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REVIEW ARTICLE

Social management of disability: from exclusion to social inclusion, a bibliographic review

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Abstract

This study is a bibliographical review, which was conducted for the master's thesis titled "Study of the Availability and Analysis of Rehabilitation Programs for Disabled Children and Youth in the Municipality of Rio de Janeiro", presented in the Graduate Program of the Medical Clinics Department of the Federal University of Rio de Janeiro in December 2016. The history of how humanity deals with individuals with disabilities from the beginning of our civilization until today represents the evolution of the social management of disability. This review provides a historical perspective from the time in which social exclusion was the norm until today's social insertion of this large population that includes children and adolescents. This review also demonstrates that different forms of socially dealing with disability still coexist, affecting health management policies and practices, which need to be reconsidered. The dissemination of this process to young physicians increases the possibility of more equitable treatment of a growing population of children and adolescents with disabilities. Expanding knowledge about rehabilitation is essential because scientific and technological advances combined with constant social achievements enable social insertion of individuals who would otherwise be excluded from society.

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The knowledge about the different forms of addressing deficiency throughout history may help understand the difficulties faced by this population and to find strategies that facilitate their social inclusion, and humanizing the activity of health professionals. History is not linear and, undoubtedly, different ways of dealing with disability by society still coexist in present day and affect policies and practices, which need to be reconsidered¹.

Deviations from the norm have always been present in the history of humanity. Primitive societies did not faithfully record how they dealt with individuals with disabilities, i.e., individuals with physical and behavioral differences, and that therefore diverged from the characteristics and behaviors expected by the group. These individuals often could not participate in the productive chain, and some required greater attention and care. From the knowledge gained from the history of humanity, quotes in ancient documents and literary and mythological texts can indicate how the problem was addressed by the early days of our civilization when the exclusion of this group from social interaction was the most common practice².

Plato's "The Republic", in the dialogue between Glaucus and Socrates on the fate of children with anomalies born in the utopian city imagined by these two characters, instructs that "those with deformities should be taken to an unknown and secret place" to preserve the purity of the nation of warriors³. The exclusion of individuals with differences became the solution in this period. In the Old Testament of the Holy Bible, in the book of Leviticus, Moses is told that a man with a bodily defect cannot come in the temple⁴. In Greek mythology, the god Hephaestus, also identified as Vulcan, has a physical defect resulting from being thrown out of Olympus by his mother, who was annoyed by the fact that the child was born with a defect in the lower limb⁵. Oedipus, another mythological character, famous for being used in psychoanalysis to designate a phase of maturation of human emotions, had a defect in his feet and was thus exposed at birth to conditions in which others would hardly have survived⁶. In the play *Richard III*, Shakespeare (1592) associated the congenital defect of the king to his malicious behavior. This literature suggests that children with congenital defects were not well received by the community and body perfection was a sign of health.

Disability in ancient civilizations could also be the result of mutilations, which were the consequence of penalties for crimes committed⁷. The defect was considered a proof of guilt carried by the subject, who was shamed until death, and served as a warning that others should not break the law. Individuals with disabilities were equated with criminals, implying that they should feel shame and guilt over their existence, and were despised by society⁸.

The New Testament of the Holy Bible documents several episodes involving individuals with disabilities and shows that in ancient Judea at the time of Jesus Christ, their fate was to beg for survival and wait for a miracle. The advent

of Christianity strengthened the impulse to help the needy because charity was a virtue to be cultivated. According to Oto Silva in his book "Ignored Epic," Jesus Christ performed 40 notorious miracles, 21 of which involved individuals with physical or sensory disabilities, which indicated impurity or sin, and only a divine action could save them. In that period among the Hebrews and among other contemporary peoples disabled individuals were on the fringe of society and at the mercy of benevolence⁹.

In Europe in the Middle Ages, cities were surrounded by walls and moats to exclude undesirable individuals, and the space of the fief was designed to shelter and protect the equal and desirable. In this period, Christianity grew and preached piety, and disabled individuals acquired a human status with a soul although they were not productive to society¹⁰. With the construction of shelters, asylums, and hospitals for the unprotected, individuals with disabilities started to find their place, although they were still marginalized from social life in this feudal model of islands of isolation.

These places, designed primarily for the exclusion of the sick and miserable, became places of healing with the replacement of religious power by the power of medicine¹¹. This model lasted for many years, strengthening an organicist view of disability by associating it directly with the disease, which was then a private problem of the subject who needed medical care¹².

In the book "Far from the Tree," Solomon¹³, in the chapter on the deaf, reports that in 1755, the Abbot Charles Michel Épee founded the Institute for the Instruction of the Deaf-Mute and was one of the first non-deaf individuals to understand sign language. According to Solomon, the American Asylum for Education and Instruction of the Deaf was created in 1817 in Hartford, Connecticut, United States. The possibility of developing language via signs enabled deaf individuals to enter public life. In this document, he reports that, after deaf individuals had gained social visibility with the development of sign language, the capacity and functionality of this social group became evident and thus orality, which would make them less different, became a requirement.

In the Congress of Milan in 1880, the educators of deaf individuals decreed the impropriety of sign language, understood as a human setback and considered a stupidity. The educator's effort became focused on the goal of making the deaf talk, often by tying the hands of deaf children. Deaf children became educated in oralism because, in that period, it was not known that signs were part of a complete and complex language, with its grammar, as in any other language and, for this reason, these children were deprived of a better cognitive development.

By Decree-Law 10.436 of 2002 of the Presidency of the Republic of Brazil, Libras-Brazilian Sign Language-became the official language of the deaf in Brazil¹⁴. Sign language is the natural language of the deaf. However, even today, it is difficult to understand this reality and the need for interpreters who

can ensure the best communication between the deaf and the listeners¹⁵.

On September 26, 1857, the Institute of the Deaf-Mute was created with the signature of Imperial Decree 839 by Dom Pedro II, and this Institute started as an asylum for deaf children from all over Brazil. Figueira¹⁶ reported that the feminine day-care center was created in 1931 with sewing and embroidery workshops, and its nature as a professional establishment was consolidated in 1925. In 1957, it became known as the National Institute of Education of the Deaf (INED) and at present is a reference in the area of deafness, supporting the education and research of new methodologies for the teaching of the deaf.

The academic education of the visually impaired was initiated by the development of a writing system by Louis Braille in 1819 based on a six-point embossed model used by the French military to make nighttime reading possible. This type of writing guaranteed the access of the visually impaired to organized knowledge¹⁷. In 1854, via Imperial Decree 428, Dom Pedro created the Imperial Institute of Blind Children in Rio de Janeiro. This Institute used Braille writing for the education of children. In 1891, this Institute was named the Benjamin Constant Institute (BCI), as it is known to this day¹⁶. The BCI has become a reference for education to the blind and teacher training in the area of visual impairment. It supports schools and institutions, provides rehabilitation, and publishes specialized material and scientific publications in Braille¹⁸.

In 1866, the English physician John Langdon Down, who worked in an asylum for children with mental disabilities, in Surrey, England, described the syndrome that he named mongolism, and differentiated these children from those whose intellectual deficit was caused by hypothyroidism, known as cretinism¹⁹. Without undermining the merits of his descriptive work, the comparison with individuals of Asian origin using minor traits, which were recurrent in the syndrome he described, denoted prejudice stemming from ignorance about the sophisticated and complex culture of the eastern world. By using ethnic aspects to classify behavioral patterns considered inferior, and to infer that the human species had evolved from Black to Asian and from Asian to Caucasian, he concluded that mongolism was, in fact, a retrocession to the primitive²⁰.

Until the first half of the twentieth century, many parents were encouraged by health workers to abandon their children with Down syndrome, persuaded by the idea that these children were an error of nature and did not have the proper human identity²¹. According to Solomon (2012b), individuals with mental disabilities were evaluated only from the viewpoint of intellectual ability, without taking into account their adaptive, affective, and functional potential, and their potential to live as productive members of society.

From the nineteenth century, society began to understand its responsibility towards individuals with disabilities and recognize their work potential¹⁰. New

organizations emerged not only for the assistance and protection of marginalized individuals but also for the development of treatment. In 1863, the citizens of New York created the New York Society for Relief of Ruptured and Crippled for disability care, with the view to insert this social group into the labor market. This organization was then transformed into the New York Hospital for Special Surgery, which is recognized to this day as one of the best hospitals for care of several types of physical disability⁹.

The success of the education of Anne Sullivan, who was blind and deaf since the age of 19 months, achieved by the dedication of Hellen Keller, who taught Anne to read and write, is a milestone in the history of rehabilitation. In the mid-twentieth century, the visit made by Hellen Keller to INED to inaugurate a course for the training of teachers of deaf children had a major journalistic repercussion in Brazil because it was an example of successful rehabilitation¹⁶.

This experience broadened the vision of the population about disability. The assessment of the problem of disability considering only biological characteristics is insufficient because medical intervention alone does not guarantee survival, and other factors are necessary to ensure the quality of life. There was a growing recognition that facing difficulties was necessary to deal with the complex relationships between biological, medical, and social aspects²².

The traditional view that disability was an individual phenomenon was no longer dominant, as arguments for the social conception of disability were raised in the twentieth century, and therefore a biological, psychological, and social approach was created to promote a comprehensive view of disability and social inclusion. This approach rejected the attempt to separate biological, psychological, and social components²³. Individuals with disabilities have an important role in society and are part of any social group, and deficiency is considered a form of the human condition that becomes a problem for everyone²⁴.

After World War I, the United Kingdom Central Commission for the Care of the Disabled was established in England and, in 1917, the United States created the Rehabilitation and Research Center to develop technologies that improved the life of disabled individuals¹⁰. A breakthrough in rehabilitation occurred after World War II, when various civil societies organized to care for the large contingent of disabled individuals that came into existence, strengthening the conviction that they could and should be part of the labor market¹².

Another major cause of disability was polio. Until the first half of the twentieth century, this viral infection was responsible for many deaths and caused important motor sequelae in children. In the second half of the twentieth century, the focus shifted from care to prevention and control. The pediatrician Fernandes Figueira described the first outbreak in Brazil in 1911, and the vaccine was first used in 1961. The last case was reported in Brazil in the municipality

of Souza, Paraíba, in 1989²⁵. Franklin Delano Roosevelt, elected president of the United States in 1932, was one of the most famous victims of poliomyelitis, which he contracted in 1921 at age 39²⁶.

The development of rehabilitation centers and the prescription of orthoses, which provided favorable outcomes, particularly for sequelae in the lower limbs, ensured the functionality and visibility of these patients. The international press, especially in North America, gave emphasis to poliomyelitis, and many campaigns to raise funds were created for the rehabilitation of children with polio, allowing them to attend schools and frequent the same social spaces used by children without the disease²⁷.

The Association for Assistance to Disabled Children was created in 1950 in the city of São Paulo, Brazil, and the Brazilian Association of Rehabilitation was created in Rio de Janeiro with multi-professional teams for comprehensive care²⁸. The first Association of Parents and Friends of the Exceptional (Associação de Pais e Amigos dos Excepcionais-APAE) was established in Rio de Janeiro in December 1954 and quickly expanded to other states²⁹. The rehabilitation process involved a multi-professional teamwork for which the ultimate goal was to promote social inclusion³⁰.

After the creation of the Unified Health System (SUS) in Brazil in 1988 with the promulgation of the new Federal Constitution, all Brazilians acquired the right to health. The Union became the primary financier of health and formulator of national health policies but did not execute the actions. Therefore, the Union depended on partnerships with states, municipalities, nongovernmental organizations (NGOs), foundations, and companies, among others, for the execution of the projects (MS, 2006). Rehabilitation programs became federally oriented, and disabled individuals gained access to care in the public network by law.

In 2005, the Unified Social Assistance System (Sistema Único de Assistência Social-SUAS) was implemented to manage the specific social assistance programs (SDSSP, 2015)³¹. This system was created to regulate social assistance programs and benefits in the national territory, allowing, in parallel to the public rehabilitation network, private rehabilitation institutions to receive financial subsidies to expand the offer of services³².

At the end of the twentieth century, governmental organizations and NGOs established normative instruments to protect and guarantee the social inclusion of individuals with disabilities. The United Nations, via Resolution 31/123 of 1976, declared that 1981 was the International Year of the Disabled, which became a milestone in condemning the anonymity of this population³³. The objective was to broaden the discussion on the subject by focusing on several aspects, including awareness, prevention, education, rehabilitation, professional training, access to work, removal of architectural barriers, and legislation³⁴.

In 1986, the Coordinating Office for the Integration of the Deficient (Coordenadoria para Integração da Pessoa

Deficiente-CORDE) was established in the Civil Office of the Presidency of the Republic, to develop public policies for the social integration of the handicapped, with an emphasis on individual rights and promotion of citizenship³⁵. In 2010, the status of CORDE was elevated to National Secretariat for the Promotion of the Rights of the Disabled, an organ of the Secretariat of Human Rights of the Presidency of the Republic involved in the articulation and coordination of public policies for individuals with disabilities (SNPDPD, 2010).

In Brazil, the citizenship of disabled individuals, comprehensive health care, education, culture, professional qualification, training, as well as individual, family, and social promotion was guaranteed by law³⁶. In 2007, the resolutions of the International Convention on the Rights of Individuals with Disabilities were adopted by the United Nations³⁷. In this Convention, Article 7 addressed the concerns of children with disabilities to ensure access to education, rehabilitation, and training³⁸.

The employability of individuals with disabilities promoted by the Law of Quotas was another milestone for social insertion, allowing greater visibility of the workforce of this social group, reducing inequality, and guaranteeing citizenship. The family of a child or adolescent with a disability could hope for a more dignified life for the child, with the possibility of a better future with profitable work. Article 93, in the Law of Quotas No. 8.213 of July 1991, included a set of actions that required companies to employ a minimum percentage of disabled or rehabilitated individuals as a function of the number of employees³⁹. This strategy aimed at hiring individuals with disabilities to ensure the inclusion of this group in the human resources of the company and not only to avoid punishment for non-compliance with the law.

The relationship between individuals with disabilities and the social groups to which they belonged passed through many types of agreements throughout history. The distancing of individuals with disabilities from social life became less common. Furthermore, the charitable actions taken by religious or charitable motivation were reduced⁴⁰. These changes occurred in part because of the perception of the competence and potential of physically and mentally challenged individuals and the distinction between the concepts of illness, disability, and incapacity.

The World Health Organization (WHO) addressed these changes by creating the International Classification of Functioning, Disability, and Health (ICF) in 2001⁴¹. Developed after systematic field studies since 1980, the ICF belonged to the group of the organization's international classifications, which also included the International Classification of Diseases (ICD). The first edition of the ICD was approved in 1893, and the last (the tenth revision, ICD-10) was approved in 1989. Since then, mechanisms have been established to update the ICD-10, which was not the case in previous versions, and ICD-11 is expected to be published in 2017⁴².

The ICD and ICF classifications complement each other because the ICD addressed the etiology of the disease whereas the ICF assumes a neutral position for etiology but addresses risk factors, health determinants, and epidemiological surveillance. The objective of the ICF was to provide a unified and standardized language that allowed the international scientific exchange of studies on human health and function with greater methodological rigor. The ICF facilitated the communication among different users, including health professionals and managers, individuals with disabilities, and served as a statistical tool for research on the impact of disability and development of supportive policies. This classification aimed at standardizing the description of different aspects of functionality, disability, and health⁴³.

Two individuals with the same disease or lesion of the same body structure have the same ICD but may have different levels of functioning, whose characterization is made possible by the application of the ICF. Therefore, the ICF allows the distinction in the condition of two adolescents with the same level of lower limb amputation due to trauma: one individual lives with depression, uses drugs, and refuses to use a prosthesis whereas the other individual is engaged in a rehabilitation program to obtain qualification for a sports activity and work.

The case exemplifies the fact that a single deficiency can result in different disabilities. In the context of the social model of health, the authors of the ICF defined disability as problems in the body structures and/or functions with the consequent significant deviation or loss, and the incapacity was defined as the difficulty of the subject in performing a certain task, which affected the relationship of these individuals with the environment. Therefore, disability is not an attribute exclusive of an individual but is part of a complex set of conditions, many of which are created by the social and economic environment⁴⁴.

In recent decades, important social and technological advances have facilitated the life of individuals with disabilities; however, these benefits do not benefit everyone⁴⁵. There is evidence on the direct relationship between disability, poverty, and violence, and it is more difficult for individuals with disabilities to leave this vicious cycle. In this respect, these individuals are more exposed and vulnerable, and more strongly dependent on external resources⁴⁶.

In fact, the environment in which these individuals live has a strong impact on their lives, and this social group faces more difficulties in obtaining treatment, education, and labor (WHO, 2011a). Investment in rehabilitation, particularly for children and adolescents, may guarantee access to better health and education, avoiding loss of work potential, improving family income, and contributing to an interruption in the cycle of poverty, violence, and disability⁴⁶.

The communication between individuals with disabilities and society had as hallmark the movement of 1990 conducted by disabled activists Michael Matusha and William Rowland in South Africa, with the theme "Nothing

about us without us"⁴⁷. With this theme, the activists highlighted the importance of the participation of interested persons, with or without deficiencies, in the studies and claims that involved them, and they should be involved in all activities. This fact shows how this movement has broadened its frontiers beyond the specific needs of physically and mentally challenged individuals and has benefited the whole society⁴⁸. With the help of these activists, civil society imposed the points of view of the patient, created new civil rights, and promoted social transformations⁴⁹. The development of specific legislation, support organizations, scientific research, and other contributors, including activists and civil associations, came to the scene to collaborate with the struggle of disabled individuals to open a space in society and demand their social inclusion by right.

Many victories have been obtained by this group and by society during the fight undertaken by this minority and its representatives for the conquest of social rights. The process of constructing the social identity is established by the relation of interference and mutual influence among the social connections that the individual establishes with the environment, modifying it and being modified. The social, economic, historical, political, and ideological factors that promote movements and changes constantly interact⁵⁰. Society is always under construction, i.e., susceptible to modifications. Mark Page⁵¹ reported that the humanization of our species has occurred over the centuries with the evolution of the capacity of aggregation, cultural development, and the ability to transmit technology and ideas. This characteristic gives human beings an advanced adaptive potential, which promotes cooperation and is based on the capacity to trust and share values.

The acknowledgment of individuals with disabilities reshapes the society that welcomes this social group, making the process bilateral⁵².

The social inclusion of individuals with disabilities is guaranteed by law; however, social inclusion is not enough. New strategies need to be created, involving a higher level of humanization, in which disabled individuals are inserted naturally, and their differences are understood as a variation of normality. Society needs to understand the presence of this expressive minority, who constitute a heterogeneous group that combines physical, sensorial, intellectual, and mental disabilities as an integral part of society.⁵³

Modified from the study by Hiede et al⁵⁴. Figure 1 shows the different ways in which society deals with disability. Carvalho-Freitas and Marques⁵² emphasize the coexistence of all these models today, which demonstrates the complexity of the subject.

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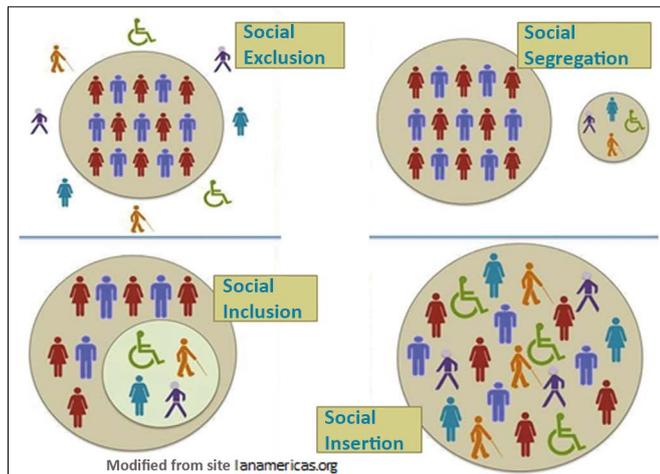


Figure 1. Ways of society dealing with different people.

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