

*Full Length Research Paper*

## Social determinants of health and inequity among people with disabilities: A Brazilian experience

Regina C. Fiorati\* and Valeria M. C. Elui

Department of Neurosciences and Behavioral Sciences, Undergraduate Program in Occupational Therapy, University of São Paulo at Ribeirão Preto, Medical School, Ribeirão Preto, SP, Brazil

Received 03 May, 2014; Accepted 12 September, 2014

This paper presents a discussion concerning the results of research conducted between 2011 and 2012 in the city of Ribeirão Preto, SP, Brazil, in which the general objectives were to understand the socio-familial inclusion of people with disabilities and their daily living needs. The methodological approach was qualitative and the data collection techniques were open life history interviews. The research subjects were ten people with acquired or congenital disabilities who were residents of the region enrolled at Primary Health Care Service of Ribeirão Preto city. Analysis of data was based on interpretation in light of dialectical hermeneutics. Our results showed that the socio-familial inclusion of individuals depends on their socioeconomic conditions, with significant indices of socially vulnerable families who have difficulty accessing primary health care and rehabilitation services, and presented indicators of social inequity. Their daily lives were marked by social isolation and not being adequately occupied with social determinants that cause negative health impacts. Due to indices of vulnerability and social inequity presented by population studied, we conclude that the creation of social vulnerability reduction programs coordinated with primary health care services is required.

**Key words:** Disability/disabled persons, health care primary, rehabilitation, social determinants of health, social inequity.

### INTRODUCTION

Disabilities have been defined as human existential states related to certain conditions, in which the affected subjects are unable to perform some activities necessary for daily living and social interaction. There is, however, no consensus regarding a definition of disability, and the concept involves historical and cultural variations (Phelan, 2011). Despite the variations and fluctuations of

specific contexts, the perceptions and treatments of disability show one historical constant: social segregation.

Historical investigation reveals that in antiquity and the Middle Ages, disability was understood within a model of divine fatalism or demonic possession. With the onset of the scientific revolution in the 16th century and its

\*Corresponding author. E-mail: [reginacf@fmrp.usp.br](mailto:reginacf@fmrp.usp.br).

Author(s) agree that this article remain permanently open access under the terms of the [Creative Commons Attribution License 4.0 International License](http://creativecommons.org/licenses/by/4.0/)

expansion beginning in the 18th century, a new model appeared, in which disability was understood according to the rationale of biosciences and medical models of treatment and was defined as a lesion, within which its manifestations consisted of corporal irregularities and biomechanical propellants of states characterized by abnormalities (Clapton and Fitzgerald, 1997).

According to Clapton and Fitzgerald, during the 20th century, the biomedical model was modified, such that after abandoning total institutionalization, a model of intervention that focused on services was adopted. However, this new practice of rehabilitation did not modify the central axis of understanding and treatment of disability as a deviation from normality. Thus, based on a notion of adaptation, systematic knowledge and technically qualified professionals, forms of action against disability remained focused on the normalization of people with disabilities, imprisoned within an individual and pathological dimension, founded on the logic of corporal correction of the lesion and pressure on the individual to adapt to physical, mental and sensorial normativity by any means possible.

A biopsychosocial model of disability gains relevance and recognition, beginning in 2001 when the World Health Organization (WHO) presented a review of the International Classification of Impairment, Disabilities and Handicaps (ICIDH), overcoming the purely biomedical approach adopted so far and acknowledging the social and political nature of disability based on the publication of the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001; Bampi et al., 2010).

The social model of disability emerges as an alternative to the biomedical model, which, as it shifts from a concept of disability defined solely as biological fact, proposes a definition of disability based on its relationship with the political, economic, cultural and social spheres as important generators of barriers to the development of people with disabilities. Accordingly, disabilities are not understood as enclosed within the individual sphere of the subject, but as generated within the sociocultural sphere, such that environmental and psychosocial barriers to the vital development of people with disabilities generate important social inequalities in relation to the means of accessibility for individual to collective opportunities and social participation (Tregaskis, 2002; Levasseur et al., 2007).

Recognition of a biopsychosocial model of disability gained relevance and developed into a central concern beginning in 2001, when the World Health Organization (WHO) presented a review of the International Classification of Impairment, Disabilities and Handicaps (ICIDH), superseding the purely biomedical approach that had marked the ICIDH. At this point, the WHO recognized the social and political nature of disability. In

2001, the WHO published the International Classification of Functioning, Disability and Health (ICF), which superseded the purely biomedical model by defining disadvantages not as the result of lesions, but as belonging to the social sphere and the difficulties imposed by a form of sociopolitical organization that excludes and stigmatizes those who are disabled. Exclusion and stigmatization occurs through the imposition of geographic, cultural, economic, political and social barriers that prevent the autonomy and self-determination of people with disabilities, limiting their freedom of movement and access to diverse environments, services and equipment present within the collective area (Farrell et al., 2007; WHO, 2001).

The framework used in this study was the social approach to disability; that is, disability is seen as a socially constructed condition and the role of society is to reorganize itself to ensure these people universal access to all public spaces, devices, services, organizations and resources available to the community, in general. Therefore, once the idea of the normalization of individuals is overcome, rehabilitation services need to provide alternatives that facilitates the full participation of individuals with disabilities in society (Tregaskis, 2002; Gannon and Nolan, 2007). Thus, understanding disability as a social construct, an adjustment in the whole of society is needed to ensure universal access for people with disabilities to all spaces, equipment, services, organizations and resources publicly available to the community. Having overcome the concept of the normalization of the individual, rehabilitation services are now required to offer alternatives to facilitate the full social participation of people with disabilities (Barnes et al., 2002).

Inserted into a new paradigm that advocates a social approach to disability, certain organized social movements formed by people with disabilities initiated the process of demanding social rights and universal accessibility. It was in this manner that an extension of the protection of human rights of people with disabilities occurred. In 1975, the United Nations (UN) published the Declaration on the Rights of Disabled Persons, culminating with the legislative framework currently in force, the 2006 Convention on the Rights of Persons with Disabilities of the United Nations (UN CRPD) (ONU, 2006; D'Aubin, 2003).

The UN CRPD is innovative in the context of international treaties ratified up to the present because it explicitly recognizes that physical, economic and social environments constitute factors that compounds the effects of disabilities and acknowledges environmental and psychosocial barriers as central obstacles to full social participation and equal opportunities with the remaining members of society.

Even though there have been advances in Brazil in regard

to the work directed to the inclusion of individuals with disabilities in the sociocultural sphere, and occupational therapy has developed technologies to support this inclusion through implementing actions within communities with the direct participation of the community itself, many individuals with disabilities remain deprived of basic rehabilitation services with no equalitarian access to education, professional qualification, work opportunities, leisure, or other activities in the community and society. Moreover, many are isolated and confined to their domestic environment, ignoring the availability of assistive and healthcare devices (Phillips et al., 2013).

In some cases, people with disabilities lose membership in their own families and have no defined place within the family association, which decreases their autonomy and self-determination. This situation repeats itself within the community, as these individuals are sometimes unable to be included in the shared world of communication and remain excluded from the material and symbolic production process of social life (Barnes et al., 2002). The social inclusion of people with disabilities is a key for promoting health and improving the quality of life of this population. For that, they need to become involved and participate in basic and general activities that compose the human existential universe. For these individuals to be effectively included and fully participate and circulate freely in social life, they need to develop occupations and become involved in daily life and social activities, acquiring autonomy and independence (AOTA, 2010; WHO, 2012a).

In Brazil, the Federal Constitution of 1988 (*CF/88*) provides for care, public assistance, protection and social integration and guarantees the rights of people with disabilities within the joint competence of the three spheres of government. Thus, the *CF/88* guarantees the defense of inclusive and integral human rights under the rule of law, including the obligation to provide health care for people with disabilities through the Brazilian Public Health System (*Sistema Único de Saúde - SUS*), coordinating among municipal, state and federal governments, at all three levels of care: primary, secondary and tertiary (Brasil, 2006). According to this perspective, one of the founding principles of the *SUS*, integrality, is highlighted as an important demarcation in the health care of people with disabilities. In the process of consolidating the expanded concept of health as a complex human existential condition that is interconnected with various sociocultural, political and economic factors, all of which are more significant than simply being in a dichotomous relationship with disease, comprehensiveness amplifies the possibilities of offering health care as an interconnected and continuous set of actions and health services, in which practices are communicated and integrated continuously, with the main

objective of achieving comprehensive, complex and humanizing care (Campos, 2000; MacLachlan et al., 2012).

Once the concept of disability as socially shared responsibility is established, comprehensive health care for people with disabilities is defined within the framework of attention and care, ranging from preventative health care actions and health promotion to rehabilitation, with access to both Primary Health Care (PHC) and specialized services and equipment, ensuring connected and extended health care for people with disabilities that covers all sociocultural, historical, political and economic bases that are determinant in the health-disease continuum, without neglecting the accumulation of knowledge and technologies in the biomedical field (Brasil, 2008; MacLachlan et al., 2012).

Thus, for the social group under discussion, interconnections among health promotion, disease prevention, early diagnosis of disabilities and primary care and specialized rehabilitation networks would be expected. What can be attested to, however, is that the delivery of integral healthcare to people with disabilities remains far from what is envisioned under the National Health Policy (NHP). Observation confirms that the central focus remains on disability from an organic perspective, on the rehabilitation process and on actions centered around specialized, highly technological services that are difficult to access for a significant portion of people with disabilities, especially those who find themselves in situations of social vulnerability (Brasil, 2008; Evans et al., 2001).

People with disabilities are among those who are vulnerable to social determinants of health. Social determinants of Health are understood as social, economic, cultural, ethnic/racial, psychological and behavioral factors that influence the occurrence of health problems and their risk factors in the population. Studies show that high rates of social inequity present in the population with disabilities, within which there is a lack of access to employment and income, education, adequate transportation and public utilities and health services (Bus and Pellegrini, 2006; Chappell and Johannsmeier, 2009). This discussion is consonant with observations obtained from a survey conducted in 2011 and 2012 in Ribeirão Preto, SP, Brazil involving people with disabilities living in the region enrolled in a Family Health Unit (FHU) associated with the School Health Center (Centro de Saúde Escola, CSE) of the Medical School (Faculdade de Medicina de Ribeirão Preto, FMRP) of the University of São Paulo at Ribeirão Preto (USP).

The assumptions guiding this study include the following: There are still a considerable number of individuals with disabilities who lack access to social opportunities, material and non-material goods that are part of society's system of patrimony, and who have

difficulty accessing the most basic forms of social inclusion, which effectively mean inclusion in family and community dynamics and structures. This is so even though there are public policies and constitutional provisions in Brazil that focus on the care provided to individuals with disabilities within the healthcare and welfare spheres, both to provide socioeconomic protection and enable universal access to healthcare services. There is a lack of coordination among the various levels of healthcare (for example, at the primary, secondary and tertiary levels) delivered to individuals with disabilities, compromising the integrality of healthcare actions. Additionally, there are immense geographical and psychosocial barriers hindering the access of people with disabilities and their social mobility. Concomitantly, people with disabilities belong to the poorest segments of the population, with poor access to education, work opportunities and activities that generate income, transportation, housing and a sustainable environment; thus, they are socially vulnerable as a result of social inequality. From this perspective, the social determinants existing in Brazil have more strongly impacted the conditions of life and health of individuals with disabilities than have conditions that are linked to physiological, anatomic-morphological or clinical factors. Given these objectives and the hypothesis, we seek to reflect on the results presented in the research.

## METHODOLOGICAL APPROACH

### An interpretive and reconstructive approach to the data

It is a field research that makes an investigation into the natural environment of the subjects and it is characterized by a descriptive exploratory study. The method followed a qualitative approach consistent with the elements involved in this investigation, which are in the symbolic dimension of human existence and include the interpersonal relationships present in the families and individuals studied, their values and the meanings that mark their health status and living conditions, cultural understanding and social representations. Therefore, as it is a qualitative methodology, statistical analysis do not apply. The instrument for data collections were open interviews of life stories (Minayo, 2008; Johnson and Barach, 2008). The study subjects were ten people with congenital or acquired disabilities, who were 16 years old or older and had sufficient cognitive abilities to narrate their life histories and living in the area covered by the city's Family Health Unit. The type of disability did not constitute a criterion for selection, that is, any variable among the manifestations of disability were accepted: physical, motor, sensorial, mental and/or multiple disabilities, because this study sought to understand the nature of the condition of disability, regardless of the specific clinical implications related to the disability. The selection of subjects was made from information from medical charts of families served by the Family Health Unit according to the selection criteria mentioned earlier.

The research locations were the homes of each subject, residents of the Western region of the city of Ribeirão Preto who were enrolled in FHU associated with the CSE-FMRP-USP. Data

were collected through open interviews regarding life stories. The interviews were based on open-ended questions concerning the life histories narrated by the subjects. During the interviews, we noted the residence, relationships and family dynamics of the survey participants. Since the interviews were conducted in the subject's home, family members were always present, which allowed contact with the family dynamics existing in each situation studied. We interviewed ten subjects at home and they were asked to narrate their lives from birth to that moment. Twenty people with disabilities were identified in the territory encompassed by the study, and the population served by the Family Health Service reference was estimated at approximately 250 families. Of these 20 subjects, four declined to participate, two had no cognitive condition to make a story of life and three were not found in their homes. Therefore the subjects selected were ten people who agreed to participate and fit the criteria laid.

We sought to allow a free narrative, but we interjected with prompts to provide some narrative linearity when necessary. The interviews were recorded with the permission of the subjects and transcribed later. The textual contents from the narratives were intersected in the analysis of the data and interpreted in light of dialectical hermeneutics (Habermas, 1989), which provided a reconstructive, rather than a descriptive interpretation of the data during our analysis: from the ordering of the data, we have developed a thorough and extensive reading of the stories of life and a link between the information and reports of the historical and cultural factors that have conditioned the telling of the stories. Additionally, we connected the perceptions of the subjects studied to reveal their expectations regarding their autonomy, the health actions of health services and their life projects, to previous information (Bauer and Gaskel, 2002). The stages of the data analysis were as follows:

- a) Reading and rereading of the interviews repeatedly and carrying out a data analysis of the printed material from the interviews according to the thematic content analysis method.
- b) Identification of emerging themes that outlined certain symbolic universes shared between the participants in the research and a crossover with data in the literature.
- c) Establishment of relations with the field of fundamental determinants, such as: cultural, political, economic and social conjunctures in which the statements find reference for their construction.
- d) Establishment of relations between the thematic axes and the historical constitution process of the social group being researched and why they build such conceptions about the phenomenon under study.

The research project was submitted to the Research Ethics Committee of the CSE-FMRP-USP and approved under protocol no. 468/CEP/CSE-FMRP-USP on the 27th of December, 2011. Ethical procedures were followed at all stages of the research as set out in the approval document Committee on Ethics in Research.

## RESULTS

Search results are presented and arranged through the table (Table 1). In regard to access to health services, the study participants reported difficulty accessing primary and secondary healthcare services, with no access to rehabilitation, due to two sets of factors: socioeconomic

**Table 1.** Results and thematic axes.

Thematic Axes	Results	Number of participants/families
Social family inclusion of the study participants	The social family inclusion of individuals with disabilities addressed in the study is related to the degree of social inclusion/integration the family itself experiences in society.	-
Participants and their families are included	Families with better socioeconomic, cultural and educational conditions have greater access to social resources and these individuals: have stronger social support and occupy a personalized position within the family; perform an articulated role in family dynamics; and have an important degree of autonomy with the ability to make decisions in regard to personal and family events. Therefore, their social participation becomes more effective as they have greater access to cultural and social resources in the community, which is important for human development	Two participants and their families presented this condition
Participants and their families who are socially vulnerable	<p>Limited socioeconomic and cultural resources, low levels of education and social support, which generate weakened family ties. Three families presented social vulnerability characterized by indicators of social inequality:</p> <ul style="list-style-type: none"> <li>(a) Low education;</li> <li>(b) Lack of access to work;</li> <li>(c) Lack of access to education;</li> <li>(d) Lack of access to transportation;</li> <li>(e) Difficult access to housing;</li> <li>(f) Lack of access to a sustainable environment</li> </ul> <p>Poor hygiene conditions were found both in regard to domestic environments and to the study participants; lack of information on the part of the family members and participants in regard to the study participant's disability and care it requires, lack of material resources such as assistive technology and transportation, and lack of financial resources to acquire basic necessities</p>	Eight of the interviewed people do not perform significant tasks in their routine, do not have effective social participation, do not work, and do not have any source of income. Four interviewees remain restricted to their homes, with difficulty accessing services, public places, and opportunities that are available to the entire collectivity. Eight individuals have difficult access to transportation, have no access to assistive technology, have economic difficulties commuting to places or accessing services, and social and cultural equipment. They also report geographical, psychosocial and cultural barriers. Economic difficulties are due to their exclusion from the job market

and cultural factors and those related to the organization and coordination of healthcare services, as described in the table (Table 2).

**DISCUSSION**

Analysis of the data obtained led to the identification of four thematic axes, which encompassed and organized the predominant themes in the narratives and systematic observations, representative of situations often experienced in the daily lives of the subjects studied,

together with their families and community, as well as sets of characteristics and common health care and social needs presented by the people with disabilities being studied. The thematic axes are: (a) the inclusion of people with disabilities in familial and community contexts and the relevant proportion of social vulnerability present; (b) the daily lives of people with disabilities and existential emptiness; (c) participation in and access to PHC and specialized rehabilitation services for people with disabilities, and (d) social and health care needs. The presentation and discussion of these four thematic axes are as follows:

**Table 2.** Access to healthcare services.

Access and the lack of access to healthcare services	Nature of the problem
Socioeconomic and cultural factors	Lack of transportation to commute to the services, and the conditions of urban mobility
	Lack of technical information and information concerning social rights or how to access such rights
	Absence of assistive technology to facilitate mobility and the presence of geographical barriers
	Poor economic conditions leading to a lack of private transportation or any other paid transportation
Factors intrinsic to the healthcare services and management	The set of healthcare actions provided by the healthcare services to the community and at home, which would promote universal access to those with disabilities, is limited
	There is a lack of cooperation within the healthcare network, which hinders the coordination and integrality of healthcare delivery

### Socio-familial inclusion of people with disabilities

Familial belonging to the people with disabilities analyzed in this study is related to the degree of social integration that the family itself occupies in society. The quality of care and attention dispensed by the family to the family member with a disability depends on the socioeconomic status of the family in question and the social and community resources available. Middle class families and those with more education provide more care resources, the individual being cared for has more powerful social support and occupies a personalized place in the family, that is, they occupy a connected role in family dynamics and present an important degree of autonomy, with the capacity for decision-making regarding personal and family events:

Subject 1 (S1): *If it's not my brother, it's my father; when I need something, my mother picks it up; she closes that there and we go by bus, car, whatever works best. In my mother's small living room, over there, I do my crafts; I sell clothes, lingerie, Avon. My cousin made a proposal to me for us to set up a shop. I'm thinking about it before I give him an answer.*

However, this reality is not observed in families whose social condition is more vulnerable, those with limited socioeconomic and cultural resources, a low level of education and poor social support, or in families with weakened ties. In one case, violence against the family member with disabilities was observed. In three family nuclei, we identified characteristics of social vulnerability, and in these cases significant problems were observed,

including: poor hygiene conditions in the domestic space and for the study subjects; a lack of information among family members and the subjects concerning disability and care needs; lack of material resources, such as assistive technology and transportation; and lack of financial resources for the acquisition of basic materials. In addition, the individual with the disability does not always occupy an autonomous place within the family dynamics; they are cared for by one family member, usually the mother or wife, and only in accordance with what is possible for this single caregiver to accomplish. Subject 6 (S6) is a 70-year-old man who, like his wife, did not complete the final year of elementary school. A former farm worker, who became a bricklayer when he moved to the city, he is an alcoholic. He remains bedridden following a fall, in which he fractured his lower limbs (LL), and a stroke. He does not have a wheelchair, presents poor hygiene and his wife is the only caregiver. She reported:

*I do everything, though sometimes our youngest helps me, but the others leave early and get home late. I try to do things like they taught me at the hospital, but I've also got back pain, I've got a lot of leg pain, so he doesn't get out of bed; I wash him right here. The guy from the ambulance says a ramp is needed here, but we don't have a wheelchair; whenever necessary, my son-in-law has to carry me. I'm hoping to go to (mentions a popular TV show). I've seen him give wheelchairs to others.*

The condition of social vulnerability is frequently associated with the reality of people with disabilities. They are among the poorest individuals, with the lowest

level of education and income in Brazil and worldwide. The development of disabilities is directly related to poor conditions of nutrition, housing, sanitation, access to health services and social facilities, and low income. These, in turn, are determinant living conditions in areas of poverty incidence (WHO, 2012b; Braveman and Gruskin, 2003).

Social inequality and poverty influence and, in certain cases, make it impossible to access the equipment of social support networks, basic information regarding social rights and the resources available in society. In addition, people with disabilities compose a social segment that is among the most excluded from the labour market and income generation mechanisms. The closest caregivers often have to abandon their own work activities and means of income generation, further increasing the conditions of vulnerability of the family nucleus. Caregivers frequently present problems of worsening health due to care activities (Marmot, 2005; Cooper et al., 2012). Conditions of social and economic vulnerability of people with disabilities impede the satisfaction of their needs, the guarantee of their independence and quality of life, and public policies have proven insufficient in responding to the problematic situations indicated (Cooper et al., 2012).

The severity of poverty and misery in Brazil constitutes an ongoing preoccupation and demands reflection concerning their social influence, particularly in the area of actuation involving the family, in which public policies still lack more expressive action. The state should ensure the rights of the disabled and provide the conditions necessary for the effective participation of the family in the development of their children, particularly for families that include individuals with disabilities; however, Brazilian public investment in the social sector is increasingly linked to economic performance (Gomes and Pereira, 2005; Prince, 2010).

It is not possible to assign a single meaning to poverty, but it becomes evident when part of the population is unable to generate enough income to maintain sustainable access to basic resources to ensure their quality of life. Moreover, the high levels of poverty that affect Brazilian society are the main determinant in the structure of perverse social inequalities in income distribution and economic inclusion. This highlights the need to revitalize the constitutionally established social rights of people with disabilities and to seek to connect sectors of society to develop and implement public policies designed to solve the prevailing conditions of social vulnerability among this population.

### **The daily lives of people with disabilities: The need to aggregate the value of existential meaning**

Our research shows that majority of respondents do not

develop activities that are structured, productive, related to leisure or, in some cases, self-care activities in their daily lives. S6 is the most serious case, remaining bedridden the entire time. However, others, even though they can move around within their domestic spaces, are isolated from social participation:

*Subject 3 (S3): Going back to where I was, to my job, was bad, but I worked with the public, I worked with people, so, it was great. It had its problems, but it was good. Now, I don't leave the house.*

*Subject 5 (S5): I don't walk or drive, because everything hurts. It's difficult for me to go out; I don't even go to my kids' homes anymore. You miss working, miss making things, cooking, but I can't do it anymore. S5 is a 75-year-old woman who used to be a seamstress and was very active in maintaining her family's income. When she lost her sight, she developed depressive symptoms and attempted suicide twice.*

In addition, there is the prejudice generated in the field of social stigmas that genuinely affects the disposition of these individuals to engage public environments, affecting their self-esteem and body image:

*S3: I'm ashamed. I don't like it. I don't like myself. I comb my hair and don't look in the mirror. That's why I don't like being around other people.*

*Subject 2 (S2): I was slower than the others, and like it or not, we're less than a normal person, we want to give the best of ourselves, but we'll never be like a normal person, it's very difficult.*

Daily existence is the territory in which human potential encounters its subjective inscription of achievement. It is the field of the human actions of creation and recreation of the world and social living. Human daily living activities range from those concerned with the maintenance of daily living and self-care to those concerned with the ongoing recreation of social living. Thus, the individual is perceived in their daily reality, inserted in an intersubjective world, whose existence only attains meaning in participation and conjunction with other people. It is here, in the terrain of exchanges and human relationships, that daily living forms and is produced. Daily existence is the context in which the subject moves, observes the passage of time, constitutes their existential experience and recreates their uniqueness (Clair et al., 2011; Lefebvre, 2002).

Arendt (1998) alludes to human action as the fundamental condition of human life in the world. The activities in which people engage involve the dimension of the biological reproduction of life, work as an activity of

construction, the instrumentalization of life, the production of objects that shape humans as producers and modifiers of nature, of mundanity, as the author called it; human action is the terrain on which individual existence is transcended. Furthermore, humans involve themselves in praxis, the political dimension of human existence, action intersubjectively mediated among people, by which they may inhabit the shared world. Engaging in activities therefore ensures an individual the condition of singularity and plurality at the same time: every person is plural, since they share the same condition with all others; however, no person in the world is exactly like any other who exists or has existed.

According to the perspective of the field of occupational therapy, occupations and activities have the potential to structure an individual's subjectivity and external reality, establishing internal mechanisms and restoring the unity of an individual in their biological and cultural conditions and in their biographical and collective experiential fields. While in the field of health production, occupations can, for this reason, occupy the centralizing and guiding element of the construction of a quality life (Pierce, 2001; AOTA, 2008). What we perceived from the research is that the daily lives of the subjects studied were clearly impoverished, void of existential meaning, mainly due to the minimal or lack of involvement in a routine and creative occupations.

The daily life of an individual is revealed at the intersection of the dimensions of subjective life and external reality. Thus, this interface between subjectivity and the social sphere has the possibility of being realized in the cultural sphere of human life in which individuals exercise all their creative potential, inscribing their subjectivity into culture and ensuring their social participation in the world, a condition that is central to occupational therapy (Larivière, 2008). Thus, an existential emptiness can be perceived in the lives of the subjects, a barely-filled void, since they are maintained without the creative exercise provided by involvement with and in occupations. This existential emptiness directly interferes in and influences the global health processes of these individuals. It interferes both in physical health, leading to becoming overweight or to obesity, and in mental health, such as depressive states, and can lead to extremes, such as the suicide attempts identified in the case of S5.

### **Inclusion in and access to PHC and specialized rehabilitation services for people with disabilities**

The individuals studied encountered difficulty accessing health care services, both primary and secondary care. This is due to several factors: lack of transport of people to accompany them, of technical information and concer-

ning social rights, and a lack of assistive technology. Even among those who are capable of walking, they were unable to get to these services due to the poor conditions of sidewalks and public roads. Thus, we observed that the majority of the subjects remained without rehabilitation. There is also, on the part of health care services, a lack of attention and care conducted within the community and within the home. Primary health care services focus on maintaining general health and do little to impact the condition of disability because they consider this to be the responsibility of specialized rehabilitation services, that is, secondary and tertiary levels of health care. Specialized rehabilitation services are located far from the subjects' residences and do not provide attention and care centered in the community or within the home. Thus, the subjects reported that, faced with the immense difficulties of getting to rehabilitation services, they eventually abandon their use. In addition, some stated that the rehabilitation services discharged them, including one individual who was extremely dependent.

*S1: It's tiring, because you go by van early and stay till late, until they come to pick you up. You can't lie down, you can only sit on the seats. There, they discharged me and the psychologist gave me a piece of paper saying that to continue, I needed another referral.*

*S3: You use a wheelchair and need your things, it's getting difficult, with the diapers and the medication... not everyone is willing to help you, not everyone can help you. My brother-in-law takes me, but he has to leave me there, take the kids to school, pick up my sister and then come back and get me. Feels like you're causing a lot of trouble. Physiotherapy ended, seems that it might start here at the local Unit; I'm waiting. My sister said that the equipment arrived, and she would talk to the lady at the Unit and leave my name.*

This lack of interconnection within the health service network that affects people with disabilities can only be broached and resolved within the field of the integrality of health, that is, the axis by which the right to and access to health care is guaranteed to people with disabilities and by which the weaknesses of the system caused by the discontinuity of the same are overcome (Sullivan et al., 2011). Integrality, understood as the scope of providing appropriate care from a minimum list of services and actions that respond to the needs of the population, is the basis of the Brazilian Public Health System (SUS), which guarantees knowledge and attendance to the health care needs of people not only as they relate to disease, but within their sociocultural contexts (Junior et al., 2012).

However, in the case of people with disabilities, intergra-



lity is not being fulfilled and the subjects of this study encountered difficulty accessing health care services, especially those providing rehabilitation services. A condition of fragility and discontinuity exists regarding care delivered to people with disabilities. According to the WHO, only 2% of people with disabilities have access to rehabilitation; however, in developing countries, this drops to 1 to 2 individuals in 10,000. In Brazil, tertiary care predominates in the case of people with disabilities, in direct contravention of the National Policy for Persons with Disabilities, which advocates integrated care among all three levels of complexity for this social segment (OMS, 2003; Brasil, 2008). There is also a problem regarding comprehension that specialized in rehabilitation services present in relation to disability. The vast majority of these services continue to work with an excessively organicist conception of disability, guided solely by a morpho-anatomical and biological point of reference. Without a social conception of disability, specialized services fail to understand that actions promoting the social inclusion of people with disabilities and the restoration of their autonomy and independence in their practical and social lives are the services' responsibility. When a given medical condition stabilizes and large gains in functional outcome are not verifiable, the service discharges the patient without considering the social dimensions of disability (Lancet, 2009). This clearly deviates from what is advocated by the principle of integrality, which provides for not only the continuity of care, but also, and above all else, extended care to the user, necessitating the consideration of the totality of their needs (Campos, 2000).

Therefore, people with disabilities require attention and care centered within the community and the home. We highlight the importance of programs aimed at eradicating poverty, and reducing social inequities in the territories and community-based. The Primary Health should coordinate activities and programs that minimize the negative effects of social determinants of health prioritizing human special groups such as people with disabilities (Hartley et al., 2009; Wood et al., 2013).

### **Social and health care needs of people with disabilities**

The social and healthcare needs (see Table 1) presented by the study subjects are:

1) Adequate public transport - the majority of the subjects emphasized the lack of adequate public transport available that is adapted to people with special needs. There is one local public service available for transporting people with special needs; however, the subjects say that this is a limited service and access is difficult because

few vehicles are available, the timetable is limited and the individual wastes the whole day when they depend on this form of transportation. The remaining vehicles are not adapted to the needs of people with disabilities;

2) Universal access - the subjects indicated difficulties accessing services, equipment and private and public environments, all of which are regularly accessed by the collective. People with disabilities start by highlighting the terrible condition in which the streets are maintained, which makes movement around the city and within the region they inhabit unviable. Conditions for wheelchair users are equally bad. In addition to these factors, the geographic, cultural and psychosocial obstacles are immense and hinder or prevent social integration, as well as deny those with disabilities equal opportunities within common and social environments;

3) Rehabilitation - the vast majority of the subjects emphasize the difficulty of accessing rehabilitation services, indicating the need for the existence of services closer to their homes, while requiring rehabilitation within the home. This topic was discussed in detail;

4) Directly related to the preceding item, the subjects presented the need for assistive technology (AT), information concerning their rights to obtain AT and access to the dispensation of the same;

5) Social support - considering the significant number of subjects experiencing social vulnerability, the need for social support is evident. Some subjects live in poor socioeconomic conditions and have basic social needs that are unmet, which consequently results in a lack of resources and instrumentalization for the caregiver, wherein the individual being cared for lives in an extremely precarious situation and domestic space;

6) Social spaces for coexistence and social participation - some subjects highlighted the need for spaces for coexistence and social participation in their region. Some presented personal situations of social isolation due to biased attitudes and physical, cultural, political, economic and psychosocial barriers resulting from the lack of attention that society devotes to this segment of the population. Other factors include a lack of AT and rehabilitation programs that facilitate social participation and work;

7) In addition, some subjects presented the need for mental health treatment. However, they lack information and the guidance required to seek this form of treatment, since the prevailing perception is that the physical dimension is more important and more urgent when searching for health care treatment (Tomlinson et al., 2009).

The social and health care needs presented by the subjects are highly interconnected to the social determinants of health and presented indicators of social inequity. Although the SUS provides care in three levels

of care system, integrality of the system and the network of health services and access to rehabilitation services, free distribution of assistive technology and equity there are still people with disabilities without access to basic health services and other public services. Although the Federal Constitution ensure the access of persons with disabilities to public spaces and public services, free transport special, at the local level these public policies have not been implemented. These data show that in Brazil significant social inequalities still persist.

From this study, it is observed that social determinants of health predominate over all other determinants health in relation to people with disabilities studied. Data analysis showed that subjects who participated in the study have difficulty accessing health services (rehabilitation and primary care), as well as wrapping other essential public services: employment and income, education, transportation, sustainable environment and quality of life. This fact shows the existence of social inequality because one of the principles of the Brazilian Unified Health is the equity, in which people who have special needs should be met with priority and this does not happen. Instead, it is observed that these people are not living their needs met in unjust inequalities of access, configuring a reality of social inequities, although there are laws which provide for the social rights of persons with disabilities.

The social determinants of health are defined, with a few differences among the existing references, as the social, economic, cultural, ethical/racial, psychological and behavioral factors that influence the occurrence of health problems and their risk factors in the population. According to the WHO model on the Social Determinants of Health (CDSH), the social determinants of health (DSS) are defined on three levels: structural and intermediate determinants; sociopolitical context; and the contexts in which it is possible to deal with social inequities. In turn, all of these factors are conditioned by the political macro-determinant linked to the globalization of the economy and its effects on National economies, resulting in political organizations that are focused on economic development to the detriment of social policies (CSDH, 2008; Starfield, 2011).

The model of CDSH establishes the social determinants of health (SDH) in three spheres: the structural and intermediary determinants; the sociopolitical context; and the contexts in which one can deal with social inequality. The structural determinants are those linked to social stratification, which generates the stratification, and include traditional factors of income and education. They also include: gender, ethnicity and sexuality as social stratifiers and social cohesion related to social capital. The intermediate determinants emerge from the configuration of subliminal social stratification and determine differences in the exposure to and

vulnerability to conditions that compromise health. These include: life conditions, work conditions, availability of food, behaviors within the population, and barriers to adopting a healthier lifestyle. This model considers the social and political contexts as determinant factors that influence the health and disease continuum in certain population segments. Social contexts include rapid urban growth with settlements and housing areas with poor sanitation and life conditions, child development that influences development, and working conditions and processes, the healthcare system and access to public services. All these factors are conditioned by a political macro-determinant linked to the globalization of the economy and its effects on nations' economies, resulting in a political organization that focuses on economic development at the expense of social policies (WHO, 2012b). Although the SDH also include the ways that people, groups and populations work, their cultural manifestations and their conceptions about health, disease and means of treatment, the iniquitous conditions in which many social segments are inserted have most impacted and determined the persistence of diseases, conditions and status that could be eradicated. In other words, there is technology and knowledge for this, but an effective resolution cannot be achieved, thus configuring an avoidable, unfair and unnecessary reality experienced by this group of populations in their social vulnerability (Moene and Wallerstein, 2001).

However, the presence of a reality that is strongly marked by social injustice and inequalities is also noted. Thus, taking into account the social determinants of health and the eradication of social inequities, it is necessary to meet the local contexts, which are still marked by difficulties in accessibility to material and non-material goods and social opportunities, such as people with disability. For this, it is necessary, the creation of comprehensive care programs that are articulated in networks in a multiprofessional and intersectoral manner, uniting the health care, social assistance, and public administration sectors with civil society to seek policies and programs to eradicate poverty and social inequities. Therefore, it is believed that it is necessary for the creation of vulnerability reduction and social inequities in community-based interface with the Primary Health Care programs.

## Final considerations

Perceptions of the existential condition of disability have changed historically and culturally. The perception and social comprehension of disability are advocated by current public health policies concerning people with disabilities and sanctioned by associations, councils and organizations working to guarantee the social rights of

this social segment. The social understanding of disability also seems to be more consistent with the principle of integrality in health, by contemplating all the dimensions related to the health and social needs of people with disabilities, ranging from the needs of functional rehabilitation, to actions intended to eliminate physical, geographic, cultural, political and social barriers, to the free and full mobility and social integration of people with disabilities, enabling their universal accessibility.

In Brazil, the democratization of health as a result of the implementation of the SUS drew attention to the segment of people with disabilities within public policy. Thus, beginning with the National Health Policy of Persons with Disabilities, published in 2002, directives for States and Municipalities to organize their actions to assist people with disabilities have been established, advocating an expanded conception of health care for people with disabilities, by contemplating interconnected and continuous care at all three levels of complexity, encompassing health-related prevention and promotion, as well as rehabilitation, seeking the integrality of actions and the individual. However, a social organization also built based on large social inequalities continues to determine a lack of access to decent living conditions.

Despite that and other progress made in recent decades, evidenced by improvement in some indices of social development and the creation of a National Health System, based on the principles of solidarity and universality of care, large portions of the population still suffer from problems that produce important health inequities, such as unemployment, lack of access to decent housing, the sanitation system, health services and quality education and an environment protected.

So it is necessary to create programs for the eradication of poverty and act on social inequities from the Primary Health Care. Monitoring these inequities and systematic study of its determinants should help identify vulnerable points to the impact of public policies that seek to combat them.

### Conflict of interest

The author declared he has no conflict of interest.

### REFERENCES

- American Occupational Therapy Association (AOTA) (2008). The occupational therapy practice framework: Domain and process (2<sup>nd</sup> ed.). *Am. J. Occup. Ther.* 62(6):625-683.
- Arendt H (1998). *The Human Condition* (2<sup>nd</sup> ed.). Chicago: University of Chicago Press.
- Bampi LNS, Guilhem D, Alves ED (2010). Social Model: A New Approach of Disability Theme. *Rev. Lat. Am. Enfermagem.* 18(4):816-823.
- Barnes C, Oliver M, Barton L (2002). *Disability studies today*. Cambridge, UK: Policy Press in association with Blackwell Publishers.
- Bauer MW, Gaskel G (2000). *Qualitative Researching with Text, Image and Sound: A Practical Handbook for Social Research* (1<sup>st</sup> ed.). Thousand Oaks, CA: SAGE Publications.
- Brasil (2006). Ministério da Saúde. Secretaria de Atenção à Saúde. Departamento de Ações Programáticas Estratégicas. *Manual de legislação em saúde da pessoa com deficiência*. 2 ed. Ver. Atual. Brasília.
- Brasil (2008). Ministério da Saúde. Secretaria de Atenção à Saúde. Política Nacional da Pessoa Portadora de Deficiência. Brasília.
- Bus PM, Pellegrini Filho A (2006). Iniquidades em saúde no Brasil, nossa mais grave doença: comentários sobre o documento de referência e os trabalhos da Comissão Nacional sobre Determinantes Sociais da Saúde. *Cad. Saúde Pública*, Rio de Janeiro 22(9):2005-2008.
- Campos GWS (2000). Saúde Pública e Saúde Coletiva: campo e núcleo de saberes e práticas. *Ciência & Saúde Coletiva.* 5:219-230.
- Chappell P, Johannsmeier C (2009). The impact of community based rehabilitation as implemented by community rehabilitation facilitators on people with disabilities, their families and communities within South Africa. *Disabil. Rehabil.* 31(1):7-13.
- Clair VA, W-St Kelse N, Smithe E (2011). Doing everyday occupations both conceals and reveals the phenomenon of being aged. *Aust. Occup. Ther. J.* 58:88-94.
- Clapton J, Fitzgerald J (1997). The History of Disability: A History of 'Otherness'. New Renaissance. Available at: <http://www.ru.org/human-rights/the-history-of-disability-a-history-of-otherness.html>
- Cooper RA, Cooper MA, McGinley EL, Fan X, Rosenthal JT (2012). Poverty, Wealth and Health Care Utilization: A geographic assessment. *J. Urban Health* 89:828-847.
- CSDH (2008). Closing the gap in a generation: Health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health. Geneva, World Health Organization.
- D'Aubin A (2003). "Nothing about us without us": CCD's struggle for the recognition of a human rights approach to disability issues. In: Enns, H. Neufeldt, A.H. (Eds), *In pursuit of equal participation: Canada and disability at home and abroad*. Concord, ON: Captus Press pp. 111-136.
- Evans PJ, Zinkina P, Harphamb T, Chaudury G (2001). Evaluation of medical rehabilitation in community-based rehabilitation. *Soc. Sci. Med.* 53:333-348.
- Farrell J, Anderson S, Hewitt K, Livingston MH, Stewart D (2007). A Survey of Occupational Therapists in Canada about Their Knowledge and Use of the ICF. *Can J. Occup. Ther.* 74:221-232.
- Gannon B, Nolan B (2007). The impact of disability transitions on social inclusion. *Soc. Sci. Med.* 64:1425-1437.
- Gomes MA, Pereira MLD (2005). Família em situação de vulnerabilidade social: uma questão de políticas públicas. *Ciência & Saúde Coletiva.* 10:357-363.
- Habermas J (1989). *The Transformation of the Public Sphere*. Cambridge: Polity Press.
- Hartley S, Finkenflugel H, Kuipers P, Thomas M (2009). Community-based rehabilitation: opportunity and challenge. *The Lancet* 374:1803-1804.
- Johnson JK, Barach P (2008). The role of qualitative methods in designing health care organizations. *Environ. Behav.* 40:191-214.
- Junior RM, Coimbra M, Matos YAPS (2012). *Direito Sanitário*. São Paulo: Ministério Público, Centro de Apoio Operacional das Promotorias de Justiça Cível e de Tutela Coletiva.
- Lancet (2009). Disability: beyond the medical model. *The Lancet*, 374: 1793 editorial.
- Larivière N (2008). Analyse du concept de la participation sociale: définitions, cas d'illustration, dimensions de l'activité et indicateurs. *Can. J. Occup. Ther.* 75:114-127.
- Lefebvre H (2002). *Critique of everyday life*. Foundations for a sociology

- of the everyday. London/New-York: Verso.
- Levasseur M, Desrosiers J, St-Cyr Tribble D (2007). Comparing the Disability Creation Process and International Classification of Functioning, Disability and Health Models. *Can. J. Occup. Ther.* 74:233-242.
- Maclachlan M, Khasnabis C, Mannan H (2012). Inclusive health. *J. Trop. Med. Int. Health* 17:139-141.
- Marmot M (2005). Social determinants of health inequalities. *Lancet* 365:1099-104.
- Minayo MCS (Ed.). (2008). *O desafio do conhecimento: pesquisa qualitativa em saúde* (11<sup>th</sup>ed.). São Paulo: Hucitec.
- Moene KO, Wallerstein M (2001). Inequality, social insurance and redistribution. *Am. Polit. Sci. Rev.* 95(4):859-74.
- Organização Mundial da Saúde (OMS) (2003). Centro colaborador da Organização Mundial da Saúde para a Família de Classificações Internacionais. CIF: Classificação Internacional de funcionalidade e Saúde. EdUSP: São Paulo.
- Phelan SK (2011). Constructions of Disability: A Call for Critical Reflexivity in Occupational Therapy. *Can. J. Occup. Ther.* 78:164-172.
- Phillips RL, Olds T, Boshoff K, Lane AE (2013). Measuring activity and participation in children and adolescents with disabilities: A literature review of available instruments. *Aust. Occup. Ther. J.* 60:288-300.
- Pierce D (2001). Untangling Occupational and Activity. *Am. J. Occup. Ther.* 50:138-146.
- Prince MJ (2010). What about a Disability Rights Act for Canada?: Practice and Lessons from America, Australia and the United Kingdom. *Can Public Policy* 36:199-214.
- Starfield B (2011). The hidden inequity in health care. *Int. J. Equity Health* 10(15):2-3.
- Sullivan WF, Berg JM, Bradley E, Cheetan T, Denton R, Heng J, Hennen B, Joyce D, Kelly M, Korossy M, Lunskey Y, McMillan S (2011). Primary care of adults with developmental disabilities: Canadian consensus guidelines. *Can. Fam. Physician* 57:541-553.
- Tomlinson M, Swart L, Officer A, Chan KY, Rudan I, Saxena S (2009). Research priorities for health of people with disabilities: an expert opinion exercise. *Lancet* 374:1857-1862.
- Tregaskis C (2002). Social model theory: The story so far...*Disability and Society* 17(4):457-470.
- Wood R, Fortune T, McKinstry C (2013). Perspectives of occupational therapists working in primary health promotion. *Aust. Occup. Ther. J.* 60:161-170.
- World Health Organization (2001). *International classification of functioning, disability and health*. Geneva.
- World Health Organization (2012a). *World report on disability*. Geneva.
- World Health Organization (2012b). *Social Determinants of Health. Report by the Secretariat*. 132<sup>nd</sup> session. 23 November.