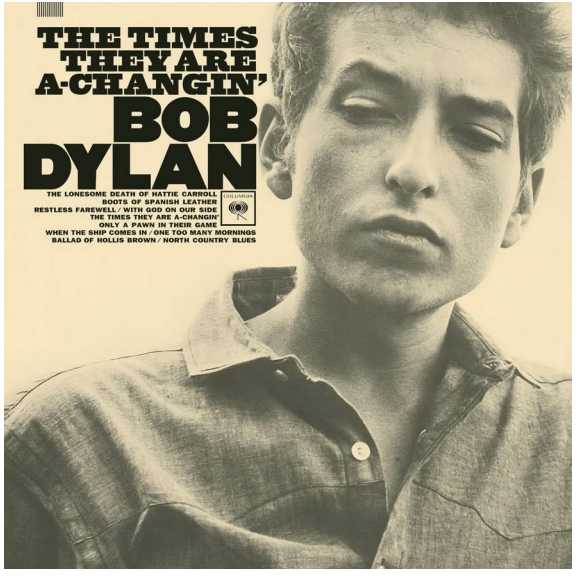


Rosenbaum & Dan. The continuing evolution of ‘cerebral palsy’ APRM 2020

- aetiological understanding: genetics, inflammation, metabolism
- clinical documentation worldwide: manifestations, LMIC
- adults with CP, adult services, lifelong
- societal and cultural understanding, self-ownership
- concepts and language of disability, ableism

EDITORIAL

Advancing definitions of paediatric neurological disorders: Lessons from adult neurology



Naming cerebral palsy 'CP': Physiology and service provision

Clinical presentations consistent with what we now call cerebral palsy, reported in the 19th century, gave rise to the clinical construct and opened discussion about risk factors, pathophysiology, classification, and the significance of features associated with the described motor disorders. Following the arguments of Freud and Osler supporting a brain origin, even for the bilateral presentations thought by Erb and Charcot to originate in the spinal cord, the group of conditions came to be known as cerebral palsy. Over the years, successive definitions have been proposed to match the evolution of knowledge, of concepts relating to development, medicine, disability, and of health-related terminology. Some of the more influential of these definitions were published in this journal in 1959, 1964, 1992, 2000, 2005, and 2007. The authors of the latest of these iterations questioned whether to retain the word 'palsy', which had long been obsolete in medical nosography.[1,2] They agreed that the term 'cerebral palsy' was still helpful to ensure continuity with data accumulated over many decades, provided it was clarified within the current state of understanding, research, and service organization, including highlighting extramotor developmental and secondary features. Moreover, the group hoped to avoid jeopardizing funding of services and research that relied on this diagnostic label.[3]

Use of this descriptive diagnosis in many languages corresponds to quite literal translations of 'cerebral palsy', some of showed no obvious cognitive impairment. Recently, there has been a move to combine both entities under 'paralysie cérébrale', a closer translation of 'cerebral palsy', to reflect the obligation to meet all functional (including educational and other participation) needs in all individuals.

In some other settings, more generic or programmatic terms might help develop strategies to meet the needs of individuals and improve their lifelong outlook,[4] bearing in mind, for example, that some languages have no equivalent word for 'movement'. The current Māori term for cerebral palsy ('hōkai nukurangi') literally means to traverse the earth and metaphorically achieve what is important to the person.[5]

Whatever the term, what matters at this stage is that it can be used to develop and share relevant and impactful knowledge to optimize the current situation and future prospects of individuals with cerebral palsy by lifting barriers, empow-

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Velkommen til
CP-KONFERANSEN
21-22 MARS 2024

Suggested update

Cerebral Palsy (CP) is the term used to describe[1] a spectrum[2] of life-long clinical conditions[3] in which the impaired development[4] of movement and posture causes limitation in activity and may impact participation[5]. These conditions[6] are attributed to non-degenerative changes (injury or malformation)[7] that occurred in the fetal or infant brain[8]. In addition to the motor features[9], people with CP[10] often experience impairments of development of other functions[11] (e.g. sensation, feeding, sleep, communication, cognition, and mental health[12]) as well as epilepsy and secondary musculoskeletal impairments. These conditions are experienced[13] individually by persons with CP, resulting in a unique experience of their world[14].

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