

The disabled and Public Policy: the gap between intentions and actions

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Abstract *This is a cross-sectional study with a quantitative approach, establishing the epidemiological profile of people with physical disabilities resident in the municipality of Florianópolis, in the Southern Brazilian state of Santa Catarina, and analyzing it in relation to the public policies related to that population. The minimum sample was determined by a statistical calculation, considering the population of the municipality with disabilities, according to data from the 2010 Population Census. The data were collected using an electronic form installed in mobile devices and stored at an online provider. The data were analyzed and handled with the software Statistical Package for the Social Sciences. A total of 139 questionnaires were processed. A separation of the results was made using these categories: Individual attributes; Social attributes; and Characteristics related to disability. As well as the descriptive profile of the disabled people, the study analyses and discusses the distance, worldwide and in Brazil, between the proposals for public policies and the actual actions of care directed towards the rights of these people. The conclusion is that there is a fundamental need to act in relation to the real needs of this population and consolidate proposals for health promotion, health protection and health rehabilitation for them.*

Key words *Health profile, Disabled, Public health*

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Introduction

When analyzing the social, economic, cultural, ethnic, psychological and behavioral factors that influence the occurrence of health problems and their risk factors in the population, we recognize the distribution and the determinants of illnesses, and also the damages to health and the associated events. This understanding is fundamental for the continuous improvement of public policies, since it enables specific measures of prevention, control or eradication of health problems to be put forward¹. Knowing the profile of the causes of illness in populations helps in the planning of public policies for health so as better to meet their needs.

In particular, studies of the profile of disabled people are essential for improving planning, administration, execution and assessment of the health actions for this portion of the population. As well as the social determinants of the health-illness process, disabled people also face attitude barriers, and architectural and financial challenges that are inherent to the disability itself².

In the formulation of programs, actions or initiatives aiming to help the disabled, whether in the private or public sphere, one should take the social reality in which they find themselves as a point of departure. Otherwise, public policies and the initiatives of private entities, even if well-intentioned, will be limited in terms of scope and effectiveness^{2,3}.

The state of being disabled is related to physical, sensory, mental or intellectual impediment that results in substantial limitations on the person carrying out one or more activities that are important in his/her life^{4,5}. The very definition of disability is still a challenge, because it brings together complex, dynamic, multidimensional and questionable elements, having been determined historically and socially². One cannot talk about disablement in an abstract and generalist manner, but rather about people who are disabled, and they come from the most varied societies, social classes and cultures. Thus, each disabled person should be treated individually, knowing that he/she has a unique life history and one that is collectively shared; and that the society in which the person lives will, with greater or lesser intensity, determine the possibilities for meeting the challenge of the disability and the limitations to which the person is submitted, based on an idea that is historically determined on the question of what is disablement and who is considered to be disabled⁶.

Physical disablement is one part of the overall category. The most recent concepts list four elements as essential, standardizing the language, to enable comparison between countries^{4,7}. These are: mobility, vision, hearing and cognition⁷; thus, physical disablement is related to mobility.

According to Brazil's 2010 Demographic Census, 45,623,910 people, or 23.9% of the Brazilian population, reported some type of disablement. The census figures report more than 13 million people with motor deficiency, or 6.95% of the population. Physical disablement is more prevalent in females, affecting 9.75% of women, representing 8 million people. Among males, the percentage is 5.33%, or a total of 5 million men⁸.

The State of Santa Catarina (SC) has a resident population of 6,248,436 (100%), and the population of men with physical disablement is 163,547 (5.27%). The figure for women is 255,646 (8.12%) resulting in a population of 419,193 disabled people (6.71%)⁸.

In contrast to countries that have study centers and lines of research exclusively for the social condition of being disabled, in Brazil research on the question of the causes of disablement and the principle needs of this population – which could make it possible to create effective public policies – is scarce⁹.

This present study aims to describe the epidemiological profile of people with physical disablement living in the municipality of Florianópolis, and analyze it in relation to the public policy directed toward this population. For an epidemiological profile, the following characteristics related to disablement were included: age, gender, socio-economic conditions, occupation, marital status, schooling, leisure activities, type and cause of deficiency, co-morbidities and associated complications, and the conditions of accessibility that are made available to this group of people.

The study of a profile of the disabled as a group aimed to reveal some social determinants involved in the health-illness process of this population, with a view to serving as a strategic tool for managers operating in health, making it possible to implement and manage more efficacious public policies aiming to be effectively useful to this group.

Brazil has advanced in implementing laws and plans to give disabled people support for the full and effective exercise of their legal capacity. One example is the *National Plan for the Rights of the Disabled Person – Living without Limits (Plano Nacional dos Direitos da Pessoa com Deficien-*

cia – *Viver sem Limite*), created by Decree 7,612 of November 17, 2011¹⁰. *Living without Limits* proposed that the federal government, the States, the Federal District and municipalities should together structure governmental policies to enable this group to have access to education, social inclusion, healthcare and accessibility.

However the inclusion of these people, and their access to health and education, presupposes knowledge of their epidemiological profile, providing minimal responses to the questions of WHO is in this population group; and WHAT are its principle needs – so that intention and action can approximate to each other in the policy directed toward this group.

Methods

This is a cross-sectional study with a quantitative approach, principally aiming to describe the epidemiological profile of disabled people resident in the municipality of Florianópolis, and analyze it in relation to public policies directed towards this population. According to Aragão¹¹, cross-sectional studies are capable of visualizing the population situation of a given group at an instant in time, as a reality. The *Strobe Statement* was used for the survey¹².

The population of the study comprised disabled people living in the municipality of Florianópolis. Disabled people were defined as those with tetraparesis, paraparesis, or hemiparesis, or who had an arm or a leg amputated¹³. Subjects were selected from lists created by community health agents of the municipality of Florianópolis, made available to the Family Health Strategy teams.

The minimum sample was determined by statistical calculation, considering the disabled population of the municipality, as per data of the 2010 Demographic Census Report which indicated approximately 28,349 people⁸. Criteria for inclusion were: to have some type of disablement, and to be resident in Florianópolis. For minors, the persons legally responsible were invited to accompany the interview. The criterion for exclusion was impossibility of verbal communication by the disabled person. Data were collected over the period January to July 2014. The interviews were scheduled by telephone and held in the participant's households. A pre-test was run over the months October 2013 to January 2014, applying the questionnaire to 21 disabled people who were selected at random in long-term institutions of

Florianópolis. This phase of the study resulted in the 19th version of the data collection instrument, making possible the adjustments necessary for its application. Collectors of data were trained in December 2013 and January 2014.

The final sample was 139 questionnaires filled in, representing a significance ratio of 95% and sampling error of 5%. The data were collected using an electronic form installed on mobile devices with storage at an online provider (*Go Canvas*). The data were analyzed and treated in the program *Statistical Package for the Social Sciences* (SPSS). Simple and relative frequency measures were used in the descriptive statistical analysis of the qualitative variables; and central tendency and dispersion measures were used for the quantitative variables.

The study was approved by the Ethics Committee for Research on Human Beings of the Federal University of Santa Catarina, via *Plataforma Brasil*, under Opinion number 216,396 of March 11, 2013. Thus, all the ethical aspects were obeyed in accordance with Resolution 466/12 of the National Health Council.

Results

The results presented below correspond to the descriptive statistical analysis of the 139 questionnaires that were answered. They were divided into: Individual attributes (gender, age, and marital status); Social attributes (schooling, income, physical activity, and relationship to the health service); and Characteristics related to the disablement (types, causes, and co-morbidities).

Individual attributes

The average age of participants was 53, and the median, 55. Ages varied from 10 to 99. The age with the largest number of people was 72 (Graphic 1).

41.7% were female and 58.3% male.

Of the total of participants, 33.8% were married, 30.9% single, and 14.4% widowed. The others were divorced, separated or in a relationship.

Social attributes

The variable *schooling* showed 64.4% of interviewees were illiterate, or did not complete primary school.

As source of financial resources, 64% of interviewees reported a retirement pension; 22.3%,

disability benefit; and 10.8% of the interviewees, salaried employment.

The average monthly family income was measured in terms of the national minimum wage (MW) in effect at that time in Brazil, which was equivalent to approximately US\$243 at the time of the data collection. Income diminishes after disablement takes place. The number of families receiving up to four times the minimum wage per month increased, and the number receiving between four and ten times the minimum wage decreased (Graphic 2).

The practice of physical activities is a social and health attribute for the human being and continues to be so after the occurrence of a physical disablement. Thus, carrying out some activity of this type is an important variable for knowing and discussing the profile of disabled people. In this survey, an outstanding negative piece of information is that 78.4% of the respondents do not practice any type of physical activity. The other 21.6% report activities such as muscle training, basketball, swimming, and rugby.

As to how respondents contacted the health services: 34.97% reported contacting primary healthcare units; 8.63% approached rehabilitation services; 17.99% sought out physiotherapy services; and 18.70% attended hospitals.

Characteristics related to disability

Graphic 3 shows a breakdown by type of disability.

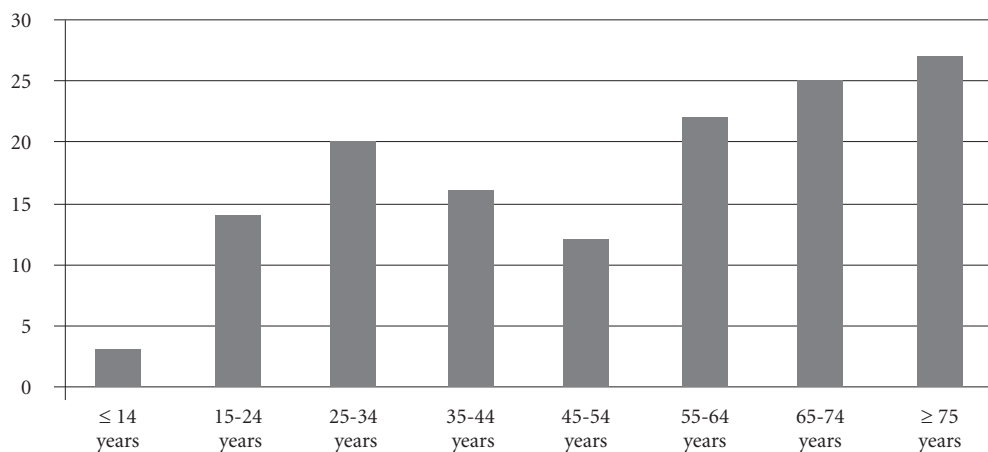
Lesions of the medulla are the most significant, principally paraplegia, with 23.7%, and tetraplegia, with 10.8%, followed by amputees, with 15.11%.

The predominant causes of disablement were chronic non-communicable diseases (47.48%), and traffic accidents (30.22%) (Graphic 4).

In answers to the question on co-morbidities and/or complication, the prevalent answer was non-communicable chronic diseases, with 66%, including systemic arterial hypertension (SAH) and diabetes mellitus (DM) totaling 23%; and pain (neuropathic or post-amputation) and urinary infection (Graphic 5).

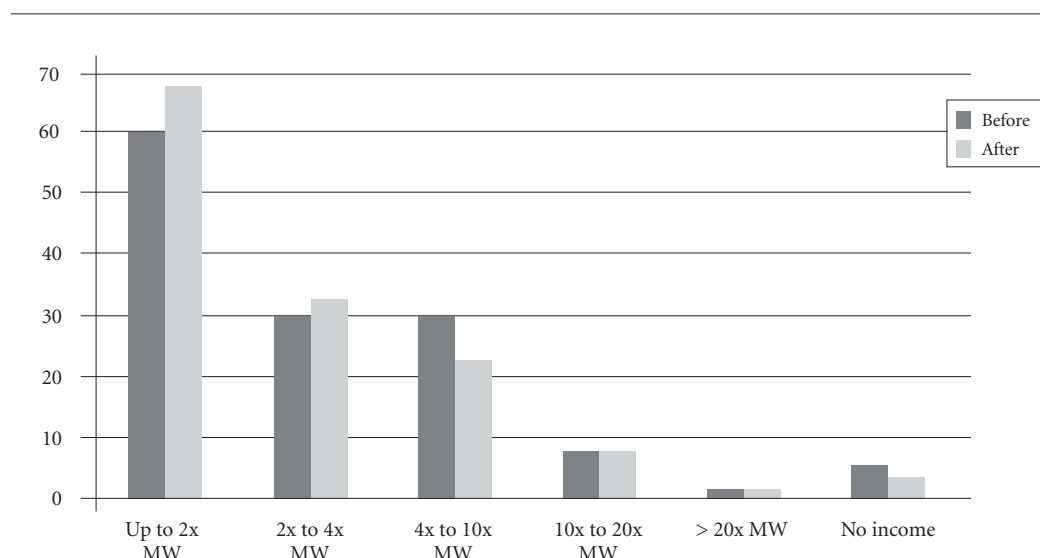
Discussion

The results show that disability in Florianópolis affects more men than women. This is reflected in other findings of the study, in which the male gender is more affected. At the same time, the data on gender do not corroborate the 2010 IBGE Demographic Census Report – which describes more significant prevalence of disability in women. However, investigators of associations of disabled people contest the IBGE figures, since



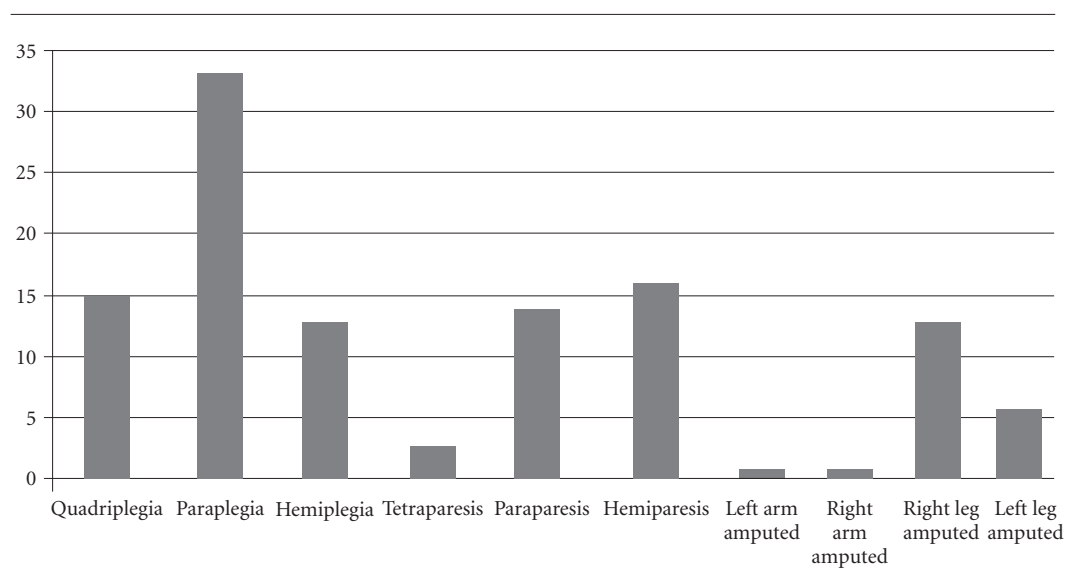
Graphic 1. Age, in years, of disabled people living in Florianópolis, 2014.

Source: Authors, 2014.



Graphic 2. Average monthly income of the families of physically disabled people before and after the causative event, Florianópolis, 2014.

Source: Authors, 2014.



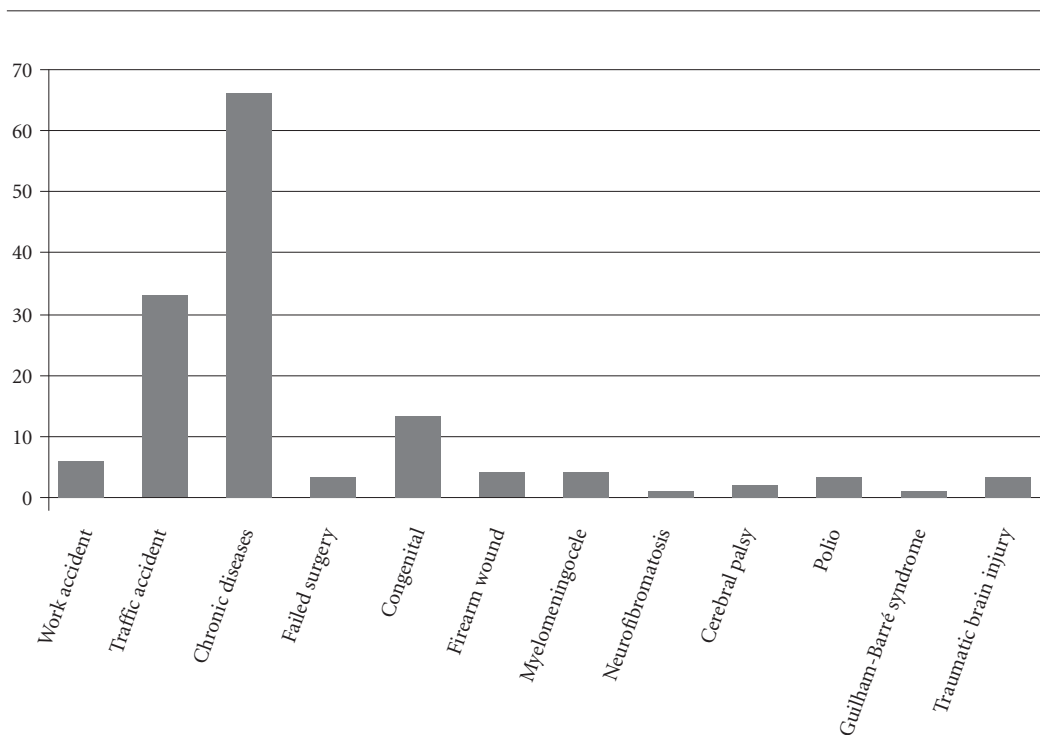
Graphic 3. Breakdown by type of disability, Florianópolis, 2014.

Source: Authors, 2014.

the census was made on the basis of not very specific questions, which could lead to imprecise or erroneous information¹⁴.

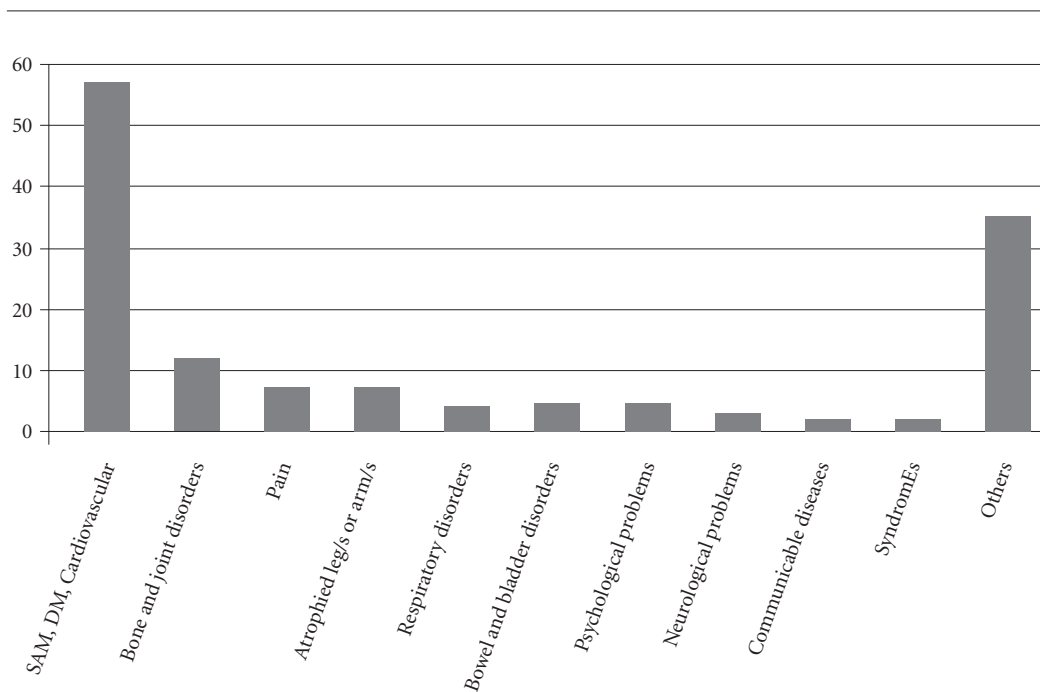
In the population studied, disablement prevails in people aged 60 or over as a result of age-

ing or chronic-degenerative diseases. The growing ageing of the world population – and the Brazilian population – has caused profound changes in societies with a major impact in the area of health¹⁵.



Graphic 4. Causes of disablement, Florianópolis, 2014.

Source: Authors, 2014.



Graphic 5. Co-morbidities and complications of disabled people living in Florianópolis, SC, 2014.

Source: Authors, 2014.

The study also showed predominance of married people, followed by unmarried, and widowed people. This finds an explanation if we take into account the lifecycle of an individual, since married people tend to belong to an older age group, and for this reason a group that is more susceptible to some type of disability. It may also be due to the fact that people seek more stable and lasting relationships, which provide greater personal and emotional security¹⁶.

A low level of schooling was found in the population studied. As well as other social barriers, this condition can also cause difficulty for access to the health services and information about healthcare. A low level of schooling can result in a shortfall of knowledge on the importance of promotion of health and prevention of health problems – influencing self-care and becoming a determinant in the process of becoming ill¹⁷.

Education is one of the key factors for inclusion not only of disabled people, but the population in general¹⁸.

The schooling profile of disabled people also articulates with the characteristics related to the socio-economic conditions of this population of the study.

A preponderant part of the group receive retirement benefit or disability benefit, which shows the effect of physical disability on work, and/or these people's low participation in the employment market, whether in terms of ability to carry out functions, or opportunities.

Poverty in general can be reflected in the high levels of unemployment among disabled people¹⁹. When investigating socio-economic inequalities in a wide-ranging group of health indicators among people with medulla lesions in a developed country, such as, for example, Switzerland, it is concluded that people's financial difficulties result, essentially, from their health problems²⁰.

This population is also characterized by non-practice of physical activities. This corroborates with the situation in other countries, in a study on longevity of disabled people living in the United States, which showed that in general these people have a greater propensity to obesity and a sedentary lifestyle²¹.

There can be many causes that prevent disabled people practicing physical activities, including the architectural barriers imposed in our society. This logic can be confirmed in the architecture of most Brazilian cities. The disabled find themselves in difficulty and, indeed, prevented from living with quality and autonomy, because

there are difficulties of access to leisure spaces, adapted public transport, buildings, schools, universities, public restrooms, etc. Just to give an idea of the problem, one has only to think of the access to sidewalks which in most cities are not adapted to these people's needs. One easily sees that spaces, equipment and behaviors in society mostly follow a standard that meets only the needs of the people regarded as normal²². Here one sees the fragmentation that exists where, in spite of the attempt to include disabled people via legislation, barriers in architecture and attitude put up obstacles to this inclusion.

Another fundamental device for care for the disabled person, if not the most important, is the health services. This study shows a low level of seeking out the basic health services and rehabilitation services. This could be due to individual needs, but it could also have a direct relationship with the supply of, and access to, health services. This finding contradicts a cross-sectional study that compared to the use of primary health services by people with lesions of the medulla in Canada, the UK and the USA²³.

The authors conclude that the people with motor deficiencies seek out health professionals who can meet their needs for care at primary health level. More than two thirds of the study participants considered the family doctor to be the most appropriate health professional to care for new health problems, as well as problems related to the medulla lesion. Interviewees in Canada and the UK tend more to seek the help of a family doctor than those in the USA, who made more use of specialized services²³.

In spite of the universal access that is intended for Brazil's Family Healthcare Strategy, in which coverage is intended to be 100% of the population for promotion of health, and in spite of a disabled person's need for constant healthcare, the demands on the health services were concentrated in those of greater complexity and specificity, with practically half of them seeking services of rehabilitation, physiotherapy or hospital care.

This study pointed to two major causes of disability: non-communicable chronic diseases in elderly women, and trauma in young men. The first of these causes is corroborated by the WHO World Report on Disability², which states that in the coming years, disability will be an even greater concern because of its increasing prevalence due to ageing of populations, and also because of the global increase in chronic diseases such as diabetes, heart disease, cancer, and mental disorders.

One factor – violence in traffic – distinguishes Brazil from other countries. The causes of disability in Europe and the United States also arise from ageing of the population, most affecting females; but there is a marked contrast with the level of traffic accidents in the young male population.

As well as causing disability, traffic accidents also result in other health complications that require greater time for recovery. This finding is in line with other studies that attest that disability is associated with urban violence, especially traffic accidents. In these, the most affected are young males under the age of 40²⁴⁻²⁶.

According to Reichenheim²⁷ traffic accidents in Brazil have a high personal and social cost. At the individual level, not only is mortality high, but survivors who suffer injuries have significant physical and psychological consequences, especially when the victims are young.

In 2008 Brazil passed Law 11705, dealing with punishment for drivers that have ingested any quantity of alcoholic beverage, establishing the Zero Tolerance policy for all drivers. As from that point the number of traffic accidents without victims was found to diminish, in a retrospective study of the period from January 2001 through June 2010 on traffic accidents in 645 municipalities of São Paulo State. Fatal accidents were reduced by 16% in São Paulo City and 7.2% in the other municipalities, and non-fatal accidents were down 2.3% in São Paulo City and 1.8% in the rest of the State. A total of 1,522,648 accidents were evaluated.¹⁴ This was a policy of high impact in prevention of disability.

The reality also showed how frequently people are disabled by chronic non-communicable diseases. The representative of Brazil in 2011 at the opening of the 66th UN High Level Conference in New York, where the growing occurrence of these diseases worldwide was debated, mentioned this in his speech. Brazil is preparing new public policies to serve people who suffer from illnesses such as hypertension, diabetes, cancer and respiratory conditions, since these were responsible for 63% of deaths in the country in 2010, and approximately 80% of these deaths were in locations of low or medium income, and two thirds of them in people over the age of 60. The disproportionate incidence of these diseases among the poorer people shows the need for an integral response to the problem. Thus, it is fundamental that there should be co-ordination between health policies and other policies that aim to deal with the socio-economic determinants of these illnesses²⁸.

Public policies are destined for the disabled are articulated with the UN's focus on a socio-ecological approach, in which disability results from the social, cultural and physical environment^{29,30}. The fundamental concepts involved in international public policies come from the International Convention on the Rights of Persons with Disabilities, promulgated in 2006 and ratified by 138 countries up to 2013. These are rights connected with the fundamental rights to life, liberty and equality³¹.

Brazil subscribed to the International Convention in 2009, through Decree 6949 of August 25, 2009. Various policies for the disabled population have been prepared and launched in recent years. One example is the *National Plan for the Rights of the Disabled Person – Living without Limits*, of 2011, which highlights commitment to the articles of the Convention on the Rights of Persons with Disabilities, ratified by Brazil with equivalence to a constitutional amendment. Strengthening this plan, in July 2015 the Statute for the Disabled was sanctioned, ensuring and promoting conditions on equality, the exercise of fundamental rights and liberties by disabled people, aiming for their social inclusion and citizenship¹⁰.

The proposal of *Living without Limits* and the Statute envisages that the federal government and the states and municipalities should jointly consolidate the precepts of the International Convention, through coordination of government policies for access to education, social inclusion, healthcare and accessibility. These policies consider that it is an obligation of the State to guarantee the rights of the disabled person, especially those of the Brazilian Constitution and the International Convention on the Rights of Persons with Disabilities.

Brazil is rich in legislations for the disabled: Brazilian Standard 9050 of the Brazilian Technical Standards Association (ABNT/NBR 9050/1994) states that constructions must provide conditions of mobility, with autonomy and security, eliminating architectural and urban barriers in the cities, in means of transport and communication. Federal Decree 5296/04 states that architectural and planning projects must comply with the principle of universal design. Every person has the right of free movement, under the constitution. There are rules for the constructions of streets, public use buildings and manufacture of collective transport vehicles (Federal Constitution of 1988). Similarly, there is vast legislation on promotion of acces-

sibility (Federal Laws 10048 and 10098 of 2000). Article 9 of the UN Convention on the rights of the disabled, transformed into a constitutional amendment by Decree 6949/2009, requires the adoption of appropriate measures to ensure access, on an equal basis with other, to the physical environment, to transport, to information, and to communication, and to other services and facilities that are open for the public, both in the city and in rural zones. In parallel to the policies of the federal government, in co-ordination with the Health Ministry, the States also propose measures for intervention to expand the inclusion of disabled people.

A highlight in this context is the *Operational Plan for Organization of the Network for Assistance to the Disabled* launched in the state of Santa Catarina in 2008. This, in harmony with the federal rules, is the start of the process of recognition of the rights of these citizens, with the possibility of expansion of the actions and areas involved, and the point of view of a progressive quest for integrality and universality in health actions.

It is important to record that the activities implemented as a result of the public policies and promulgation of the Operational Plan for Organization of the Network for Assistance to the Disabled were required to ensure that there would be gains for this section of the population – primarily, access for them to a group of actions and services that are necessary for solving their health problems, at any level of healthcare from the primary to the most complex.

At the same time, in spite of the policies designed for the disabled, both at the Federal and State level, there is still a gap between public policies in health and the causes of disability in the country: the public policies should make it possible to confront those causes, to diminish their frequency. This is corroborated by the major role played by violence in disablement of young men (in spite of the Zero Tolerance Law), and the related lack of articulation between the health and security sectors for its prevention. The health sector, responsible for care for disabled people, does not take part in preparation of programs, and policies to promote health and prevent the causes of disablement. The lack of accessibility to health services, especially primary healthcare service, also contributes to this gap. A study has shown that the scarcity of access goes beyond architectural

barriers, and includes transport to the health unit, and geographical and attitude barriers³².

Having a juridical apparatus in favor does not necessarily materialize in the form of rights. At the same time as the process of inclusion advances, an interaction between the disabled and the non-disabled becomes more frequent, the legislation assumes a coadjuvant role, and naturally individuals start to question a history of exclusion and begin to demand a society that is more aware, more balanced on the question of its differences, more fair, and more thought-out for all.

Final considerations

The study shows a gap between the proposals by Brazil's public policies and the reality of the profile of disabled people in Florianópolis. The information obtained on the epidemiological profile of these disabled people proves the need for urgent work on questions related to prevention of chronic non-communicable diseases, alerting for situations of higher risk, since the people most susceptible to this type of disability were identified. The study is important because it draws attention to the need to adopt both practices to reduce traffic accidents, and also practices that increase opportunities for access to work, education and leisure for this part of the population.

It was possible to conclude that disabled people need interventions capable of eliminating both environmental and social barriers. They have the same health needs as any other person, and their state of health is influenced by the social context in which they live, such as income, difficulty of access to health services, and rehabilitation. This issue needs to be resolved, since these people are more vulnerable to development of health problems, such as pressure ulcers or infections of the urinary tract, arising from their disability itself.

This study aims to contribute to the development of solutions, and formulation of proposals for public policies for social inclusion and healthcare that will add to or improve the existing policies, adapting them to the reality lived by disabled people in Brazil. Its limitations could be stated as the need to broaden the number of municipalities investigated, for a wider knowledge of the reality.

Collaborations

GC Nogueira, SD Schoeller, FRS Ramos, MI Padilha, AMFB Marques and LCF Brehmer contribution to the concept; outlining or analysis and interpretation of the data; drafting of the paper and critical revision; and approval of the version to be published.

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