Disability – Quality of Life

Disability - Quality of life

- **The United Nations Convention on the Rights of Persons with Disabilities (CRPD),** adopted in 2006, aims to :

"promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity".

- It reflects the major shift in global understanding and responses towards disability.

*WHO 2011[1]

Disability - Quality of life

Quality of life is a **complex experience** influenced by:

- objective conditions in which a person lives (**social indicators**)
- subjective response of the person to their life conditions (**psychological indicators**)
- the adjustment of expectations and needs of the person with their lifestyle (**social policy**)
- external influences

*Andelic Bakula et al. 2011 [2]

Disability - Quality of life

Disability affects:

- the satisfaction with health

- the ability - of independent functioning
  - to work and earn for a living
  - to have and raise children
  - to achieving partnerships

- own body image, self concept and self-esteem

a **lower quality of life** for people with disabilities

*Andelic Bakula et al. 2011[2]

Disability - Quality of life

For disabled persons and their families → **doubly difficult**

- general health problem
- unique social stigma

attached to various types of disability.

*Pune 2007[3]

Disability - Quality of life

- **Most pressing issue** faced globally by persons with disabilities=

lack of equitable access to resources (education, health care facilities, employment, social participation activities) and **not their specific disability.**

Ref6 LINK 22 cum sa scriem?[4]

Disability - Quality of life

- More fragile general health
- ↑ dependency
- Limited participation in society
- Poverty rate→ higher for people with disabilities

Barriers

- health
- education
- transportation
- information
- work services

(link 15 prevalenta in lume)[5]

Disability is **not just a health problem or attribute of individuals**, **BUT**

it reflects **difficulties** individuals may experience **in interaction with society**

*Fellinghauer et al. 2012[6]

Barriers to health care

- **Prohibitive costs**
- **Limited availability** of health service
- Vulnerability to **secondary conditions**, **co-morbid conditions**, **age-related conditions** and **higher rates of premature death**
- **Inadequate skills and knowledge** of health workers
- **Physical barriers:** -difficult access to buildings (hospitals, health centres, dental offices)
  -inaccessible medical equipment
  -poor signage
  -narrow doorways
  - internal steps
  - inadequate bathroom facilities
  - inaccessible parking areas

*Andelic Bakula et al. 2011[2]

Barriers to education

- **Accessibility** - difficult access in school buildings

  -difficult access to education for children from remote rural area or from families with low socio-economic level.

- **Inadequate teacher training and support**

- **Inflexible curriculum and materials –** Less than 5% of published books are available in formats appropriate for people with visual impairments.

*(LINK 15 PREV IN LUME cum sa scriem?)[5]

Barriers to education

- **Poor policies and plans**

- Many countries **do not have plans, targets or policies** that include children with disabilities.

- **Education budgets** in developing countries → often **limited, insufficient** resources for children with disabilities.

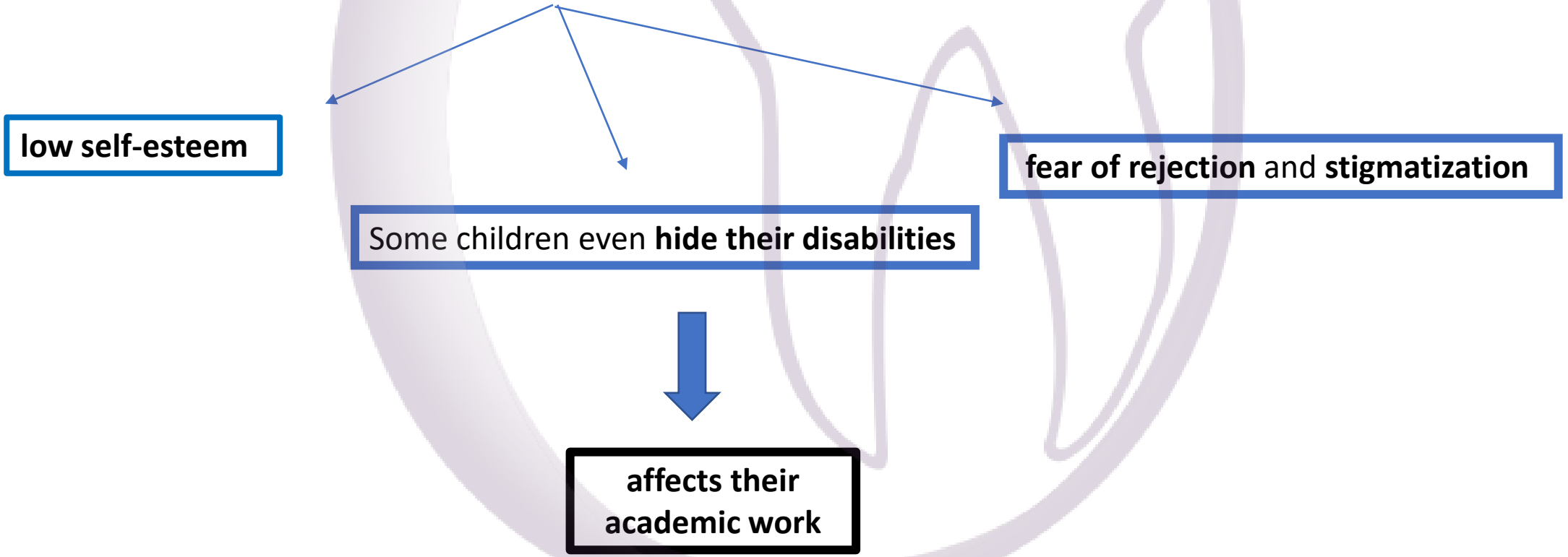
- **Lack of accurate data** → works against effective laws and policies being introduced.

*LINK 15 PREV IN LUME)[5]

Barriers to education

Cultural barriers

Negative attitudes to people with disabilities leading to **bullying**, **abuse** and **exclusion from school** (teachers/parents/other children)



* https://theirworld.org/explainers/children-with-disabilities#section-2

Disability - Quality of life

World Health Organization (WHO) & World Bank estimate that in some countries

"being disabled more than doubles the chance of never enrolling in school".

An estimated **1:3 out-of-schoolchildren have a disability ***

(*) https://theirworld.org/explainers/children-with-disabilities#section-2

Different opinions between studies

- Some → **poor** quality of life for disable people

BUT,

- Other →**more satisfaction** in some aspects of life for disabled people

*Gojceta et al.: subjects with **cerebral palsy** → greater satisfaction with:

- social aspects
- relationships with other people
- spiritual values
- school performance

*Andelic Bakula et al. 2011 [2]

Different opinions between studies

- Some → **duration of the disability is not related to quality of life**

- Other → **the longer duration of disability, the better the quality of life** for people with physical disabilities, because over the time:

  - accept their disability and go through changes in self perception
  - recognize values other than those that are in direct conflict with the disability
  - devalue of the importance of those aspects of physical ability and appearance that contradict their disabling condition
  - handicap is not extended beyond actual physical impairment to other areas of the functioning
  - emphasize of own assets and abilities

*Dowler et al.(2001) [7], Ford et al. (2001) [8] in Andelic Bakula et al 2011[2]

Disability - Quality of life

- Persons with **congenital disabilities** are more likely **to accept their disability** than persons with acquired disability *Li et al. [9] in [2]

- **Social participation and interpersonal relationships** are important for quality of life of persons with physical disability

positive social relations

*Tonack et al. 2008 [10], Levasseur et al. 2004. [11] in [2]

Life satisfaction

- The **level of education** is positively associated with satisfaction with life in people with disability.

- **Employed persons** with disabilities are more satisfied with life than unemployed.

- **The quality of housing** has proven to be important for the life satisfaction of persons with disabilities.

*Andelic Bakula et al. 2011[2]

Inclusive education

- enables children with disabilities to be educated in local schools rather than be educated separately
- requires system-wide and structural changes to reduce and remove the barriers

*https://theirworld.org/explainers/children-with-disabilities#section-2

Disability - Quality of life

- Education can help people with disabilities get increased access to resources and develop a better awareness of their rights.

- When people with disabilities **get a quality education**

They are enabled to:

take up **key positions** in their communities
challenge stigmas
change negative attitudes about their abilities

Draga mea tara, fii mai incluziva! Învață să respecți drepturile tuturor! Fa trotuarele din oras drepte si fara denivelari. La evenimentele publice fa un loc special pentru persoanele cu dizabilitati.

Vlad Andrei Stamate

Disability - Quality of life

People with disabilities have the same health needs as non-disabled people.

(LINK 12) [WHO data about disability][12]

Disability - Quality of life
Oral health

Individuals with disabilities → highly vulnerable population group particularly as far as oral health is concern.

*Couto et al. 2018 [13]

Dental disease

Negative impact on life quality, affecting not only physical wellbeing, but also psychological and social wellbeing -ref 36 link 39

- concerns over facial appearance→ tendency to avoid social contact
- persistent pain → isolation & depressing effects
- verbal and non–verbal communication disturbances→ self–image damage, alteration of the ability to sustain and build social relationships[37]
- physionomy and speech disturbances

*Australian Department of Health and Human Services [14]

Oral health

- Even **specific protocols** for treatment under **GA** in patients with disabilities can have a **negative impact** on QoL- e.g.: a primary tooth with complicated decay is recommended to be extracted even if it is an upper central incisor and this has a negative impact on his/her appearance.

For an autistic child, this situation has consequences on social integration, which is already difficult.

Oral health

Disabled people

→ vulnerable to **poor oral health**

→more **complex** oral health care **needs**

*Wilson et al. 2019[15], Horwitz et al. 2000 [16]

- **Poor oral health** status → impact on
  - nutrition
  - digestion
  - chewing
  - appearance
  - speech

*Saravane et al [17]

Oral health

Dental conditions in childhood:

- can restrict children's participation in schooling and education through days lost to illness.

- can further limit children's ability to socialize with confidence and develop social norms and relationships.

*Australian Department of Health and Human Services [14]

Poor oral health factors

- **Oral Conditions**
  - genetic disorders → enamel defects, anodontia or supranumerary teeth, malocclusions, gum disease.

- **Physical limitations**.
  - Difficulty to chew/move their tongues properly→do not benefit from the natural cleaning action of the tongue, cheek and lip muscles

*California Childcare Health Program[18]

Poor oral health factors

- **Difficulty of brushing and flossing**
  - poor motor coordination (spinal cord injuries, muscular dystrophy or cerebral palsy)→ not able to clean their own teeth/use the usual brushing and flossing methods [18]
  - parents→ difficulty in carrying out proper regular oral hygiene measures [19]
- **Reduced saliva flow**
  - Children who need help drinking → may drink less fluid than other children

→ may not have enough saliva in their mouth to wash away food particles [18].

*California Childcare Health Program[18]

*Purohit et al. 2012 [19]

Poor oral health factors

- **Medications**
  - sweetened medications for a long time → tooth decay [18].
  - anti-seizure medications → swelling/bleeding of the gums [18].
  - medication used to treat cerebral palsy, seizures, depression, asthma or allergies → low saliva=xerostomia [20].

- **Restricted diets**
  - Difficulty of chewing and swallowing → puréed food that sticks to their teeth [18].

*California Children Health Program [18]

*Brush Up on Oral Health. U.S.National center on Earlichildhood Health and Wellness 2020 [20]

Poor oral health factors

- **Communication difficulties**

ID → difficulties in communicating oral health needs.

*Faulks et al. 2000 [21]

→difficulty in understanding the significance of oral cleanliness

→tend not to cooperate

→resistance while toothbrushing (another barrier to parental success in helping their children with oral hygiene)

*Xiaoqiu 2008 [22]

- **Dental anxiety**
  - impaired communication→ **more dental anxiety and communication difficulties** like in children with autism- articol EAPD[23]

Disabled children and oral health pathology

I. **Caries** and **periodontal disease** prevalence→ **higher** in children with special healthcare needs than in the healthy controls.

*de Jongh et al. (2008)[24], Saravanah et al. 2003[25]

▪Dental caries prevalence= 78.3% to 89.6% in different types of children with special health care needs.

*Reddy et al 2011[26] ; Shyama et al 2001[27] in [20]

II. **Overgrowth of gums** caused by medications used to treat seizures, high blood pressure and weak immune systems → increased risk for periodontal disease

*California Children Health Program [18]

Disabled children and oral health pathology

III. Malocclusion in many children with developmental disabilities

- May be associated with: -muscular abnormalities
  -delayed tooth eruption
  -underdevelopment of the jaw
  -chewing and speaking difficulties

Increased risk of - periodontal disease
- dental caries
- oral trauma

*California Children Health Program [18]

Disabled children and oral health pathology

IV. Tooth anomalies

- variations in the number, structure, size and shape of teeth. *California Children Health Program [18]

V. **Trauma and injury** of the face and mouth

- more frequently in children who have mental retardation, seizures, cerebral palsy, abnormal protective reflexes or lack of muscular coordination *California Children Health Program [18

VI. **Tooth eruption** depends on genetic factors, growth of the jaw, muscular action and medications.

- may be delayed, accelerated or inconsistent.
- some children may not get their first primary tooth until they are 2 years old.

- *California Children Health Program [18]

Disabled children and oral health pathology

- **Damaging oral habits** can be a problem for children with disabilities and special needs.

- Some of the most common of these habits are:
  - grinding or clenching
  - food pouching
  - mouth breathing
  - tongue thrusting
  - picking at the gums
  - biting the lips

*California Children Health Program [18]

Oral health problems-signs

- teeth grinding
- food refusal/preference for softer foods
- behaviour changes such as touching in or around the mouth, teeth, jaws and cheeks
- smelling breath
- discolored teeth

*California Children Health Program [18]

Treatment needs

- Mean values for treatment needs= higher in subjects with special healthcare needs.

- Treatment needs for pulp care= higher among children with special healthcare needs.

*Purohit et al. 2012 [19]

Treatment needs

- Policies and treatment for decreasing the number of missing teeth

- Dental accessibility improvement:
  - mobile care units
  - administrative system (expansion of the existing workforce of a mobile dental care team)

*Lee et al 2019 [28]

Disability - Quality of life

For all the mentioned reasons, **PREVENTION** is essential.

Primary prevention - the simplest and most effective method to:

- avoid symptoms & complex treatment sessions
- reduce costs
- ease the burden on - families and caregivers
  - society

significantly improve QoL of disabled children/patients

Disability - Quality of life

According to AAP (1992):

medical care of children of all ages is best managed when there is **a relationship established between a practitioner who is familiar with the child and the child's family**

applied to dental medicine → **Dental Home**

Dental Home in Romania

- Given the oral health of children with disabilities in Romania, but also the difficult access to specialized medical services, it would be desirable that the Dental Home system to be implemented in our country, initially at a small, individual scale and then progressively on a larger scale.

- For this purpose, information and education programs for families, caregivers and medical assistants should be initiated and then developed

Equal rights

In order to achieve the purpose of ensuring equal rights and opportunities for the disabled persons, a series of ‘legal instruments’ were developed internationally:

- United Nations Convention on Rights of Persons with Disabilities (2006)
- The European Disability Strategy (2010-2020).
- Specific legislation at national level against discrimination on grounds of disability.

*Baciu et al. 2017 [29]

Global goals for 2030

- Equal access to education and vocational training
- Building or upgrading education facilities to make them inclusive learning environments
- Safe, accessible transport systems for all

The UN Convention on the Rights of Persons with Disabilities (2006) has now been ratified by 157 countries, which means they are committed to providing inclusive education to all children with disabilities.

https://theirworld.org/explainers/children-with-disabilities#section-2

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