

Primary Factors That Affect the Social Participation of Children With Neuromuscular Diseases

PERSONAL FACTORS

Decreasing Abilities

- ✦ Deteriorating change in strength, coordination and balance
- ✦ Gradual appearance of contractures
- ✦ Deteriorating change in sensitivity, etc.
- ✦ Deteriorating respiratory ability
- ✦ Endurance, fatigue
- ✦ Loss of the ability to walk in some cases

Deteriorating condition and increasing losses in the nervous, musculoskeletal and cardiorespiratory systems

- ✦ Increasingly complicated state of health
- ✦ Maintenance prevention impact
- ✦ Severe and quick deterioration of functional control

- ✦ Choices, mourning and renunciation
- ✦ Accepting assistive aids, human assistance and compensatory means
- ✦ Self-determination, motivation

Informed consent

Possibility of a variety of cognitive and communication disorders

ENVIRONMENTAL FACTORS

Physical Factors (obstacles and help)

- ✦ Accessibility adaptations to the home, residence, school and public places
- ✦ Climate, geography
- ✦ Accessible transportation, adapting a motor vehicle
- ✦ Accessible equipment, materials and commercial products
- ✦ Assistance with ADL (assistive aids)

Social Factors (Obstacles and Help)

- ✦ Accessible health, rehabilitation and social services that meet the needs when they arise
- ✦ Parenting skills;
- ✦ Capacity to adapt the family and social environments, , or other.
- ✦ Financial constraints (family and societal)
- ✦ Discrimination or integration (family and social values, beliefs and attitudes, etc.)
- ✦ Assistance with ADL (human)
- ✦ Assistance in school or in an alternative educational facility
- ✦ Laws and normes related to employment
- ✦ Network of respites and supervised residences for sick children
- ✦ Scientific knowledge
- ✦ Community organizations

The social participation of children living with a neuromuscular disease primarily depends on their ability to adjust to the disease, the degenerative aspect of the disease and their environmental context.