

# Disabled persons on the way to participatory democracy<sup>1</sup>

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**Abstract:** This article aims to discuss the social participation of disabled persons and the exercise of social control in the specific Organizations, Associations, Groups and Council of the segment. For this, the study builds a relationship between: understanding about disability, the issue of representativeness and the role of this segment in the struggle for rights and in the social control of public policies. And it brings as a key reading the conceptions of participatory democracy, social control; the different perspectives of understand the deficiency and the conceptions of Hannah Arendt for public and private space. This is an exploratory study carried out with organizations OF and FOR disabled persons, through semi-structured interviews with coordinators and presidents; participant observation of meetings and assemblies; documentary research on municipal and national laws and decrees, municipal conferences on education, health and social assistance, statutes, folders, minutes and leaflets produced by the Organizations and through the construction of a field diary. The results and discussions approach the reality of a specific municipality, however, are also marked by the national context of the struggle organized by the rights of disabled persons. The social representations of disability, coupled with the dynamics of the functioning and management of the Organizations and the changes in the social movements formed in the streets, in the public and private spaces, present, at the same time, weaknesses and potentialities in the defense and strengthening of the participation of disabled persons in decision-making processes.

**Keywords:** *Social Participation, Disabled Persons, Handicapped Advocacy, Social Movements*

## Pessoas com deficiência no caminho da democracia participativa

**Resumo:** O presente artigo objetiva discutir sobre a participação social das pessoas com deficiência e o exercício do controle social nas Organizações, Associações, Grupos e Conselho específicos do segmento. Para tanto, o estudo constrói uma relação entre a compreensão sobre deficiência, a questão da representatividade e o protagonismo desse segmento na luta por direitos e no controle social das políticas públicas. Traz como chave de leitura as concepções de democracia participativa e controle social; as diferentes perspectivas de compreender a deficiência e as concepções de Hannah Arendt para espaço público e privado. Trata-se de um estudo exploratório, realizado com Organizações DE e PARA pessoas com deficiência, através de entrevistas semiestruturadas com coordenadores e presidentes; observação participante de reuniões, encontros e assembleias; pesquisa documental sobre leis e decretos vigentes em âmbito municipal e nacional, Conferências locais de educação, saúde e assistência social, estatutos, folders, atas e cartilhas produzidos pelas Organizações e por meio da construção de um diário de campo. Os resultados e discussões abordam a realidade de um município específico, todavia, também se balizam pelo contexto nacional da luta organizada pelos direitos da pessoa com deficiência. As representações sociais da deficiência, atreladas à

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dinâmica de funcionamento e gestão das Organizações e às mudanças no contexto dos movimentos sociais formados nas ruas, nos espaços públicos e privados apresentam, ao mesmo tempo, fragilidades e potencialidades na defesa e fortalecimento da participação das pessoas com deficiência nos processos decisórios.

**Palavras-chave:** *Participação Social, Pessoas com Deficiência, Direitos das Pessoas Portadoras de Deficiência, Movimentos Sociais.*

## 1 Introduction

This article addresses the participation of people with disabilities in the planning, creation, implementation, evaluation, and control of public policies that ensure the rights of this area. Therefore, the issues of participatory democracy and the social representations of disability are used as theoretical references.

This is the presentation and reflection of the partial results of a dissertation, in which it was sought to investigate the social movements of people with disabilities and their organizations as the way to exercise the social control. In the research, the main object of study was the Organizations, Groups, Associations and the Municipal Council, created and composed by civil society and involved with debates and actions in the field of disability.

Organizations are recognized as organizations OF people with disabilities when they are built and managed by this segment and in general, aimed at fighting for the achievement of rights and for a more accessible and inclusive society. Organizations identified by their philanthropic character and offer services directed to health, education, employment, habilitation, rehabilitation, and social assistance are called Organizations FOR people with disabilities (ROCHA, 2006; CRESPO, 2009; JUNIOR; MARTINS, 2010).

Associations or Groups, mostly composed of people with disabilities and their families, have the purpose of being places for coexistence and support among its participants, to also seek a space of greater visibility in society. Therefore, they can be classified as Organizations FOR disabled people (ROCHA, 2006; CRESPO, 2009; JUNIOR; MARTINS, 2010).

### The Councils

[...] [are] provided in the national legislation [...] with legally established responsibilities in the formulation and implementation of public policies, [...] comprising the planning and control of the actions. They are also conceived as public forums for attracting demands and negotiating specific interests of the different social groups and as a way to broaden the participation of segments with less access to the State apparatus (TATAGIBA, 2002, p. 49).

From a political perspective and from the perspective of Hannah Arendt<sup>2</sup> (ARENDR, 2010), Organizations, Associations, Groups, and Councils can be considered public or private spaces depending on their objectives and the way they act and are organized.

Arendt's (ARENDR, 2010) in his work "The human condition" understands the human life in the scope of the work, the work, and the action. The action is the activity where all political activity is concentrated and through it, the public space is built.

Therefore, the public spaces are places of political practice, that is, spaces conducive to the debate between people, to expose the different ways of interpreting and understanding the world and to jointly build actions that incorporate interests and collective measures (ARENDR, 2010).

For the author, political practice occurs when individuals talk with each other when there is intercommunication for the construction of a new world common to all. Both the action and the discourses and debates are indispensable conditions for political organization and do not appear in a solitary way, built in the scope of collective relationships. The common world does not mean a set of values, norms, and rules instituted by society, but rather a space of understanding between the individuals, which is the public space (SANCHES, 2015).

Private space corresponds to subjectivity and particularity. This presupposes that interests and actions fall under the domain of a single person or group, protected from publicity and interference from third parties. Consequently, actions and the word do not manifest themselves as a power in the private space (ARENDR, 2010; SANCHES, 2015). However, private spaces can act in the consolidation of public spaces, to enable debates on the collective themes or to be their extension, expanding the possibilities of social participation.

From these reflections, it is considered that the Organizations OF and FOR people with disabilities are private spaces, because they are not arenas fully open to the community, for the debate of ideas and proposals. On the other hand, the Councils of Rights of People with Disabilities, as well as other Management Councils are public

spaces, since they are places where citizens must establish relationships of speech, listening and action, building collective actions and, deliberating and supervising the creation and implementation of public policies.

In Arendt's discussions, both spaces are important since they highlight the different experiences in life in society. Also, it is possible to say that the plurality of participatory mechanisms, constituted by the Organizations OF and FOR people with disabilities, Councils and social movements, allows new formats between civil society and the State, constituting powers for the exercise of social control and strengthening of participatory democracy.

In this article, the concept of social control in the perspective of participatory democracy is chosen, which implies the participation of civil society in the public management process, that is, in the production, implementation, monitoring and evaluation of public policies; in the identification and resolution of problems, demands and social needs and in the monitoring of the transfer and use of public funds (PEDRINI; ADAMS; SILVA, 2007).

Similar to Gramsci (2000) discussions, social control may involve the organization and action of civil society, so its interests and needs are recognized and addressed by the State. In this sense, there is no contradiction between civil society and the State, but there are unity and a dialectical and organic relationship between both for social development.

From Gramsci's thinking, the relationships between civil society and the state qualify social control in its conception and practice.

Only the proper correlative analysis of strength [...] in each historical moment, and it will evaluate which class gains social control over society as a whole (CORREIA, 2009, p. 1).

In Brazil, the role of people with disabilities in the exercise of social control was recorded during 1979 and 1980. Initially, the segment was along with other sectors of civil society, in the struggle for the re-democratization of the country and in the discussions on public policies in the health, labor and education sectors. In 1981, with the establishment of the International Year of Disabled People, they began to fight for the interests and needs directly related to their disability status (CRESPO, 2009; JUNIOR; MARTINS, 2010; ROCHA et al., 2011; BERNARDES, 2012).

The militants wanted to address the disability beyond medical and religious perspectives. Therefore, they began to demand the construction and change of public policies and the guarantee of the equalization of essential opportunities and rights from the State. Concomitantly, they sought visibility and social inclusion of the segment and the conquest of autonomy to lead the life (CRESPO, 2009).

The collective manifestation was highlighted by the expressive participation of people with physical and visual disabilities who contributed to the advances in the disability area since the creation of Councils of Rights of People with Disabilities at the three levels of government; the insertion of the theme "disability" in the 1988 Constitution; the promulgation of the National Policy for the Integration of People with Disabilities in 1989 and the increase of debates aimed at understanding and intervening on the deficiency in the interface of human rights (FERREIRA, 2008; JUNIOR; MARTINS, 2010; SANTOS, 2016).

The collective work of national and international organizations and councils in this segment has resulted in the proposal for the International Convention on the Rights of People with Disabilities to promote, protect and ensure the full and equitable enjoyment of human rights and has been an important reference for the creation of programs that meet the essential needs of the population with disabilities (BRASIL, 2009; SANTOS, 2016).

Based on these assumptions, the objective of this article is to discuss the social participation of people with disabilities and the exercise of social control in public and private spaces, that is, in the Municipal Council and in the Organizations OF and FOR people with disabilities. The hypothesis is the creation of organizations and changes in social values for disability motivated and also influenced by the social participation of people with disabilities in micro and macro social contexts.

The debate about the social participation of people with disabilities and the social control exercised in the context of their organizations is broad and complex, especially considering that access to social, civil and political rights is not yet a reality in the lives of many Brazilians, including people with disabilities. Therefore, with the study of a certain reality of social participation of people with disabilities, it is expected to contribute to the consolidation of the field of knowledge about disability, particularly on promoting the social participation of the segment in the construction of a new world, more sensitive to human diversity and the specific needs of that plurality.

## 2 Methodological Procedures: Entry Into the Field

The research field was built in the city of São Carlos-SP. It is known as the Technology Capital, for gathering industries, research centers, and higher education Institutions. The city is a reference in the development and dissemination of research (ASSEMBLÉIA..., 2011). According to the 2010 census, there were 221,936 inhabitants, 38,808 of them were identified with at least one of the deficiencies (INSTITUTO..., 2012).

The choice of this place is justified by the involvement of the researcher as a voluntary occupational therapist in one of the Organizations and by the existence of different types of Organizations and movements engaged in the development of alternative care as well as in the struggle for rights (SÃO CARLOS, 2014). Also, some of these places have important leaders of the first municipal mobilizations (started in the 1990s) and are still representatives of the segment in the Regional and National Conferences on Disability, Health, and Education.

Considering the guidelines of Schraiber (1995), through an interpersonal indication mechanism, three Organizations OF people with disabilities were identified in the city: Non-Governmental Organization Disability Information Movement (NGO MID), Association of the Deaf of São Carlos (ASSC) and the Inclusion Pastoral; and four Organizations FOR people with disabilities: the Autistic Parents Support Group (Group AMais São Carlos), the Association Caring for Special Caregivers of São Carlos (SP) (NGO Guarda Anjo) the Association for Training, Guidance and Development of the Exceptional (ACORDE), the Association of Parents and Friends of Exceptional People of São Carlos-SP (APAE) and the Municipal Council of People with Disabilities (CONDEF).

All these entities participated in the research and the coordinators and/or presidents answered a semi-structured interview, recorded in audio and later transcribed (MANZINI, 2004).

The choice of the semi-structured interview is due to the possibility of the interviewer and the interviewee to produce questions and speeches freely. According to Manzini (2004) and May (2004), it seeks and understands experiences, historical events, and life history, opinions, conceptions, and perceptions about objects or facts, expectations and wishes, attitudes and feelings.

The interviews lasted an average of two hours and took place at the headquarters of the Organizations

or at the participants' home, who signed the Free and Informed Consent Form, following the ethical precepts of research on human beings.

Mediated by a script, the interview identifies the members of each entity, the services and actions they developed, the target audience, objectives, community access to these entities and the issue of accessibility of the physical space of their headquarters, as well as the history of their constitution, the challenges they face for the work they do and the question of the representativeness of people with disabilities in these spaces.

Documentary research was also carried out on statutes, minutes, reports, booklets and folders produced by the entities, as well as reports from the Municipal Conferences of People with Disabilities, Health and Education and laws and/or projects related to disability, promulgated at the municipal, state and national levels (MINAYO, 2010; CELLARD, 2014).

A previously structured script allowed to register the documentary source of the period of its elaboration, the topics approached, the objectives of the document, the authors to whom they were destined as well as the type of document (informative, historical record, claim, analysis of any problem or disclosure of events or works). The documents, selected in print and electronic, were produced from 2002 since it is the year of the foundation of CONDEF and an important reference of the struggle for the rights of people with disabilities in the city.

Finally, participant observation (MAY, 2004) was also carried out through ordinary meetings with the researcher held by the entities, as well as meetings of the technical team, about assisted therapy by animals (Pet Terapia do Group AMais) and General assembly (from ASSC). The observation proposal was clarified at the time of the interview and the participant, together with the researcher, established the best activity to be monitored and recorded.

In some activities, it was possible to participate more than once, for two or three hours. The choice of this working methodology enabled a greater understanding of the field studied and approaching people, in specific time and spaces. Therefore, becoming part of what is investigated, the researcher recorded the way the actions developed, the construction of personal relationships and the inclusion and participation of people with disabilities in an objective and subjective. Figure 1 illustrates participation in a meeting.

A field diary also provided an analytical description of participant observation and interview processes and the recording of reflections, events, and



**Figure 1.** Entry into the field: participant observation. Source: photo took by the researcher of the meeting held in the municipal city hall of São Carlos-SP.

relationships with the participants, to complement the construction of the data.

The process of analysis followed the strategy proposed by Creswell (2014). According to the author, the first stage of the analysis consists of organizing the data and for that, individual files were produced with interview transcripts and documentary and participant observation data.

In the second stage, a reading immersion of the data was performed and then ideas, reflections, key concepts, and a process of interpretation and establishment of categories were built (CRESWELL, 2014).

Through this system, two categories and five subcategories were established. In this text, the categories that discuss the participation of people with disabilities will be discussed, in a way to understand the distance between the ideal of participatory democracy and the reality experienced by the Organizations OF and FOR people with disabilities and their members.

### 3 The Representativeness and Social Representation of Disability: Possibilities and Constraints on Participation

All the interviewees reported their testimony on the history of the movement of people with disabilities in the city of São Carlos-SP. The answers offered fragments of a trajectory that was not written in the documents, but they remain in the memory and in the conversations between the new and old militants.

Initially, a re-reading of the trajectories were presented in a dialogue with mobilizations at the national level registered in the literature, to identify

and understand the social participation of people with disabilities.

In Brazil, the first Organizations providing services to the disabled population were created through social mobilizations, led by health and education professionals and the families of people with disabilities.

In a claiming scenario, Pestalozzi Societies (1932) called APAEs (1954) and rehabilitation centers, such as the Association for Assistance to Defective Children (AACD), which today are Association for Assistance to Disabled Children, established in 1950 were created and the Brazilian Association of Rehabilitation Benefit (ABBR) was created in 1954. As philanthropic and civil society institutions, they implemented services in the areas of rehabilitation, social assistance and education (JUNIOR; MARTINS, 2010).

Together with these processes, other Associations for Blind, Deaf, and Physically Disabled people were created as spaces of coexistence and solidarity support among the members, since they experienced similar situations of social exclusion and stigma related to the disability (CRESPO, 2009; JUNIOR; MARTINS, 2010).

As in the national territory, APAE and ACORDE founded in 1962 and 1988 respectively also resulted from the mobilization of parents and relatives of people with disabilities in partnership with health and education professionals in the city of São Carlos-SP.

Both Associations were built in important spaces for the assistance of the segment, however, without fulfilling all the demands of the population. Thus, between the end of the 1980s and the beginning of the 1990s, families gathered in their homes to share experiences and list proposals to be presented to government agencies, especially those related to the expansion of health care and education for their children with disabilities.

However, faced with the lack of support from local management, the mobilization of these relatives was over and each one of them followed their own struggles in search of access to rights and greater visibility in the social context.

During this same period, Brazil was also a stage for the movements of other segments of civil society (such as students, workers, black people, and women).

According to one of the interviewees (one of the first militants in the city), and in line with the literature, people with disabilities were also engaged in these movements, whose main objectives were: the struggle for the conquest and access to rights and for the re-democratization of the country.

[...] [the mobilizations of people with disabilities in Brazil] began in the 1960s. But, very sporadically in the cities [and] very connected to the student movement. [...] they were people who were part of some movement, the black people or the student or the woman, the church [...].

*So there is enough, but everything connected to another movement or religious or political or student movement.*

*But in this way, I can tell you that the entities OF people with disabilities only came into existence, after 1981. [...] At that time, there was the first great movement of people with disabilities in Brazil, and it was even chosen the September 21 to be the national day of that struggle.*

*From then, various entities and Councils, State Councils began to emerge. The municipal ones have already come a little after this... in 1984, 1985 (President 1).*

In the city of São Carlos-SP, the years of 1992 and 1993 are observed as the period of greater prominence of people with disabilities, mainly through the constitution of the first Organization OF in the city: the Association of Disabled People of São Carlos (ADESC).

[...] other disabled people who already had, they published in the newspaper that they were going to meet with other disabled people and they ended up organizing and founding the organization.

[...] it [ADESC] did a lot of things [...] we have accessible transportation and it was thanks to it; That was to fight. Because at the time, there was nothing. So this transport that carries and brings door to door, in 1997, it was the first one that had [...] been the entity that fought, to have this transportation [...].

*The labor market was not also talked about [...]. So we got several people to engage in the labor market, through the entity [...].*

*Education too, it was horrible, there was no school accessible and we got something also in that sense. So, I think it was quite productive, right, in the 1990s.*

[...] there was a nice group of people with disabilities and family members involved, maybe it was the best period the disabled person had in São Carlos (President 1).

ADESC was a legitimate space for the participation and solidarity between the directors and the people with disabilities and their families, who also helped to maintain the entity and the development of actions. However, due to administrative problems, ADESC closed its doors in 2002, in the same year CONDEF was created.

For four years, disability-related issues were the responsibility of the Council. However, in 2006, to compose this scenario, the NGO MID was founded by the efforts of people who had already participated in ADESC and by new individuals. In 2011, 2012 and 2013 the Inclusion Pastoral, the Group Amais, the NGO Guarda Anjo and the ASSC were founded.

Since then, these Organizations with their different ways of acting have developed practices in search of greater access to the rights of people with disabilities in the city and, consequently, contribute to keep the social movement of the segment active, which is evidenced by one of the people interviewed (involved in processes for social inclusion of people with disabilities):

*I think it's a movement that has been strengthened [...].*

*It is a group that has strengthened and occupied its space (Coordinator 1).*

Another participant (who began to participate in the mobilizations in 2011), when discussing the strength of social movements, he remembered the creation of the Municipal Secretariat of People with Disabilities as a result of the collective effort of the Organizations:

*I think it's in the middle of the road, because until then, for example: with all that force they did, they got this Secretariat for the disabled people. There are only eight in the state of São Paulo, so it's already something different. [...] but we can do much more, we can.*

*So, I think it's halfway there (President 4).*

Also, In the national territory, there was also an advance in the constitution of Organizations OF and FOR people with disabilities, which also catalyzed the access to the rights, through the elaboration of decrees, laws, and actions for the disabled segment (BERNARDES, 2012; JUNIOR; MARTINS, 2010).

According to Dagnino (2002) and Gohn (2013), the creation of THE Organizations (in different sectors) is part of a new conjuncture of the mobilizations. Therefore, the social movements integrated by people with disabilities and their families, health

professionals and educators, previously carried out on the streets and through the media, were transferred to the institutional level, acquiring an isolated, private performance characteristic with specific objectives and actions.

For example, the Group AMais develops actions for people with Autistic Spectrum Disorder and their families, ASSC covers the hearing impaired population and the NGO Guarda Anjo represents the families and caregivers of people with any type of disability.

The other entities represent all the deficiencies and aim to develop actions for all, nevertheless, one prevails over the others. The APAE and ACORDE provide services, mainly, for the segment with intellectual disability. The NGO MID consists essentially of individuals with physical disabilities and the Inclusion Pastoral develops actions with an emphasis on the population with physical and hearing disabilities.

CONDEF has only one counselor with a disability (physical) and another representative with a visual impairment. In fact, this last segment is the only one that has no specific representative entity in the city, which marks isolation of the organized struggle.

In this context of institutionalization of militancy, a model of representativeness emerges. Thus, a single Organization can represent a particular group of people. Given that not all people with disabilities want or can participate in public and private spaces, this model can be effective in their intention to identify collective needs and interests and to elaborate proposals that advance the conquest and access to rights.

On the other hand, representativeness is related to the power given to someone or to some institution, to act and speak on behalf of others. According to the discussions of Côrtes (2009), the representativeness exercised by the entities can be understood as a substantive political action, where the actions of an individual as a spokesperson of other people requires a close relationship between the representative to discuss and identify collective interests and the way of acting to achieve them.

The different types of disability and the ways of experiencing it, the living conditions and the socio-cultural context of the people bring a complexity to the representativeness of this segment since there is a plurality of interests, needs, opinions, and feelings that do not may be reliably expressed by third parties. Also, it is expected that the activity of representing is able to contemplate the demands and real needs

of life, awakening to a collective consciousness about these aspects.

In the area surveyed, representativeness has not been substantive, since the participation of people with disabilities is fragile or non-existent.

For one of the presidents, the low participation of people with disabilities attenuates the strength of the movement:

*[...] I think if we take the Census that says that São Carlos has thirty-eight thousand people with disabilities and that we pick up the people who are engaged in the movement, that's nothing. So I guess the movement is not strong. Maybe we make some noise, but we do not have a strong movement (President 1).*

The interviewees' answers and knowledge about the entities' way of doing things also led to the conclusion that most of the people with disabilities in the community are not consulted in the process of planning actions or claiming rights, especially in the space of Organizations FOR people with disabilities, led by people who do not have disabilities. Although some entities have coordinators with disabilities (as in the case of the NGO MID, CONDEF e ASSC), there is an autonomy, since the subjects and actions carried out arise from the experience of life of the one he represents and assumptions about possible needs and demands, following a perspective of generalization of interests.

In this context, the non-participation of people with disabilities in public and private spaces also demonstrates the permanence of a welfare practice of some Organizations and the Council, which plan and develop compensatory and emergency actions to assist the population with disabilities.

From another point of view, the transformations of the society and the social representation around the person with the disability also influenced and still influence the social participation of this segment.

Social representations come from relationships established between people and from the change and coexistence of paradigms, models, thoughts, concepts, and values, and manifested through individual and collective behaviors (MINAYO, 2010).

In this sense, the social construction of disability, which began in the 1960s in the Anglo-Saxon countries (Canada and England), began to be debated when people with disabilities, as researchers and thinkers of their reality, began to question the biomedical model of understanding deficiency, and reducing it to body-related or illness-related impairments disregards the experiences and opportunities posed socially and

historically to this group. These reflections created the proposal of a social model of understanding of the disability, confronting the limitations of the biomedical paradigm and favoring the development of the Disability Studies (FRANÇA, 2013).

In Brazil, the construction of the social model of disability is a process started in the late 1970s and early 1980s, a time of intense mobilization of civil society, debates in defense of rights with the active participation of people with disabilities (CRESPO, 2009; FRANÇA, 2013). This defense brings the demand for public health care and rehabilitation systems and support for the creation of communal houses maintained by the public sector for the people with disabilities institutionalized in rearward services or shelters and asylums (OLIVER, 1998). These proposals were influenced by the debates about the deinstitutionalization<sup>3</sup> brought by the movements of the psychiatric reform and the anti-asylum fight, started in the 1970s also in Brazil (OLIVER; NICÁCIO, 1999; MALFITANO, 2005).

In this context, Brogna (2009) highlights that disability as a social construction shows the state of segregation in which people with disabilities live and exposes vulnerable individuals in their dignity and rights. Therefore, the deficiency cannot be understood only by the presence of bodily impediments and/or injuries; but it must also be seen as a result of the ways of life marked by inequality and social exclusion and consider economic, political and cultural aspects, as well as issues of physical accessibility and communication as determinants of disability.

In today's society, this understanding model coexists with other approaches and social representations of disability, which have been constructed throughout history and that interfere with the daily lives of people with disabilities, mainly in the construction of their identity as individuals and in their processes of inclusion and social participation. Thus, representations remain that identify people with disabilities as human beings punished and cursed by a deity or victims of fate, resulting in discriminatory and excluding actions and behaviors, as well as those identified with the figure of the hero, who must be a model of overcoming, including those who do not have disabilities (ROCHA, 1990; BROGNA, 2009).

From the perspective of the biomedical and welfare paradigm, for example, actions and activities that focus on the deficient and abnormal body that needs to be treated/rehabilitated or separated from the community considered normal by society's standards are supported. In this sense, the individual way of experiencing disability is highlighted, that is, there is a concern about the etiology (acquired

or congenital), duration (permanent, progressive or transient), the severity of disability and integrity of functions and structure of the body. Consequently, a social representation is constituted and strengthened that recognizes the person as a human being unable to control one's own desires and live independently, which may even justify the little attention given to areas of life-related to work, sexuality and family and community life (FERREIRA, 2008; BROGNA, 2009).

Under the biomedical paradigm, welfare practices do not consider the opinions and interests of the disabled person, since they are perceived as a passive person with no capacity to decide on their own life and other issues and the person becomes only the recipient of actions and services (ROCHA, 1990).

Many of the speeches produced by society and some representatives of people with disabilities are discriminatory and exclusionary when they emphasize only the limits and impediments of the body and reinforce attitudinal and socio-cultural barriers to social participation. This is also revealed in the Organizations OF AND FOR in São Carlos-SP when they are not prepared to create strategies to effect the participation of the segment that is still excluded from the decision-making processes.

The possibility of participation becomes more distant with people with intellectual disabilities, which is evident in the speech of one of the interviewees:

*And the members that make up the condef, do they have any type of disability? what are they?*  
(Researcher).

*They are wheelchair, physical and visually disabled people... the intellectual may not be able to participate, but they have a representative of the family. Someone from that area, who works*  
(President 1).

Considering the performance of only legal representatives of people with intellectual disabilities or the professionals of the institutions related to their assistance reveals a prejudiced positioning of some leaders. In the general population, there is the idea that these people are eternal children who are unable to make decisions, act and speak for themselves, not able to participate in the processes of claiming and solving problems, remain under the tutelage and representation of family members, professionals, institutions or civil society entities (NEVES, 2003).

CONDEF is a concrete example of this scenario and therefore, it exposes a contradiction with its function of guaranteeing citizens that they are free to express their ideas and contributions in the



construction of a more accessible and egalitarian daily life.

Especially in the Organizations FOR people with disabilities, there is a false perception about the legitimacy of representation and a weak knowledge about the meaning of being representative. Thus, under the hegemony of the rehabilitative medical paradigm, there is a behavior that approximates the protectionist view that justifies a task done by people with disabilities and does not allow a task with them, which favors participatory processes.

Thus, the understanding of disability from the religious, charitable, rehabilitative, and normative perspectives reinforces the stigma of the abnormality borne for centuries by this group, which results in a significant number of people with disabilities discussion and does not access all goods and services that are their right (BROGNA, 2009).

For this reason, this article defends the social model of understanding disability and when considering the cultural, economic and political factors that involve the life of individuals, it allows discussing the conditions of segregation and discrimination of the people with disabilities. These conditions limit or impede the possibilities of accessing rights and actively participate in family, community and political contexts.

Understanding disability as a social construct modifies the research focus on the conditions of participation of people with disabilities and the meanings attributed to them. It goes beyond the mystical and biological aspects and incorporates the socio-cultural, political and economic barriers that disable people with disabilities and prevent them from playing the role of citizens, for example by their direct action in the decision-making process.

Thus, it is fundamental to analyze the demands and needs of individuals from the point of view of rights and social justice to overcome the reductionist paradigms and the assistance bias of Public and Social Policies, governmental programs and actions. Also, it is important to highlight the promotion of social participation in the areas of debate, enabling discussions about living conditions and the exercise of social control, especially in the construction and execution of Public Policies and critical evaluation of the priorities and actions of the State (PEDRINI; ADAMS; SILVA, 2007; FIGUEIRÓ, 2010).

One of the characteristics of Public Policies is “democratization”. It means that there must be possibilities of social participation for its control and in all its instances (planning, creation, implementation, monitoring, and evaluation) (PINHEIRO, 2003).

In the city of São Carlos, SP, the rare involvement of people with disabilities in the control of public policies and decrees is concentrated in the inspection process, that is, when they are not subordinated to representatives or entities. Little attention is still given to the implementation and evaluation stages of policies.

This reality follows the national context since the creation of public and social policies is established from the top down, that is, the participation and contribution of civil society are little considered and many of the social problems are considered, treated and sometimes solved as management problems. As a result, social groups in situations of exclusion and social vulnerability tend to remain as objects of state benevolence (JUNQUEIRA, 2004; SANCHES, 2015).

In the documentary research of this study, only the NGO MID and the Group AMais are involved in proposing law projects that can cover the local particularities directly related to the disability issue. Nonetheless, the involvement of people with disabilities or members of the community is carried out through a consultancy and evaluation of proposals prepared by the coordinators of the NGO and the Group.

According to studies by Pedrini, Adams and Silva (2007), the situation of inequality and social exclusion is the reality of 80% of the population world and it is also reflected in the low participation in political, economic, social and cultural processes. The exercise of social control and its quality depends on the democratization of the spaces of representation and, in the Brazilian scenario, the public and private spaces are marked by the power struggle and by corporative or ideological interests, which are also obstacles in the incentive of social participation.

This barrier to participation affects, in particular, groups without access to information and in situations of vulnerability and exclusion, such as rural workers, urban dwellers, the unemployed people and people with disabilities.

In São Carlos-SP, for example, there are divisions in the collective work of the Organizations, provoked by divergences of opinions, by the dispute for greater space, decision-making power and social representation in the city and to conquer resources and government support.

Another peculiarity of the city studied is that most entities are characterized as a private space focused on the provision of health services, rehabilitation, education, and social assistance and little representation in CONDEF and other councils. As a result, the

community in general, and especially the population working with and in the field of disability, become susceptible to the hegemonic functioning and organization of these spaces, which are distanced from participatory democracy.

#### 4 The Municipal Council for the Rights of People with Disabilities: a Path to Participatory Democracy?

Most of the Councils, as mechanisms of participation and social control, aim at the fulfillment of a decentralized and participative public management. These spaces were constituted from the 1990s, with the promulgation of the Federal Constitution and as a result of popular movements, the “crisis in the legitimacy of traditional forms of representation of interests in liberal democracies” and the “stimulus of international development agencies” (JUNQUEIRA, 2004; SILVA, 2007; CÔRTEZ, 2009; BRAVO; CORREA, 2012).

The State Council for Disability Issues (CEAPcD) in the state of São Paulo was the first to address issues related to disability. Created in 1984 and composed of representatives of government Organizations OF and FOR people with disabilities, it was an important reference for the expansion of other Councils at the municipal level and for the creation of the national council (CRESPO, 2009). According to data from the Special Secretariat for the Rights of People with Disabilities, there were 590 Municipal Councils of People with Disabilities distributed in Brazil in October 2017, of which 128 (21.7%) were present in the state of São Paulo (BRASIL, 2017).

According to the Booklet edited by the National Council for the Rights of People with Disabilities (CONADE) and guiding the creation and functioning of the Councils for the Rights of People with Disabilities, their main function is to be a space of social control in the struggle for rights and in the definition, monitoring and evaluation of policies aimed at this segment, which also includes the monitoring of financial resources to execute them (CONSELHO..., 2007).

CONDEF of São Carlos-SP was established by law in 1998, but began to exercise its activities only in 2002, after the claim of a group of disabled people and their relatives with the Legislative Branch.

For one of the interviewees (active in two Organizations), the presence of CONDEF and the development of actions in a partnership with the State Council for the Rights of People with

Disabilities has contributed to strengthening local mobilizations and visibility:

*So a lot of things have been happening here in São Carlos, state meetings come here. So, I think with that also improved a lot (President 2).*

Although CONDEF has been a conquest of civil society and, in its definition and proposition, constitutes a way to increase the social participation of the population, it is perceived a distancing from the power to exercise social control in the defense of needs and demands of people with disabilities. This assertion is based on that this Council has been shaped by the greater participation and representativeness of government bodies, which also influences decision-making processes.

By 2013, CONDEF retained its parity with 50% representatives of civil society and 50% of government agencies. Of the first group, 60% were people with disabilities and 40% were representatives of the Organizations. According to the interviewee,

*[...] the representatives of the government within CONDEF are several secretariats: there is education, health, assistance, sports, work and now the city hall, the chamber and the University [Federal University of São Carlos] (President 1).*

Since 2015, the Council has faced decreasing participation, particularly from civil society. Some people gave up their positions, others left without giving justifications and some entities closed their doors. In the Organizations OF and FOR people with disabilities, only the APAE and the NGO MID have advisers in the CONDEF. The AMais Group, the Inclusion Pastoral and the ASSC comprise the so-called captive chair, that is, they collaborate with the discussions and decision-making processes, but do not have voting rights in the Council. ACORDE and the Guardian Angel NGO are the only ones that are not engaged in this space.

In addition to this issue, civil society still maintains a relationship with entities and does not understand CONDEF as a space for exercising citizenship. As mentioned earlier, there is still a culture in which it is only expected to receive actions and services from the Organizations and the Council. This may be one of the possible justifications for the maintenance of the current composition of CONDEF.

It is rare for families to seek the Council, and when they access it, they want to request assistive technology equipment (wheelchairs, orthosis, and prosthesis, for example). Therefore, they interpret CONDEF as a provider of their needs and not as a public space for citizen participation.

Sectorial Councils are understood as public spaces, which can promote participatory democracy; however, how they function and are organized can create barriers to the fulfillment of their purpose.

According to Tatagiba (2002), it is common that the decision-making processes and the planning of the discussion lines in the Councils are centralized in the hands of the governmental organs. The author also highlights other organizational and practical problems, such as the lack of qualification of the directors, the lack of representativeness, the difficulty of accepting and meeting the diversity of interests, the maintenance of patronage patterns in the relationship between State and society and the refusal of the state in sharing power with other social sectors.

In the lack of training of the councilors and also of the community, there is a lack of knowledge about the organization and functioning of the Council and the creation, planning, implementation, monitoring and evaluation of public policies. For Bógus (2007, 2009), training is necessary, so the social participation is effective and achieves the emancipation and autonomy of the subjects and their groups.

The lack of representativeness comes from the disparity in the composition of the representation of the government sector and civil society, and from the lack of a relation of exchange (of knowledge, interests, and experiences, for example) between representatives and their represented.

This failure can also be an obstacle to receiving and meeting demands and needs, especially when there are no specific spaces (forums, meetings, and assemblies) that seek to know and consider the daily lives of people with disabilities, lack or access to social goods.

On the other hand, the influence of the relationship between State and civil society on the exercise of social control must be considered. Bravo and Correia (2012) point out the dictatorial context and struggles for re-democratization as the period of creation of the idea of a split between the State and civil society. Under a characteristic of liberal thought<sup>4</sup> are placed as two opposing poles: civil society belongs to the positive side, is the bearer of collective interests and assumes a characteristic of homogeneity, where there are no division and class disputes. The state, however, is located on the negative pole, where the interests of a minority holding economic and political power are privileged.

In the post-dictatorship period, when facing a new rule of law, it gains a new position: that of the provider of goods and services for the well-being of society (MACHADO; MEDEIROS, 2007).

In both contexts, the social control exercised by civil society is weakened. In the first case, this is justified by the de-politicization of popular movements, organizations and other non-governmental entities. It is illusory to think that this sector is free of political and ideological positions, which end up creating divisions and struggles for private benefits (BRAVO; CORREIA, 2012).

In the second reading, there is a risk of perpetuating paternalistic practices, in which civil society plays a passive role depending on the programs and projects developed by the State to meet the basic and urgent needs of the population (MACHADO; MEDEIROS, 2007; BRAVO; CORREIA, 2012).

In a critical analysis, Brazil is immersed in a conception of State supported by the neoliberal current, which perpetuates the Manichean division between State and civil society and proposes the idea of the Minimum State, in which the privatization and the voluntary work of the various entities prevail non-governmental organizations, as complements of the state action in the promotion of a dignified life to the population. This scenario can influence the decline, quantitative and qualitative of social and political participation of civil society in different public spaces and social structures.

Tatagiba's considerations discussed so far also illustrate the reality of CONDEF, which has not been constituted as an effective public space for the exercise of social control and has been characterized as an advisory and non-deliberative space.

Also, the lack of participation of the community was identified, together with the disarticulation of the Organization and with other social sectors and the state conjuncture (marked by compensatory public actions, capital hegemony and the low incentive to the participation of the civil society), undermine the sense of collective action and weaken the construction of participatory democracy and the exercise of social control (PEDRINI; ADAMS; SILVA, 2007). In this way, in the city studied, the mode of functioning and organization of the entities still has obstacles, so the social movement of people with disabilities is an effective practice in the daily life of the segment.

## 5 Final Considerations

The plurality of participatory mechanisms, such as NGOs, Associations, Groups, and Councils, as well as organized social movements in the streets, institutions or in the digital world, is a way of strengthening the relationship between civil society and the State, seeking solutions to the demands and needs of the population. However, just like

the example of São Carlos-SP, only the presence of these spaces does not guarantee the full participation of people with disabilities and so little exercise of social control.

The reality of the city studied corresponds to a general change perspective of the social movements in the national scenario: the scarce participation has not effected the social control and there are no concrete actions to promote the empowerment of the popular strata.

Involving civil society in the social control of public and social policies is a challenge to be faced not only in the city of São Carlos but also in other places with similar experiences, which requires a change of practices, behaviors, patterns and values of the community and organizations that still restrict participation, including of people with disabilities.

The social participation of people with disabilities, besides interfering with the way the entities organize and function, is directly related to the social representation of the disability. The different ways of conceiving and treating the person with a disability interfere, positively or negatively, about the role of this segment and also the construction of personal identity.

On the other hand, the participation of people with disabilities can consolidate the redefinition of disability based on the human rights and citizenship matrix. Thus, struggles organized collectively through public and private spaces can be a form of resistance to exclusionary power relationships and questioning the reductionist ways of treating and conceiving the disabled person.

Disability is a form of being in the world and belongs to one of the many expressions of human diversity. Therefore, people with disabilities need to be free from the conditions of tutelage and segregation, with the same possibilities of access to material goods and services and the chance to participate in the dynamics of social, family and community organization. Therefore, it is essential they be trained and have access to information, to know the existing public policies, to know the essential rights, to understand how public administration works and to recognize public spaces as relevant instances to democratize the discussions and decisions regarding the deficiency.

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## Author's Contributions

Ana Cristina Cardoso da Silva worked on the text design and the development of the research. Fatima Correa Oliver worked on the final writing of the text and the guidance for the research development. Both authors approved the final version of the text.

## Notes

- <sup>1</sup> This article is part of the results of the master's research study "Organizations OF and FOR people with disabilities in the city of São Carlos - SP: creating threads of stories, achievements and challenges", supported by the Coordination of Improvement of Higher Education Personnel. The study was approved by the Committee of Ethics in Research in Human Beings of the Federal University of São Carlos, with the opinion n ° 864.135.
- <sup>2</sup> The option to discuss social and political participation, considering the reflections of Hannah Arendt, is justified by the possibility of a dialogue and the construction of knowledge that encompasses the author's discussions about politics, public and private space and the insertion of the disabled person and their organizations can be understood in these contexts.
- <sup>3</sup> Deinstitutionalization is in the context of the organized struggle of people with disabilities and the re-meaning of disability, as it has also enabled (and still allows) to advance in the discussions on: social participation, citizenship, rehabilitation, social reintegration and the construction of life projects of the segment (HIRDES, A. The psychiatric reform in Brazil: a (re) view. *Ciência & Saúde Coletiva*, Rio de Janeiro, v.14, n.1, p. 297-305, 2009).
- <sup>4</sup> Therefore, liberal thinking is opposite to the Gramsci's view of relationships between the state and civil society. For this philosopher, within each of these spheres, there is heterogeneity of interests and ideas, but it is possible to establish a dialectical relationship between both.