Overview of Habilitation and Rehabilitation for Children and Adolescents in Europe

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According to the World Health Organization, "rehabilitation [of people with disabilities] is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination."[1] The World Health Organization's Website illustrates this definition with a photo showing a child in a wheelchair; however, the spectrum of rehabilitation goes far beyond neurologic disabilities and includes virtually all organ systems with or without neurologic comorbidities. Unfortunately, these other indications for rehabilitative care are sparsely mentioned in the relevant literature dealing with rehabilitation of children.

In Europe, the tradition and degree of pediatric rehabilitation vary widely. Although some countries, such as Germany, have widely adopted trends of the 1980s to establish pediatric rehabilitation as an separate field or even discipline,[2] other countries have not felt the need to do so, and consider rehabilitation a responsibility of hospitals or other already existing health care providers.

Some uncertainty also remains as to which children and adolescents actually are candidates for rehabilitation. Some national regulations consider rehabilitation a measure to "restore the ability to work" (thus excluding children by definition) or distinguish between inborn and acquired disabilities/diseases, providing rehabilitation only for the latter.[3-6]

Although it is common to provide rehabilitation for adults after myocardial infarction, stroke, neurosurgical and orthopedic interventions, and for adults with rheumatic and other chronic diseases, this does not hold true for children. Whether children and adolescents receive appropriate rehabilitative measures currently depends on national/regional regulations and, to some extent, on the individual commitment of doctors and other health professionals.

Pediatric Rehabilitation as Part of Children's Rights to Health

Approximately 10% of all infants are at risk for developmental disabilities, and 1% of all children have severe persistent handicaps. According to the United Nations Convention on the Rights of the Child, Article 6, these children have the right "to survive and develop healthily."[7] Article 23 states that "children who have any kind of disability have the right to special care and support…so that they can live full and independent lives."[3] Thus, although the term "rehabilitation" is used only in Article 39 (Rehabilitation of Child Victims), the United Nations Convention clearly expresses that children should have access to rehabilitative measures in the event of relevant underlying health problems.[1,2,8]

The Fields of Habilitation and Rehabilitation

Discussions regarding "habilitation" of children with congenital or hereditary diseases and "rehabilitation" of children and adolescents with acquired diseases occur mostly in connection with neurologic disabilities. However, many other organ disorders represent indications for rehabilitative interventions.[2,9-11] Disability is extremely diverse. **Table I** (available at www.jpeds.com) displays potential fields of rehabilitation and some typical diseases. Habilitation and rehabilitation are cross-sectoral activities and may be provided by health professionals in conjunction with specialists in education, employment, social welfare, and other areas.

Neurologic Rehabilitation: The Multiphase Model

Neurologic rehabilitation in children and adolescents plays a pivotal role in the field of pediatric rehabilitation[12] and involves acquired brain and spinal cord injury, hypoxia of the central nervous system, inflammatory diseases, epilepsy, muscular diseases, vascular processes, and central nervous system tumors. Management of acute brain injury has 4 phases (**Table II**; available at www.jpeds.com); after initial stabilization at the pediatric intensive care unit, a continuous

EU	European Union
SPC	Social Pediatric Center

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and increasing rehabilitation process is initiated, with a transitional process from intensive, intermediate care to full rehabilitation of the stable patient.[13] Long-term neurologic rehabilitation in children requires a multidisciplinary and interdisciplinary approach that includes neuropediatricians, physiotherapists, occupational therapists, speech therapists, psychologists, social workers, orthopedic surgeons, and orthopedic equipment technicians.

Social Pediatrics and Rehabilitation in Children with Vision, Hearing, Mental, Motor, and Skeletal Disabilities in Different European Union Settings

Significant differences exist among European Union (EU) countries in the conceptual approach to social pediatrics and rehabilitation for children, reflecting the original differences in the organizational structures of the various public healthcare systems. For instance, since 1989, Social Pediatric Centers (SPCs) and their responsibilities have been defined by German law (§119 Soziales Gesetzbuch, SGB/Social Legislation), and every primary care pediatrician in Germany can refer patients with visual, hearing, mental, motor, or skeletal disabilities to a licensed SPC for further diagnosis and therapy.[14] The costs are covered by health insurance.[14] Today, there are 145 certified SPCs throughout Germany. Owing to the federal organization of health care in the 16 German regions, the spectrum of diseases qualifying for care in regional SPCs has expanded differently, from neurologic indications to metabolic and other disorders. Approximately 1% of 12 million children are enrolled in one of these SPCs on an outpatient basis, receiving multidisciplinary therapy by pediatricians, psychologists, physiotherapists, speech therapists, occupational therapists, and social workers, frequently in collaboration with other specialists (eg, orthopedic surgeons, geneticists, psychiatrists). SPCs are often located in the vicinity of children's hospitals to provide easy access and allow for efficient collaboration.

In Germany, children with a more complicated disease course may be referred for a 4- to 6-week inpatient stay to 1 of the 46 pediatric rehabilitation centers located throughout the country.[15] Most of these centers specialize in few subspecialties to guarantee high-quality treatment. In 2014, 10% of all admitted children were admitted by 1 of the 420 children's hospitals to shorten their hospital stay (eg, transfer of preterm infants according to §43 Abs. 2 SGB V). The transfer from pediatric to adult rehabilitation social medical centers (Sozialmedizinische Zentren für Erwachsene mit Behinderung) is regulated by §119c V SGB.

In Austria, a long process of national planning has recently resulted in the assignment of 343 pediatric beds for rehabilitation, covering all organ disorders as well as mental health.[9] At present, an agreement is being developed regarding: (1) how many centers should provide pediatric (re)habilitation; (2) which indications should be combined in a specific center; and (3) where these centers should be located. Ideally, approximately 4 pediatric rehabilitation centers should be spread throughout the country, preferably in the vicinity of a children's hospital, providing therapy in patients' neighborhood whenever possible. Owing to the small patient numbers for some indications (eg, hemato-oncology, rheumatology), only one center may be assigned to guarantee an appropriate quality of subspecialty care.

In the Italian pediatric population, the overall prevalence of disability requiring rehabilitation care is 10% (conditions of intermediate severity 2.5%; multiple, severe, and complex conditions with limitation of autonomy 0.5%).[16] The Italian government issued national guidelines for rehabilitation in children in 2011 and established a network of rehabilitation services dedicated to children. Specialized departments are based mainly in large children's hospitals and in a limited number of pediatric units in general hospitals. Rehabilitation services for children are provided by regional public health care centers. Family pediatricians are trained to interact with these centers. In addition, several private rehabilitation centers are active throughout Italy. The costs of care in public and private rehabilitation centers are covered by the national tax-based health system.

At present, the aforementioned countries—Germany, Austria, and Italy—are lacking data on the clinical and cost benefits of investing in neurobehavioral rehabilitation in children and adolescents, in contrast to adults.[17]

Pretransplantation and Posttransplantation Rehabilitation

Physical and mental disability may accompany all stages of organ failure and transplantation. Preserving functional ability and quality of life in the pretransplantation and posttransplantation phases of care in children is a complex task. In nephrology, for instance, there is no general contraindication regarding renal transplantation in children with disabilities, such as trisomy 21.[18] In one study, one-third of young European adults starting renal replacement therapy during childhood had one or more disabilities,[19] and 44% were unemployed, many still living with their parents. The major factors influencing employment were the presence of disabilities, lack of education, method of treatment, underlying primary disease, and geographical factors.[20] We conclude that rehabilitative care should start during chronic kidney disease stages IV and V and continue during dialysis and throughout the acute and postacute transplantation phases. Adequate health education, intensive communication with caregivers, and participation of children in decision making to the greatest degree possible will empower patients and reduce costs originating from preventable late complications.

Two rehabilitation centers in the German-speaking EU countries offer repeat pretransplantation and posttransplantation rehabilitation, with each cycle lasting a minimum of 3 weeks. Young patients may be accompanied by their complete family. Adolescents are treated in absence of family members to train autonomy. Targets of patient care are increased physical strength and improved self-confidence,