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Sandoval, Hugo; Pérez-Neri, Iván; Martínez-Flores, Francisco; del Valle-Cabrera, Martha Griselda; Pineda, Carlos

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# Disability in Mexico: a comparative analysis between descriptive models and historical periods using a timeline

Hugo Sandoval, MEc,<sup>(1)</sup> Iván Pérez-Neri, PhD,<sup>(2)</sup> Francisco Martínez-Flores, PhD<sup>(3)</sup> Martha Griselda del Valle-Cabrera, MD,<sup>(4)</sup> Carlos Pineda, PhD.<sup>(4)</sup>

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**Abstract** 

Some interpretations frequently argue that three Disability Models (DM) (Charity, Medical/Rehabilitation, and Social) correspond to historical periods in terms of chronological succession. These views permeate a priori within major official documents on the subject in Mexico. This paper intends to test whether this association is plausible by applying a timeline method. A document search was made with inclusion and exclusion criteria in databases to select representative studies with which to depict milestones in the timelines for each period. The following is demonstrated: I) models should be considered as categories of analysis and not as historical periods, in that the prevalence of elements of the three models is present to date, and 2) the association between disability models and historical periods results in teleological interpretations of the history of disability in Mexico.

Keywords: disability evaluation; attitude to health; Mexico

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#### Resumen

Se argumenta que tres modelos de discapacidad (de prescindencia, médico/rehabilitador y social) se corresponden con periodos históricos en sucesión cronológica. Esta visión a priori ha permeado dentro de los principales documentos oficiales sobre el tema en México. El presente trabajo se propone probar si esta asociación es plausible, mediante la aplicación de una metodología de línea temporal. Se diseñó una estrategia de búsqueda con criterios de inclusión y exclusión en bases de datos para seleccionar estudios representativos, con los cuales se retomaron hitos a representar en la línea temporal por cada periodo. Se muestra que los modelos deben plantearse como categorías de análisis y no como periodos históricos, dado que: 1) existe prevalencia de elementos de los tres modelos en la coyuntura actual y 2) la asociación entre modelos y periodos da lugar a interpretaciones teleológicas de la historia de la discapacidad en México.

Palabras clave: evaluación de la discapacidad; actitud frente a la salud; México

- (1) Hospital Epidemiological Surveillance Unit-Sociomedical Research, National Institute of Rehabilitation Luis Guillermo Ibarra Ibarra. Mexico City, Mexico.
- (2) Department of Neurochemistry, National Institute of Neurology and Neurosurgery Manuel Velasco Suárez. Mexico City, Mexico.
- Skin and Tissue Bank, National Institute of Rehabilitation Luis Guillermo Ibarra Ibarra. Mexico City, Mexico.
- (4) National Institute of Rehabilitation Luis Guillermo Ibarra Ibarra. Mexico City, Mexico.

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Corresponding author: Hugo Sandoval Zamora. Hospital Epidemiological Surveillance Unit-Sociomedical Research, National Institute of Rehabilitation Luis Guillermo Ibarra Ibarra. Calzada México-Xochimilco 289, Arenal de Guadalupe, Tlalpan. I 4389 Mexico City, Mexico. E-mail: sanzam@gmail.com

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The care of persons with disabilities in Mexico is characterized by inequalities. A total of 23.1% of the Mexican population with disabilities >15 years of age lack access to formal education, and their participation in economic activities is 39.1%, compared with 64.7% of their counterparts without disabilities. Among indigenous population above the age of three years, the prevalence of disability is 7.1%, while in whole Mexican population, this is 6%. Furthermore, only 46.5% of the disabled population aged 3-29 years attends school, compared with 60.5% of the population without disabilities. I

Inequalities are influenced by systematized preconceptions from large descriptive representations denominated disability models (DM). The DM discussed in this work include the following: 1) charity; 2) medical/rehabilitation, and 3) the social model.<sup>2-4</sup>

In the charity DM, disabilities are identified with imperfections, impurities, faults, penalties, or damages that obey supernatural causes resulting from the irascibility of the gods, the expiation of sins, misfortune caused by spirits, ill omens, or sorcery.<sup>2</sup> In this view, persons with disabilities are depicted as unproductive, useless, dangerous, or unnecessary to society.

Two variants of this model are recognized: 1) the eugenics submodel, with an emphasis on practices such as infanticide or forced sterilization, and 2) the marginalization submodel, which promotes the segregation, abandonment, or confinement of persons with disabilities.<sup>5</sup>

The medical/rehabilitation DM states that the etiology of disabilities is due to scientific reasons. Disability is defined as a deficiency, an alteration, a failure, or a need to be addressed: "as a 'personal' problem caused by disease, trauma, or any other impairment of health requiring medical and rehabilitation assistance such as a individualized treatment provided by professionals".6 To the extent possible, medical intervention seeks the social inclusion of people affected by the failure, loss, or injury of an organ, a sense, or a bodily function. To achieve this, medical facilities have developed services staffed by specialists, among which are rehabilitation medicine, orthopedics, ophthalmology, neurology, neumology, and rheumatology. In this DM, persons with disabilities are considered to be useful provided that they can be standardized through their habilitation or integral rehabilitation.

The social DM assumes that the causes of disability are not religious or medical, but that they result from a society designed to meet the needs of "normal" people; thus, diversities are not taken into account. It also presupposes that all human life is equally worthwhile and valuable; therefore, persons with disabilities can contrib-

ute to society, as does the remainder of persons without disabilities, always by means of inclusion, equity, and respect. This model is related with the defense of human rights. It attaches great importance to principles such as autonomy, allowing advocacy for the removal of barriers to equal opportunities. Even the right of persons with disabilities to live outside of health care institutions (as do persons without disabilities) is promoted, through deinstitutionalization policies.<sup>2</sup>

There is a mixture of medical/rehabilitation and social DM<sup>7</sup> that is known as the *integrator* or biopsychosocial DM. Driven by the World Health Organization (WHO), this DM is characterized by supporting principles such as personal autonomy, while maintaining the preponderance of certain deficiencies and medical conditions. This perspective attempts to balance the interaction of contextual, environmental, or social factors with the health status of individuals.<sup>8,9</sup>

Tacitly, some documents often argue that DM correspond to historical periods in chronological succession. <sup>2,3</sup> This a priori view has permeated the main official documents on this subject in Mexico. To test whether this association is correct or not, in this paper we analyzed the three main DM described, by means of periodization with timelines, depicting the major milestones in disability in the country.

# Materials and methods

Study selection. We designed a search strategy focused on documents published in English and Spanish from 1980 to 2015, conducted in the following specialized databases: Medline; ScienceDirect; EBSCO; Google Scholar, and Bibliounam, seeking studies on the three DM analyzed in the Mexican official discourse on disability.

Inclusion criteria were as follows: 1) articles analyzing DM in Mexico over time; 2) official documents where these models apply to particular historical periods, and 3) federal care programs in disability. Exclusion criteria were the following: 1) fragmentary studies in which DM have no direct application to historical periods or are incomplete, and 2) studies referring other classifications or typologies of DM. By not including patients, this study does not require the evaluation of an Ethics Committee.

After a first inclusion of 169 documents, five of them were considered to be representative of DM associated with historical periods within the Mexican official discourse, and were finally analyzed: three from the Instituto Nacional de Estadística y Geografía (INEGI)<sup>1,10,11</sup> and two federal programs.<sup>12,7</sup>

*Timelines.* Once the documents were selected, we employed timelines to plot visual structures in the corre-

sponding historical periods within each DM. Situating events through this proposed method, in addition to being a valuable tool for thinking, <sup>13</sup> can help locate patterns, non-numerical trends, gaps, and turning points.

Applied to the historical analysis of DM in Mexico, the resulting timelines provide the graphic representation of a chronological sequence of events, <sup>14-16</sup> with an emphasis on the specific milestones outlined in each period. <sup>17</sup> The timelines allowed us to examine the relevance of the association of DM with historical periods, as assumed in the official discourse on disability in Mexico.

## Results

The use of timelines permits a graphic representation of the relative distribution of the major DM milestones for each period analyzed, as depicted in tables I, II, and III, in which the sequence of the items is highlighted by date, but the interval was omitted for simplicity. Time is represented from top to bottom, and from the past to the present.<sup>13</sup>

## Discussion

### **Charity period**

This period is the longest, but also the most difficult to document, given the scarcity of sources. Its antecedents comprise the pre-Hispanic Era, during which certain benign attitudes toward persons with disabilities deviate from the conventional characteristics of the charity DM, as documented by leading chroniclers of that time: Diego de Landa<sup>18</sup> and Juan de Torquemada.<sup>19</sup> There are few references on eugenic practices, although it is possible to infer negative attitudes and exclusion towards persons with diversities<sup>11</sup> and a sophisticated knowledge of the herbolary tradition.<sup>20</sup>

The charity model exhibits a better fit within the Colonial Era, with the emergence of welfare centers comprising a constellation of hospices, houses of mercy, orphanages, nursing homes, and hospitals, <sup>21</sup> which represented the only chance of survival for the poorest individuals. <sup>22</sup> The response to disability in this period is ambivalent: on the one hand, there was the discourse of compassion, applied through Christian charity, which considers that persons with diversities deserve compassion. On the other, there were exclusion and punishment practices, when disabilities were suspected to have a malefic origin, such as mental illness being attributed to witchcraft. <sup>23</sup>

The first timeline is mapped from the pre-Colombian Era to a year before the enactment of the Reform Laws, as depicted in table I. However, the prominent features of this DM have prevailed until the present, such as the following: 1) a range of stereotypes that identify persons with disabilities as objects of charity and compassion;<sup>24</sup> 2) practices of forced sterilization on girls, adolescents, and women with disabilities without their free and informed consent, and pressures to abort,<sup>24-26</sup> and 3) strong social exclusion, now leading back to variables such as level of disposable income, age, gender, ethnicity, rurality, migratory status, educational level, employment characteristics, and disability type.<sup>24</sup>

#### Medical/rehabilitation period

Although it is difficult to establish the onset of this period accurately, its development is linked with the emergence of the Mexican secular state from the year 1859. Since that time, church property, including charity centers, became part of public property.<sup>27</sup> Later, the term "charity" is replaced by the concept<sup>28</sup> of "public assistance", provided to citizens by government institutions.

During this period, the religious causes of disability were left behind and a scientific etiology and medical treatments were imposed. As illustrated in table II, care for motor disabilities is stressed, deriving from a strong

Table I

TIMELINE OF DISABILITY IN MEXICO. CHARITY PERIOD

Pre-Hispanic Era-1521	Pre-Columbian. Last stage of independent development of Mesoamerican civilizations in large cities such as Tenochtitlan.
1524	Hernán Cortés inaugurates the first hospital on the American continent, known as "Hospital de Jesús".
1566	In Mexico City, Bernardino Álvarez Herrera founded "Hospital de San Hipólito", consecrated to mentally ill people.
1572	"Hospital de San Lázaro" is set to confront the Hansen's disease of amputees.
1794	Monterrey began operations in the "Hospital Civil", with a section for individuals with mental disabilities.
1847	"Hospital de San Pablo" is opened, is thereafter named "Hospital Juárez de México", and establishes a Physical Medicine Service.

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# Table II TIMELINE OF DISABILITY IN MEXICO. MEDICAL/REHABILITATION PERIOD

1859 Laws of "La Reforma" provide that charity centers under the control of religious institutions become the property of the Mexican state.

- National Deaf School begins activities in Mexico City.
- Specialized teacher-training college devoted to deaf children is opened.
- 1870 National School for the Blind is inaugurated.
- 1881 Charity centers including the Hospital for the Insane and the Women's Hospital for the Insane are inserted under the authority of the Ministry of the Interior.
- The "Hospital General of México" (HGM) opened the first Department of Physical Medicine and Rehabilitation in the country, with hydrotherapy services, mechanotherapy, and electrotherapy.
- 1909 The HGM created a section for ear, nose, and throat.
- 1910 On the grounds of the "Hacienda la Castañeda", a general mental asylum of the same name is established.
- 1934 Some preventive bills on work disability in the Mexican Federal Labor Law are applied.
- The "Hospital Colonia" is opened and operating. This medical facility will provide a rehabilitation center for paraplegics, quadriplegics, amputees, and individuals with fractures. It: 1) establishes the first hospital inpatient unit of the specialty in Mexico; 2) will host the first medical residency specializing in Physical Medicine and Rehabilitation, and 3) delivers specialized courses in Rehabilitation Nursing.
  - The "Hospital Infantil de México" (HIM) opens with a Department of Physical Medicine and Rehabilitation to treat polio, cerebral palsy, and congenital, traumatic and neurological disorders.
- The Social Security Act, which establishes the obligation to protect workers affected by disability or old age, is published in the Federal Official Gazette. The Social Security System is inaugurated, led by the Mexican Social Security Institute for private sector employees (IMSS).
- The HIM Language Clinic is established: I) first course of Occupational Therapy is created, and 2) First Mexican Congress of Radiology, Physical Medicine and Rehabilitation is organized. This event will lead to the Latin American Medical Rehabilitation Association.
- 1950 The National Rehabilitation Center "Francisco de Paula Miranda" opens to care for patients with polio. Later, it will become the Hospital of Orthopedics and Rehabilitation for Children and the Elderly "Teodoro Gildred".
- The HIM trains physical therapists, occupational therapists, and physicians. Early works of Rehabilitation Research are conducted by the Laboratory of Neurophyiology and Experimental Surgery, Years later, the Hospital reconverted its retirees ward to provide Physical Medicine, Electromyography, Audiology, Speech Therapy,
  Physical Therapy, Occupational Therapy, Speech Therapy, Rehabilitation Nursing, Social Work, an Orthotics Workshop, and the Neurophysiology Research Laboratory.
- 1952 Rehabilitation Center No. 5 is established. Later it is revamped as the Center for Rehabilitation of Musculoskeletal System.
- 1954 National Institute of Audiology is created. Afterward, it is designated as National Human Communication Institute "Dr. Andrés Bustamante Gurria".
- 1959 Social Security Institute for Public Employees (ISSSTE) is founded.
- The National Institute for Child Protection (INPI) is set up. The same year, the Child Development Center is created, offering free assistance services such as Orthotics.
  - The first Latin American Medical-Congress of Rehabilitation is held at the IMSS,
- The First Congress of the Latin American Medical Rehabilitation Association (AMLAR) is offered at the Ministry of Health and Assistance (SSA).
  - The General Directorate of Rehabilitation is established in the SSA by Dr. Luis Guillermo Ibarra Ibarra.
- The Zapata Rehabilitation Center "Gaby Brimmer" is established for the care of children suffering from polio. The Center trains physical and occupational therapists.
- The IMSS begins its first Graduate Program in Rehabilitation. This institution, along with the National System for Integral Family Development (SNDIF), will become the major provider of rehabilitation services in the country.
- Children's Hospital (later renamed the National Institute of Pediatrics) is created.
- The National Institute of Audiology is established.
- 1970 The Association for Persons with Cerebral Palsy (APAC) is created.
- 1971 The first National Rehabilitation Program is designed.
  - The Center for Rehabilitation of the Musculoskeletal System becomes the National Institute of Rehabilitation Medicine.
  - The Psychological Center of Integration and Learning opens.
- 1976 The Hospital of Orthopedics and Rehabilitation for Children and the Elderly "Teodoro Gildred" becomes the National Institute of Orthopedics.
  - The National Institute of Child Protection (INPI) is revamped into the Mexican Institute for Children and Family (IMPI). The Mexican Institute for Assistance of Children (IMAN) is founded.
- 1977 The National System for Integral Family Development (DIF) is established by merging the IMPI and IMAN, with the purpose of providing social assistance to marginalized individuals and to persons with disabilities.
- 1978 The Mexican Confederation of Organizations in Favor of People with Intellectual Disabilities is created.
- SNDIF is integrated into the Federal Health Sector for developing programs of Social Welfare. Thus, SSA' Centers for Rehabilitation and Special Education are transferred to the SNDIF.
- 1983 The National Development Plan 1983-1988 establishes the commitment to provide social assistance to persons with disabilities.
- Modifications to the General Health Law for persons with disabilities.
- SNDIF establishes a rehabilitation program focused on the neuromusculoskeletal system, human communication, blindness, visual weakness, and mental health.
- The Law on the National Social Assistance System establishes, as subjects in need of social aid, persons with disabilities due to blindness, low vision, deafness, muteness, neuromusculoskeletal system disorders, mental impairments, language problems, and other deficits.
- 1987 Rehabilitation Program is established with care services for the neuromusculoskeletal system, human communication, blindness, visual weakness, and mental health disorders.
- 1988 Creation of the National Institute of Human Communication is enacted. SNDIF develops the Disabled Assistance Program, later designated as the National Program for Persons with Disabilities, which provides non-hospital-based rehabilitation.
- 1991 Citizen National Council of Persons with Disabilities is created.
- 1992 The General Assembly of the Organization of the United Nations proclaimed December 3 as the International Disabled Persons Day.
- 1994 The National Development Plan 1994-2000 incorporates public policies for persons with disabilities.
- 1995 Mexican Federal Government published the National Program for the Well-Being and the Integration of Persons with Disabilities, one of the first attempts to transform traditional assistance-oriented public policies in Mexico.
- 1997 First telethon is held to capture donations and establish rehabilitation centers for children and youth with disabilities.

# Table III TIMELINE OF DISABILITY IN MEXICO. SOCIAL PERIOD

The Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities is adopted at the Twenty-ninth Regular Session of the General Assembly of the Organization of American States in Guatemala City, Guatemala.

Mexican Official Standard NOM-173-SSA1-1998 for the Comprehensive Care for Persons with Disabilities is enacted by the Mexican Federal Government.

The Representative Office for the Promotion and Social Integration of Persons with Disabilities (ORPIS) is created. One year later, ORPIS encourages the creation of the National Consultative Council for Integration of Persons with Disabilities.

The Institute of Rehabilitation Medicine, the National Institute of Orthopedics, and the National Institute of Human Communication are merged to establish the National Rehabilitation Center.

Mexico amends its Political Constitution to prohibit all forms of discrimination, including that motivated by different capacities.

2001 The National Development Plan 2001-2006 include multisector public-policy coordination for the care of persons with disabilities. Program for Prevention and Rehabilitation of Disabilities (PreveR-Dis 2001-2006) is inaugurated.

2002 National Program for the Strengthening of Special Education and Educational Integration is launched to serve disabled children and youth with special educational needs.

The first General Law of Persons with Disabilities is enacted.

The National Rehabilitation Center becomes the National Institute of Rehabilitation (INR).

2006 United Nations General Assembly adopted the Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol. The SNDIF unveils the Agreement establishing the Care Program for Persons with Disabilities Rules of Operation.

2007 The Secretariat of Health installs the Technical Secretariat of the National Council for Persons with Disabilities.

The Federal Official Gazette enacts the Emergency Mexican Official Standard NOM-EM-001-SSA3-2010, Social Assistance. Provision of social services for children and adolescents at risk and with vulnerability.

The National Institute of Statistics and Geography (INEGI) installs the Specialized Technical Committee on Disability Information, to integrate the Disability Information System (SIDIS).

The General Law for the Inclusion of Persons with Disabilities is enacted.

The National Council for Development and Inclusion of Persons with Disabilities (CONADIS) is established, with the authority to establish disability policy and to develop the National Program for Development of Persons with Disabilities.

The National Center for Research and Care Burn (CENIAQ) at the INR is inaugurated.

The National Center for Research and Care in Sports Medicine (CENIAMED) is inaugurated as part of the INR.

The INR Division of Orthopedic Rehabilitation is designated as a PAHO/WHO Collaborating Center for Medical and Rehabilitation Research.

2012 Mexican Official Standard NOM-015-SSA3-2012, for Comprehensive Care for Persons with Disabilities is enacted.

The Ministry of Social Development (Sedesol) is empowered as responsible for State Policy for persons with disabilities; thus, Conadis is concentrated in Sedesol.

Mexican Official Standard NOM-030-SSA3-2013, which establishes the architectural features for the easy access, transit, use and permanence of persons with disabilities at institutions for outpatient and hospital care in the National Health System, is enacted.

Transition to the Social model is enhanced by the following actions:

The Federal Executive Branch enacts the Law on Social Assistance.

Reform of the Federal Law to Prevent and Eliminate Discrimination.

Federal Telecommunications Act and Broadcasting.

Law on Public Broadcasting System of the Mexican State.

Reforms in telecommunications and broadcasting.

National Human Rights Programme 2014-2018.

National Program for Development and Inclusion of Persons with Disabilities 2014-2018.

National Labor and Employment Program for Persons with Disabilities 2014-2018.

National Program for Equality and Non-Discrimination (2014-2018).

Comprehensive Program to Prevent, Address, Punish and Eradicate Violence Against Women 2014-2018.

Program Prevention, Rehabilitation, and Social Inclusion of Persons with Disabilities.

Special Migration Program 2014-2018.

Protocol for the administration of justice in cases involving persons with disabilities.

boost starting during the 1950s,<sup>29</sup> due to the need of caring for children affected by the polio epidemics at that time in the country<sup>27,30</sup> (table II).

By emphasizing their deficits and alterations during this period, persons with disabilities were often perceived as dependent and inferior from a biological perspective; thus, they were labeled as disabled or handicapped, notwithstanding the scientific progress achieved.<sup>31</sup> Also, a link was established between disability and welfarism under a paternalistic concept. This perception was institutionalized through coercive policies<sup>29</sup> and legal practices such as substitution, where persons with severe disabilities were subject to procedures of interdiction.<sup>32</sup>

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From this period, the following endure until the present: 1) a model of "special" education and barriers to accessibility in schools;<sup>24</sup> 2) the difficulty of eradicating the practice of substitution, and 3) legislation that continues to enforce the internment of persons with intellectual and psychosocial disabilities,<sup>24</sup> without respecting their free and informed consent.

#### **Social period**

Again, there is no consensus on the exact date of onset of this period, which was characterized by greater legal recognition of inclusion and acceptance of diversity and the rights of persons with disabilities, starting from the signing of international treaties and amendments to the Mexican Political Constitution<sup>33</sup> (table III).

The transition that was underway formed part of the mainstreaming of human rights in public policy, which seeks to conceptualize disability as a collective subject. Within this context, society has a responsibility of not placing or allowing barriers to exist that discriminate or impede the full enjoyment of the rights of persons with disabilities.<sup>12</sup>

The social model faces the following difficulties to date:<sup>24</sup> 1) a legislative framework on accessibility that does not include all aspects established in the Convention on the Rights of Persons with Disabilities; 2) a lack of regulation, monitoring mechanisms, a national accessibility plan (and another for situations-of-risk and humanitarian emergencies), with an emphasis on persons with diversities; 3) the low employment rate of people with disabilities and noncompliance with the labor quota of 3% in the government; 4) lack of updated statistics on disability and information on these persons' current situation,<sup>34</sup> and 5) denial of the right to vote for persons with acute intellectual and psychosocial disabilities, in addition to the lack of accessibility alternatives to voting.<sup>24</sup>

#### Conclusion

The three DM analyzed should be used only as conceptual categories. The timeline method applied shows that DM are not historical periods, nor sequential chronologies, because of the following: 1) there is a prevalence of characteristic features of each DM in the current situation, and 2) some of their features overlap, thus frontiers between periods cannot be established precisely; therefore, start and end dates are unreliable.

DM should not be employed to presuppose evolutionary historical steps, assuming that a period represents an improvement or completion over the previous one, in terms of progression. This last approach leads to teleological interpretations of the history of disability<sup>35</sup> that minimize the serious complications present up to the present day, such as discrimination and substitution practices.

The timelines depicted suggest that the care of disabilities in Mexico requires a reconfiguration to a less unequal and more inclusive system, aligned with the principles and assumptions of social DM, which require strengthening. To date, disability healthcare comprises a constellation of four fragmented and heterogeneous disability healthcare subsystems, 36,37 which continue to exhibit strain due to the inherited inertia of the charity and medical/rehabilitation DM:

*Private providers.* While not offering inclusive comprehensive care for disabilities, these provide personalized services to the population with economic solvency through a conglomerate of 28.6 privately owned hospitals per one million individuals, compared with 11.4 publicly owned hospitals.<sup>36</sup>

Social security system (SSS). Includes the Mexican Social Security Institute, for private sector employees (IMSS, by its Spanish acronym), the Social Security Institute for Public Employees (ISSSTE), the Institute of Social Security for the Armed Forces (ISSSFAM), the Ministry of Navy (Semar), Mexico's national oil company (Petróleos Mexicanos, Pemex), and the healthcare services of the state governments (SESA).

The SSS provides full disability healthcare benefits for public and private employees (including pensioners) and their households (such as paid sick days, retirement plans, and so forth). Funded by both the Mexican Federal Government and by contributions from employees and their employers, SSS encompasses a heterogeneous array of independent healthcare institutions.

Public insurance subsector. A set of agencies financed by the Mexican Federal Government, state governments, and/or individuals. It covers non-salaried, informal workers, and unemployed and rural persons without affiliation with the SSS. Main Institutions in this group include the following: 1) Ministry of Health (through the National Institute of Rehabilitation Luis Guillermo Ibarra Ibarra, and certain rehabilitation services offered by other National Institutes of Health, High Specialty Hospitals, and programs such as "Health Caravans"); 2) National Commission of Social Protection for Health, also referred to as "Seguro Popular". This agency protects the poorest persons with some disabilities through a restricted package of services with fewer benefits, and omits important treatments of secondary and tertiary care,36 not providing benefits against temporary or permanent disability; 3) "Different Community" Program and "Care Program for Persons with Disabilities" of the National System for Integral Family Development (SNDIF); 4) Special Basic Community Healthcare Programs for the Uninsured, such as the IMSS-Prospera Program and Seguro Médico Siglo XXI-IMSS, among others.

*Non-profit organizations*. Civil societies, civil associations and private assistance institutions (IAP) that offer rehabilitation and orthopedics.

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