



# Disability, Technology, Humanity and Childhood.

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Disease onset

Impairment

Acute care



Signs and symptoms

Disability

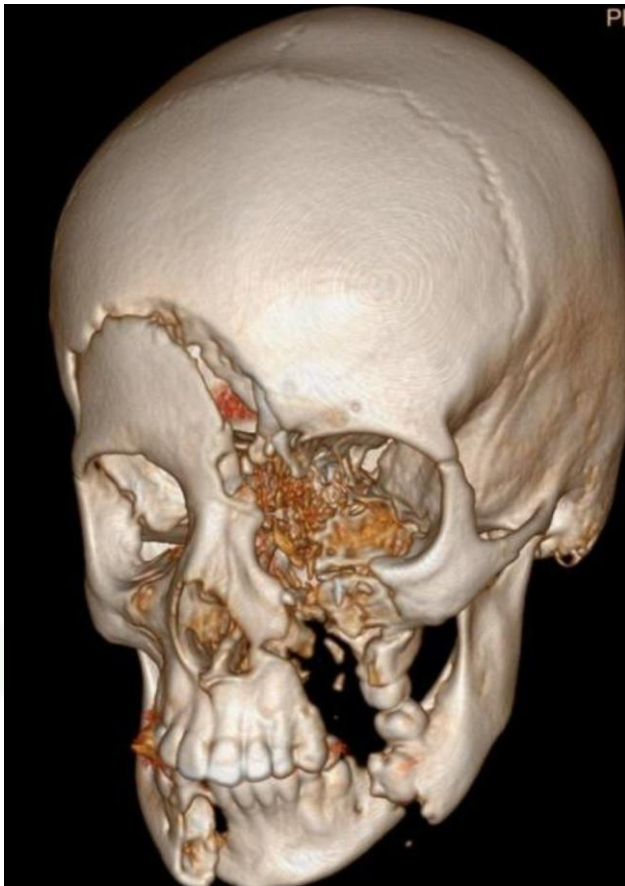
Rehabilitation



Consequences

Handicap

Home



# ות בריאות

## הדסה: הרופאים חיברו את ראשו של שנחצה לשניים

יוסף ג'רדאת בן ה-10 רק רצה ללכת לשחק עם חברו שגר בקומות מתחתיו. כשהחבר לא ענה לו, הוא שב לעלות לביתו, ונפתחה הוא נפל חמש קומות לתוך הפיר. רק חצי שעה אחרי התגלה על ידי השכן שהזעיק אמבולנס שפינה אותו להדסה. על איחוי ראשו ופניו שנחצו לשניים, וקיבוע ידו ורגלו שנחצו לשניים, הרופאים הצליחו לחבר את החלקים. "השכן יעץ לי לא לתת לאמו להסתכל עליו"



ל

פורסם: 09.01.19, 09:00







**“Health is the ability to adapt  
and to self manage”**

Huber et al. BMJ 2011

# The Challenge



- The success of medical care ➡ Prolonged survival of people with chronic conditions
- Children with chronic conditions look at 50-70 years of health care needs with loss of potential working ability and ongoing need for personal care

**Every child going through rehabilitation  
saves years of living with disabilities**

# The ALYN Hospital

## Pediatric & Adolescent Rehabilitation Center

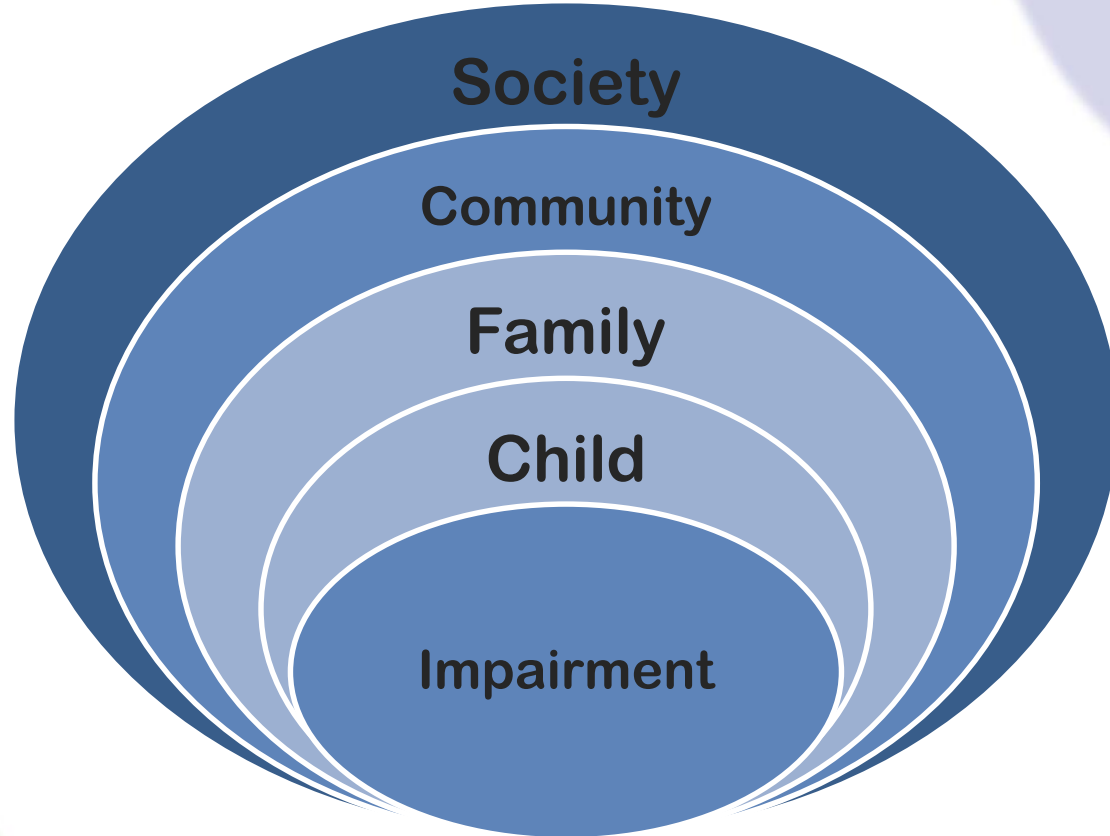


- In-patient rehabilitation
- Out-patient clinics
- School for children with chronic medical problems
- Complex care
- Innovation space for children with disabilities

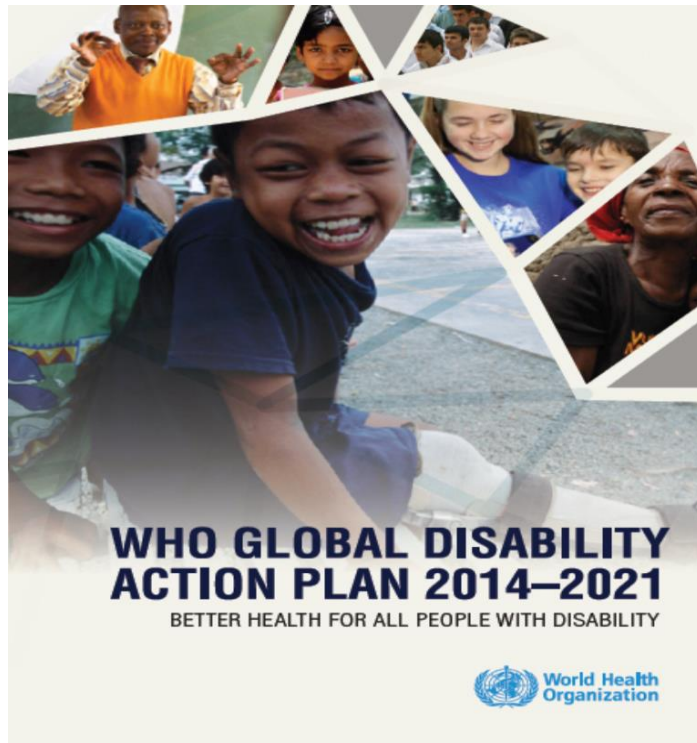




# Holistic Rehabilitation








# World Health Organization (WHO) Action Plan

# WHO Action Plan

## Better health for people with disabilities





World Health Organization

**1** Over **BILLION** people globally experience disability

People with disabilities have the same general health care needs as others

But they are:

- 2x** more likely to find health care providers' skills and facilities **inadequate**
- 3x** more likely to be **denied** health care
- 4x** more likely to be treated **badly** in the health care system


**1** in **7** people

## Rehabilitation and assistive devices can enable people with disabilities to be independent

- 200 MIL** people need glasses or other low-vision devices and do not have access to them
- 70 MIL** people need a wheelchair. Only **5-15%** have access to one
- 360 MIL** people globally have moderate to profound hearing loss. Production of hearing aids only meets: **10%** of global need **3%** of developing countries' needs


### Making all health care services accessible to people with disabilities is achievable and will reduce unacceptable health disparities

- remove physical barriers to health facilities, information and equipment
- make health care affordable
- train all health care workers in disability issues including rights
- invest in specific services such as rehabilitation



**1/2** of people with disabilities cannot afford health care

They are: **50%** more likely to suffer catastrophic health expenditure



These out-of-pocket health care payments can push a family into poverty

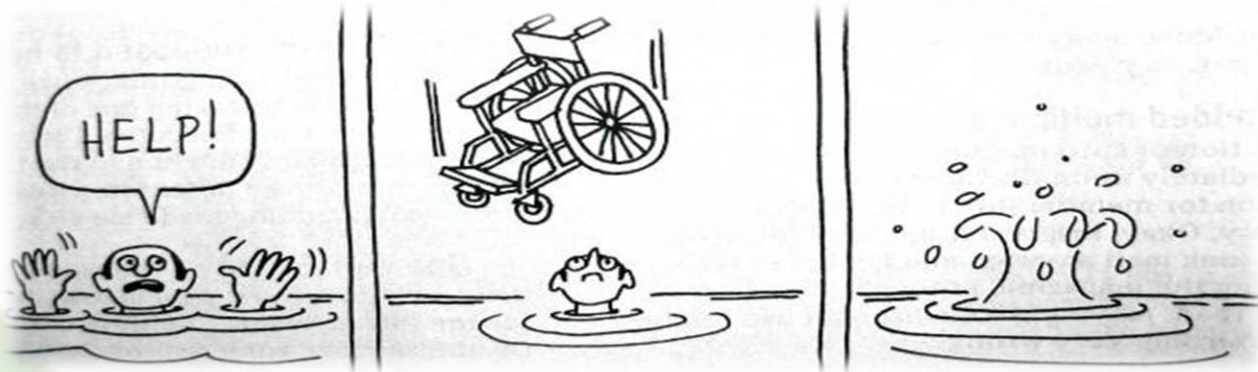
# Agenda



- ① The WHO led principles of rehabilitation
- ② The growing need for Chronic Care & Rehab
- ③ How assistive devices improve quality of life
- ④ How innovation improves care

# Goal

How do we enable children with chronic conditions and disabilities integrate in school, society and work?

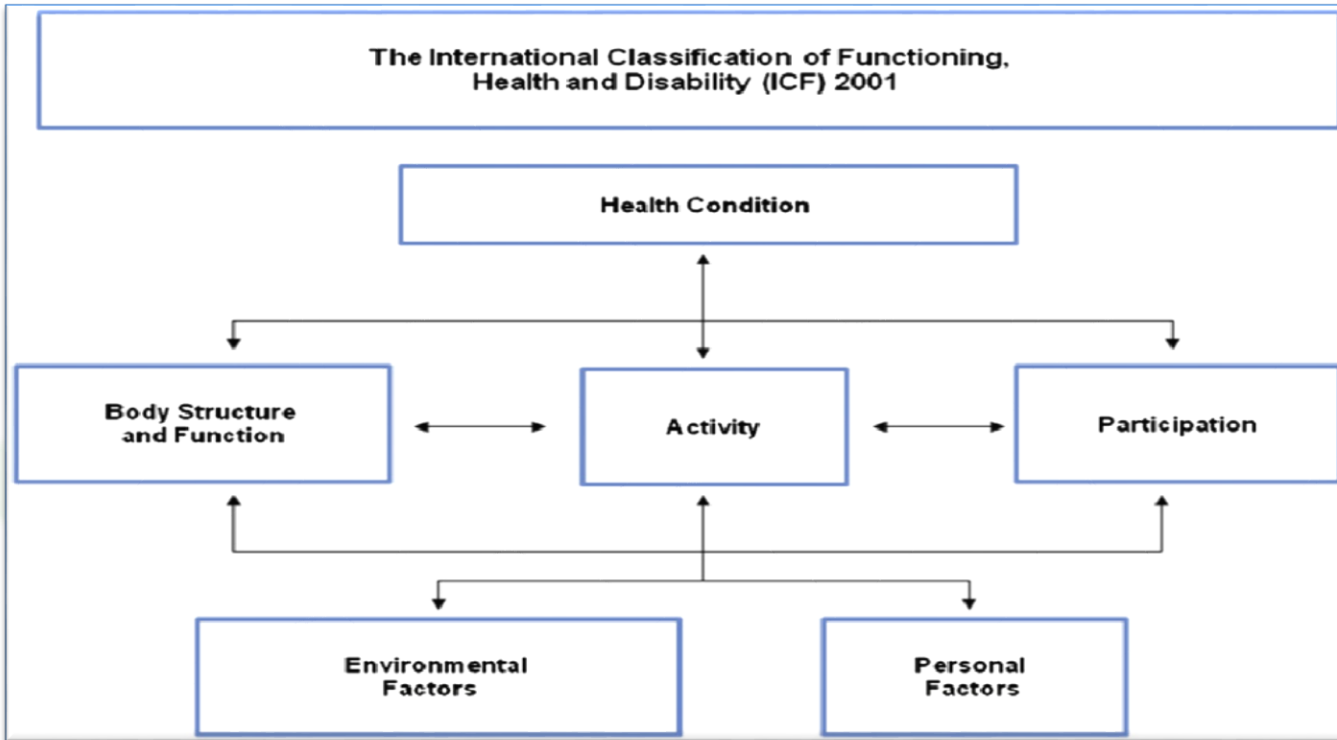


# What Has To Be Done



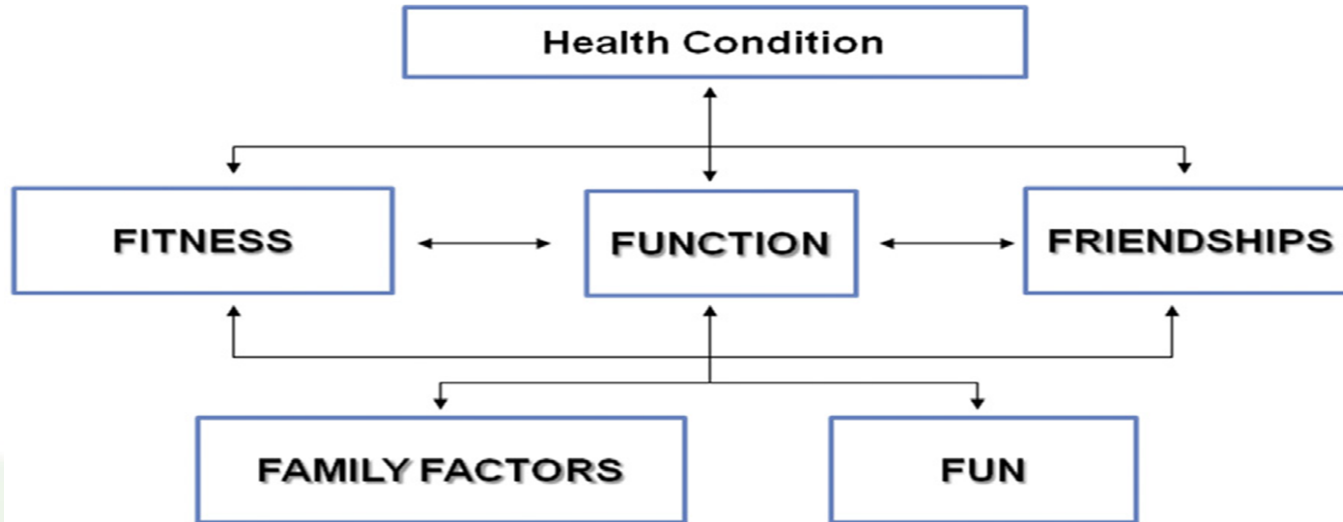
- **Treat acute conditions**
- **Prevent secondary complications such as delayed growth, malnutrition, infections and pain**
- **Enable childhood practice of basic life skills**

# International Classification of Functioning





## The International Classification of Functioning, Health and Disability (ICF) 2001



# PARÁLISIS CEREBRAL: MIS PALABRAS FAVORITAS

1



## FUNCIÓNES

Es posible que haga las cosas de manera diferente, pero muchas veces **PUEDO** hacerlas. No es importante cómo las hago. ¡Por favor, déjeme intentar!



## 2 FAMILIA

¡Mi familia es quien mejor me conoce y hace lo mejor para mí.

3



## ESTADO FÍSICO

Todos necesitamos estar en forma y tener buena salud. Por favor, ayúdenme a encontrar maneras de mantenerme en buen estado físico.



## 4 AMISTAD

Es importante tener amigos durante la niñez. Por favor, facilíteme oportunidades para tener amigos de mi edad.

5



## FELICIDAD

La niñez es sinónimo de diversión y juego. Así es como aprendo y crezco. Por favor, ayúdenme a realizar las actividades que más me gustan.



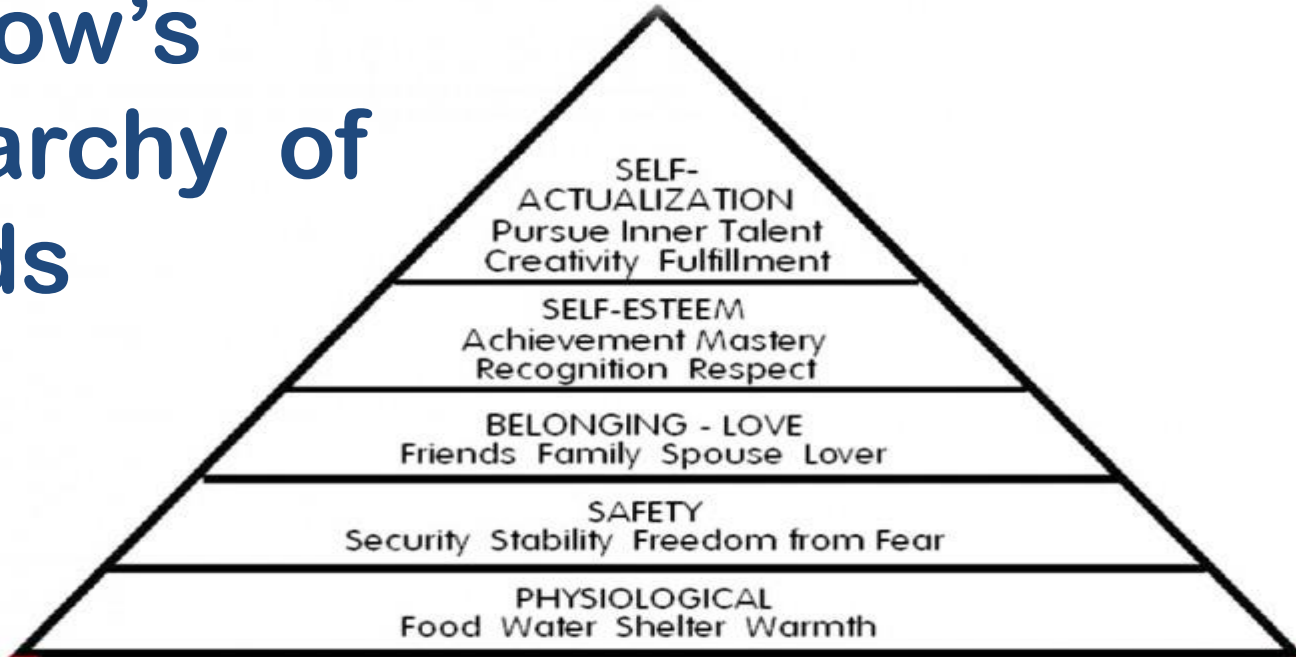
## 6 FUTURO

Algun día seré grande. Por favor ayúdenme a encontrar formas para desarrollar la mayor independencia posible y sentirme incluido en la sociedad.

World Cerebral Palsy Day  
worldcpday.org

\*Apoyado con lenguaje por The AbleGamers Foundation  
Funded in part by: #1 & Games 2019 (2019), the #1 source in disability disability / issue this is how we should think! Child Care, Health and Development (2019), visit <https://www.canchild.ca/en> research in practice / needs in childhood disability for more resources.

# Maslow's Hierarchy of Needs



# Agenda



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- ④ How innovation improves care

# Teamwork



# Shira



# Active Rehab Technologies



**Diagnostic technologies**  
gait labs, pressure  
analyzers



**Therapeutic  
technologies**

drugs, intra-theal pumps, botox,  
genetic intervention



**Virtual Reality  
Simulators**



**Augmented  
communication devices**



**Prosthesis**  
low and high tech



**Surgeries**  
dorsal rhisotomies,  
osteotomies, pacers



**Mobility devices &  
exoskeletons**



**Tele- rehabilitation**





# “Health is the ability to adapt and to self manage”

Huber et al. BMJ 2011



# Is Expensive Rehabilitation Worthwhile?



## Can a Paralyzed, Ventilated Person Contribute To Society?



But... even if they cannot contribute to society, don't they still have a right to live?

# Conclusion

- ✓ Rehabilitation of chronically disabled children requires a multi-disciplinary and holistic approach.
- ✓ Even paralyzed, ventilator-dependent children can have good quality of life, if we give them:
  - ✓ A support system (family, society)
  - ✓ Tools for mobility and function

# Agenda



- ① The WHO led principles of Rehabilitation
- ② The growing need for Chronic Care & Rehab
- ③ How Assistive Devices can improve QOL
- ④ **How Innovation improves care**

# Goal & Challenges



- 93 million children worldwide have a physical disability and need rehabilitative devices
  
- Most remain without appropriate devices because:
  - Appropriate devices do not exist
  - Devices are too expensive
  - Devices are suitable for adults only

# Diaphragmatic pacing



# Quality of Life - Challenges



- Moving from technology-oriented care to child- life centered care
- Sever the technology = hospital concept
- Improving accessibility and participation
- Helping government and institutions close the gap with medicine

