

Disability Policies and Management in Bolivia: Changes and Challenges

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Abstract

The Plurinational State of Bolivia has experienced significant social changes with a growing commitment toward policies that favor vulnerable populations. Acknowledging movements led by people with disabilities to promote progress in social policies is a crucial task. The public sector has responded to the demands and needs of this population through recognition and promotion of their rights. Nevertheless, to ensure progress, we must support the voices of the stakeholders and promote their participation in identifying the strengths and weaknesses of the system, and the real needs and demands of people with disabilities in Bolivia. To this end, in this study, we gathered statements of key informants, using a focus group technique. The results of the data analysis indicate an increase in social awareness and recognition of the needs of this collective and the importance of their full inclusion in society. However, there is a distortion in the application of certain assistance and inclusion policies in favor of people with disabilities because these policies do not have their intended impact.

Keywords

Bolivia, disability, social policies, social and labor inclusion

Over the past decades, significant progress has been made worldwide toward acknowledging the rights of people with disabilities (PWD), and several limitations related to social inclusion and participation for this collective have been overcome (United Nations, 2019). Recognizing the rights of a collective necessitates translating the values and principles of freedom and justice through regulations that serve as protective action for PWD. The important consequence of a legal framework is primarily substantiated by the following (United Nations, 2006): (a) safeguarding the group's right to claim suffered violations, (b) articulating public protection through services and social benefits, and (c) highlighting the reality of PWD in public debates and issues. Conversely, the lack of a legal framework or limited exercise of rights leads to a public system of residual protection and the absence of guidelines for social organization and individual behavior that guarantee the welfare of PWD. Therefore, a socially inclusive model must be based on the recognition of rights, promotion of societal participation, and civil society empowerment. Although the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) has attempted to act as an agent for the development of this paradigm, considerable differences have been noted among member states in relation to the political, social, and economic conditions of their citizens.

Several countries have experienced governmental and economic transformations that have improved the living conditions of their citizens. Bolivia is one such country; its

political situation has been stabilized, and the economy has improved over the past decades. Consequently, since 1990, civilians have begun to recognize their rights and, in the context of the modernization of state policy, social and advocacy movements have led to the creation of policies promoting the rights of minority populations, including PWD. In Bolivia, PWD have organized and conducted demonstrations across the country to demand the attention of the government in La Paz and participated in hunger strikes to increase their visibility and have their rights acknowledged. Studies (Linares, 2005; Martí i Puig & Bastidas, 2012) have shown that the acknowledgment of the rights of Bolivian citizens has always been preceded by strong social movements led by those in the affected groups. Therefore, social and political awareness, and the categorization and quantification of disability in Bolivia, is gradually transforming due to the efforts of those in the affected communities and the influence of the international community.

In 1995, the first law for PWD (Law No. 1678) was approved. However, this law defines disability based on the

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absence of an ability to conduct any activity in a manner that is considered normal and was based on a medical rehabilitation model that focuses on a person's reduced abilities. The current legislation (Law No. 223, effective as of March 2, 2012) reflects progress toward a social conceptualization of disability by considering the interaction between PWD and their environment. In Bolivia, disability is assessed based on the existence of permanent disabilities that are the result of non-recoverable organic or acquired alterations. The current classification (Law No. 223) refers to four degrees of severity: very serious, serious, moderate, and mild. Disabilities are further divided into seven types: physical, intellectual, multiple, auditory, sensory, mental/psychic, and visual.

With the exception of visual impairment, the assessment system recognizes different degrees of impairment: >50% is categorized as very serious/serious and <50% as moderate/mild. The assessment is conducted based on the limitations that an individual exhibits in two levels or areas: performing basic functions and tasks, and conducting instrumented activities. Basic activities include self-care (dressing, eating, grooming, and personal hygiene) and other activities related to daily living (communication, physical activity, sensorial functions, and hand functions). Instrumented activities include autonomy while using means of transport and participating in social and leisure activities.

Even if personal and social aspects are included to determine the level and degree of disability, the assessment primarily relies on a personal component. Contextual factors, such as architectural barriers or support for personal development, do not determine the level or degree of disability (Díaz-Aristizábal et al., 2012). In accordance with disability assessments, depending largely on individual characteristics, assessment teams consist of a rehabilitation physician, psychologist, and social worker.

Regarding the collection of data on PWD, Law No. 1678 (1995) promoted the creation of the National Committee for People with Disabilities (CONALPEDIS). This institution coordinates, counsels, and plans strategic policies that focus on the care of PWD and promotes their rights. The institution also gathers data regarding PWD. Over the past years, CONALPEDIS has highlighted the lack of quantitative and qualitative information that would allow counting and describing the situation of PWD. Until 2010, this lack of data and statistical analysis was particularly significant. However, in the same year, the Regulation on the Operations of the System for the Single National Registry of People with Disabilities (SIPRUNPCD) was approved by Ministerial Resolution No. 1127. This regulation ensures that the SIPRUNPCD gathers, maintains, processes, and disseminates statistical data regarding PWD. Such data are collected and provided by the Department of Committees for People with Disabilities (CODEPEDIS). The quantification

of the prevalence of disabilities in Bolivia represents an important change in its perception and recognition of PWD. The impact of this quantification will be presented in the "Results" and "Discussion" sections.

Before the SIPRUNPCD began gathering and disseminating statistical data on the provision of identity cards and registering PWD, the only available data came from the Population and Housing Census, which lacked reliable and consistent tools for assessing the situation of PWD in a quantifiable manner (Gómez, 2010). Despite the progress made toward this acknowledgment and the quantification of this reality, the number of PWD in Bolivia may still be higher than the figures provided by the SIPRUNPCD because many people are, for various reasons, not included in these registries. Consequently, a significant percentage of this population still lacks visibility.

In terms of legislative progress, the recognition of the rights of PWD was strengthened after two primary regulatory frameworks were accepted. The first was Bolivia's ratification of the UN Convention on the Rights of Persons with Disabilities in 2009. The binding nature of this convention, and other international regulations, has been the driving force for change in state regulations in Bolivia. The second legal framework was the approval of the Plurinational Constitution in 2009, which includes 10 articles that guarantee a safety network for the promotion of the protection and equality of PWD and ensure the prevention of discrimination (Articles 14, 45, 64, 70, 71, 72, 105, 107, and 302). The involvement of civil society through participation and counseling desks fostered the inclusion of PWD in the country's political agenda. Many of the ideas suggested by these desks are transferred to the relevant stakeholders involved in subsequent regulations on disability.

This was the case in Law No. 1678 of 1995—the first specific piece of legislation regarding the issue—which, despite its limitations, had strong social acceptance precisely because it was the result of a wider participative process.

The General Law on People with Disabilities No. 223 was passed in 2012 and acknowledges the rights of PWD in every aspect of life. As established in its Article 1, this law aims to guarantee the full exercise of rights and duties on equal terms and promote equal opportunities under a comprehensive protection system. Moreover, this law stipulates a solidary income for people with severe and serious disabilities.

The current situation in Bolivia is also significantly influenced by Law No. 977 of December 26, 2017. This law emphasizes participation and, as noted by Faundes and Gaete (2016), is recognized as a driving force toward social justice through both redistribution and recognition. Law No. 977 guarantees the inclusion of PWD—and their parents, spouses, or legal guardian—within the public (at least 4% of administration personnel) and private (at least 2% of

employees) sectors. Moreover, it introduced a monthly bonus (250 Bolivian pesos/around US\$36.20) that replaced the former solidary income for people with severe disability who cannot participate in the labor market. However, this law continues to face certain challenges that prove the need to review its impact in terms of appropriate inclusion.

Despite this gradual evolution over the past decades, authors such as Groce (2013) noted that, although significant progress has taken place in Bolivia in terms of economic and human development, PWD remain in the background and do not benefit as much from the progress as people without disabilities. This indicates the presence of gaps that may be hindering the inclusion of PWD, such as the presence of a socio-communitarian productive model (Fuentes et al., 2021). This model aims to improve the status of PWD through measures that target PWD and their support systems (primarily carers, family, and relatives). Furthermore, there is a lack of capacity building in society to accommodate PWD. Finally, during the initial literature search for this article, a lack of both quantitative studies and qualitative studies analyzing the reality of social inclusion of PWD in Bolivia was noted. Therefore, it is crucial to explore this reality by reviewing disability policies and management in Bolivia and identifying the progress made and the challenges posed.

Method

Participants and Setting

The focus group consisted of key informants from official and social institutions with a recognized background and impact on the social reality of PWD in Santa Cruz (Bolivia). Representation of the agencies—such as institutions representing sensory (visual and hearing), physical, intellectual, and multiple disabilities—for people with different types of disabilities was guaranteed.

Through intentional sampling, the researchers selected participants from representative social institutions in the field of disability in Bolivia. This type of non-probabilistic sampling was applied to facilitate and ensure access to informants. The primary variable for inclusion was participants' membership in representative social institutions working in the field of disability in Bolivia. Other variables considered were memberships in institutions (religious or secular), level of activity (local or national), and duties and positions held in the represented institution (director, chief of department, or direct care assistant).

Including participants with different backgrounds allowed for a greater diversity in debates and speeches. Participants were informed over the telephone of the purpose of the meeting, that it would be recorded, and the subsequent use of the data for research purposes. Except for one male who could not participate for personal reasons

unrelated to the research, all participants agreed to participate in the focus group. Finally, nine participants linked to nongovernmental organizations, special education centers, and universities and government agencies at the departmental and local levels participated in the focus group. The group consisted of seven females and two males.

Procedure

A qualitative method was used to generate the raw data of our research. The first stage of this work consisted of reviewing the references, documents, and legal material on how disability is managed through social policies in Bolivia. At a later stage, a focus group technique was used to obtain raw data to examine legislative developments linked to the social and labor recognition and the inclusion of PWD.

The focus group technique was chosen (a) because participatory, combined, and feedback debates were considered enriching for information that had already been noted and (b) to provide a deeper understanding of the context. Participant interaction is one of the strengths of this qualitative technique because it allows participants to believe that they belong to the same group, thus providing a positive synergy. Furthermore, this ensures that new ideas from the debate are allowed to flourish, which would not occur in individual interviews (García-Calvente & Mateo-Rodríguez, 2000). A relaxed and comfortable atmosphere was created by the researchers to encourage participants to speak and express their opinions freely, and the researchers discouraged domineering attitudes.

In detail, the session lasted for 1.5 hr and was conducted in an accessible, warm, and quiet environment (meeting room at the Faculty of Human Health Sciences, Universidad Autónoma Gabriel René Moreno [UAGRM]). Chairs and tables were arranged in a circle within the room. One of the authors of this study, along with an assistant, oversaw the focus group. The researcher served as moderator and the assistant as a secretary. The secretary provided participants with an informed consent form to ensure that they could expressly provide consent for the use of the data obtained for the research while respecting their anonymity and confidentiality of the data.

Furthermore, a content guide was prepared for the focus group to develop the debate. The guide included the following issues:

1. Reference legislation and policies addressed to PWD (national and regional).
 - (a) Identifying the most relevant regulations and the management and financial support derived from them.
 - (b) The evolution of social policies over time and their impact, philosophy, and other related issues.

2. The social reality of people living with disabilities.
 - (a) The social and demographic features of disability and identifying associated problems.

The guide was distributed to participants 10 min before the session. Participants did not express any concerns or discomfort regarding the proposed questions.

During the focus group debates, there were units of analysis that had not been considered ad hoc and which were particularly interesting, such as discussions between experts regarding the progress and dilemmas of the current political management of disability.

Data Analysis

Once the focus group activity was completed, the information obtained was transcribed manually using Express Scribe software. We eliminated any personal details that would allow the identification of participants. The interviews were coded using Atlas.ti-8 software, based on the following criteria: (a) Profile: technicians (T); (b) Type of disability with which they work: general disability (GD), physical disability (PD), sensorial disability (SD), and intellectual disability (ID); (c) Gender: female (F), male (M); and (d) a unique number assigned to each participant. First, an inductive revision was conducted, through which the basic topics were identified. The focus group was codified, considering the inclusion of new topics that arose during the session (in vivo codes). The information gathering process was considered complete once there were sufficient data to conduct the analysis. Various researchers from Spain and Bolivia conducted the same preliminary analysis to ensure the reliability and validity of the procedure. Once all the participating researchers had conducted their analyses, they held a meeting wherein they agreed on a thematic map (Braun & Clarke, 2006) for the results of the focus group discussion and identified the analysis units from the topics discussed.

Results

Three thematic axes were deduced from the obtained information, which included the statements and ideas from the techniques used: (a) the importance of mass movements and social protests for the recognition of the rights of PWD, (b) the recognition of the condition of disability and its impact on social awareness and access to social resources, and (c) the ineffectiveness of social policies such as the social-labor inclusion of PWD.

Social Movements Fighting for the Recognition of PWD in Bolivia: Action, Reaction, and Repercussions

According to the key informants, the recognition of the rights of PWD began during the mid-1990s and precipitated

the subsequent legislative and regulatory framework. Law No. 1678 on PWD was approved in 1995. This progress was initiated and driven by society through the mobilization of citizen engagement:

What happens in our country, maybe it has always been like this in all countries, is that after a certain pressure, a march, a protest, and all those things, goals can be achieved. (T.GD.m.8)

That law came into force as a result of the previous work and efforts made by civil society, and was more or less organized. (T.ID.w.5)

The national march, from home towns toward La Paz, included the participation of departmental federations of people with disabilities from Santa Cruz, Cochabamba, La Paz, and Chuquisaca, who promoted this mobilization. Within these federations, almost all disabilities were represented. (T.ID.m.6)

Informants referred to the self-organization power of PWD as a (new) social movement in Bolivia, where, in the 1990s, PWD gathered to demand specific changes in terms of civil rights for the collective. Through these processes of public action and protest, PWD in Bolivia created a group consciousness and an identity—they were politically defined as a group that was oppressed and deprived of rights. Surprisingly, despite the different sectors involved, with different disability types leading the fight to achieve rights according to the merits of each case, protests were not promoted by and for PWD as a collective but in a fragmented manner instead.

Another factor was the approval of specific regulations, such as the Supreme Decree No. 27477 of May 6, 2004, regarding the incorporation, promotion, and employment stability of PWD. One of the interviewees explained the political and social context that surrounded the emergence of this regulation:

In the march called by the Bolivian National Federation of the Blind, people joined because they were demanding labor inclusion for people with visual impairment. Then, the president of Bolivia cleverly said, “If I am to grant this to them, I better give it to all of them. Otherwise, tomorrow I will have on my doorstep the deaf, then the physically disabled, then the intellectually disabled.” Thus, the 27477 was born. (T.GD.m.8)

Key informants agreed that people with intellectual disabilities were the least present in marches and protests, despite being represented by their relatives.

Registering Disability in Bolivia as a Precursor for the Recognition of Rights

We are currently experiencing an increasingly organized society that demands “to be” and to participate. Regarding the need “to be” recognized as a person with disability in Bolivia, Law No. 1678 foresees the necessity to provide disability identity cards and create an official registry of

PWD in Bolivia. Therefore, for the first time, the importance of raising awareness about the situation of PWD was recognized, as well as the need to establish a rating and classifying process that would allow this collective to access a network of specific services and benefits. Key informants considered the emergence of this particular law a milestone for Bolivia, which provided momentum for measures oriented toward inclusion:

Law 1678, which created the CONALPEDIS (. . .) Thereafter, again, society itself, as T.ID.m.6 was saying, we had to fight because there was talk about a registry and that people with disabilities had to be identified using a disability card. That caused us to demonstrate to the government how we made our living and how we existed. (T.GD.m.8)

The Bolivian valuation system to rate PWD was led by professional experts who received specific training by professionals from other countries (primarily, Ecuador), where similar systems were already in place. These experts were also provided with specialized rating tools. However, notably, implementing these systems led to some mistakes due to its immaturity and involved a process of improvement, readjustment, and settlement to ensure it functioned correctly:

Rating is performed, the Ministry of Health is involved, teams are created, trained, and they come, but that does not mean that they came well trained because there were many problems, even in terms of filling in the form, the type, and the grade of disability. No one is born knowing how to do things, and practice is what makes the expert. This rating system has currently improved. (T.GD.m.8)

This legislative momentum altered societal perception regarding PWD, who went from being considered victims to legal subjects:

Before, in the eyes of the State, we lived, but we did not exist. (T.GD.w.1)

Statistics and official data regarding disability in Bolivia were collected for the first time, thus allowing authorities to understand the context of people living with disabilities and apply specific measures to improve the situation. Until then, there were only vague questions about deficiencies and a simplistic, partial, and poorly reflective approach in census data designed to be used for other purposes. As noted by Guzmán-Suárez (2013), a disability assessment serves as a support tool toward accessibility to rights and social inclusion, thus becoming a compensatory element for social disadvantages and equal opportunities.

In the case of Bolivia, this new statistical information is registered in the SIPRUNPCD through data gathered by the CODEPEDIS.

Social and Labor Inclusion Challenges: Saying and Doing

In the interest of the collective inclusion of PWD, the key informants identified a lack of effectiveness in social policies. They noted the deficiencies of social policies in terms of labor inclusion, in particular, as one of the primary areas where there is a greater disconnection between theoretical postulates of inclusion and the real impact of the application of regulatory measures.

In Article 156, the Political Constitution of Bolivia foresees the right and duty to work. To guarantee this right, Law No. 1678 includes, within the rights of PWD, the right to paid work. However, guaranteeing this right remains a challenge in Bolivia, against which our participants continue to fight through their contributions to identify and understand ongoing obstacles and key actions to overcome them.

Labor inclusion has been subject to various legislative reforms, thus leading to the recently approved Law No. 977 on Labor Insertion (2017). However, opportunities provided by inclusive societies, which benefit from the capacities of their different citizens, were noted during the group discussion. The key informants emphasized that the advantages of inclusive societies are insufficiently recognized by Bolivian society and that the value of citizens with disabilities are also undermined:

The skills that people with disabilities can have and with which they can contribute to the development of this country, this region, and all of us, are not recognized. (T.GD.m.8)

The approval of Law No. 977 on Labor Insertion and Financial Support for People with Disabilities, which came into effect on September 29, 2017, recognizes and foresees the right to work of PWD, as well as their parents, spouses, and/or the legal guardians of minors or older adults with serious or severe disabilities. It is a notable achievement. However, in practice, this opportunity to include the relatives of PWD in the labor market has been leveraged by public institutions to cover the legal quota by including parents, guardians, and spouses among their personnel, and not as many PWD. This situation does not match the initial aim of the law and overshadows the inclusion of PWD in the labor market, thereby limiting it to specific cases:

Then, the 29608 was extended by the decree after which parents and guardians were also included. That is the current problem in this country, where mayors' offices, government departments, and other institutions are full of parents and legal guardians. For example, I requested a report in 2012 about the number of people with disabilities who had been incorporated as workers, and was informed there were 96 people. Among these 96 people, there were not even 10 people with disabilities, because all of them were parents or legal guardians. (T.GD.m.8)

The spirit and philosophy of that decree and our demand is that the person with disability goes to work, but the parents and legal guardians were already recruited. Moreover, if an employer says, "I need people to work for me" and people with disabilities and parents/guardians show up. Is the employer going to prefer people with disabilities? Of course not, the employer will choose parents or legal guardians instead. (T.ID.m.6)

The situation is the same regarding the percentage of employees with disabilities among the personnel working for public institutions, which rarely exceeds the minimum required by the law. The most recent law on labor insertion, Law No. 977, was approved in 2017 and legislated an increase in the required percentage of labor inclusion regarding PWD, relatives, or guardians for both private companies (2%) and public institutions (4%). An increase in the recognition and awareness of PWD was expected after this measure. However, the expected and desirable impact of this measure already appears to be in jeopardy because it focuses once again on the labor inclusion of relatives of PWD, rather than PWD:

Because many people say, "Oh! No, the required 4% is for public institutions." But that is in fact the minimum, and not the maximum. There are some institutions that say, "I complied," but again, they only hired the minimum number of personnel required. (T.GD.m.8)

It is wrong again, because it says, "We are increasing the percentage." (. . .) However, who is that percentage for? For parents and legal guardians again. (T.GD.m.8)

Informants noted that there is a significant distortion between legislative discourses, which focus on equality based on an economic model called the socio-community productive model (Bolivian Constitution, 2009), and the unreal impact on their lives as PWD.

Moreover, this is not the only case where the gap between legal recognition and real implementation is shown. Another clear example is the application of the General Law No. 223 on People with Disabilities of March 2, 2012. This law and its development regulation established a solidary income of 1,000 Bolivian pesos (around US\$144.70) in favor of people with severe and very serious disabilities who do not work in the public sector, based on data from 2013. Such a solidary income cannot be received by people with visual impairment (who receive a bonus), nor by those with disabilities who work in the public sector. This recognition was achieved after protest marches conducted by the collective. However, the goal of extending it to all PWD was not achieved. Instead, it includes only those rated as having severe or serious disabilities. In addition, this law includes the term "income," meaning monthly income. However, it consists of an annual income:

The issue is that according to Law No. 223, a 1,000-Bolivian-pesos income will be paid. During our last march and protests last year in La Paz, we told our mates that if it's an income and it's 1,000, then it's 1,000 and should be paid on a monthly basis. (T.GD.m.8)

As shown in the above extract, key informants said that the term "income" (foreseen by the law) refers to a quantity that is received monthly. Until 2018, people with severe and serious disabilities received a "bonus" (annual remuneration). Since the enactment of Law No. 977, people with severe or serious disabilities (except visual disability, where the classification does not require degrees of severity) were to receive a monthly bonus of 250 Bolivian pesos (around US\$36.20), financed by autonomous local governments from January 2018. Compared with the previous situation, this recognition was a success. However, notably, the rating provided by professional teams has become stricter. Therefore, the percentage of people with a recognized disability has decreased for a part of the population:

The degree of disability must exceed 50%. Now all of them are rated around 40%. People with disabilities are supposed to have 50% at least in any case and that's from where the disability degree must be rated. We already have difficulties in learning, regardless of the type of disability, we are already at 50% from the moment we are born. However, many people with disabilities are now being rated as 48% (. . .). We have a student who went to obtain her disability identity card and scored 43%. She does not know how to read nor to write, but she got 43%. (T.ID.w.5)

It seems that they are trying to save money, because if there are less people with severe or serious disabilities, they have to pay less money. (T.ID.m.6)

For instance, (name not shown due to confidentiality) was rated 66% because of his disability, poliomyelitis, and other such aspects. Then, one day, he was driving, and his legs broke. He said, "Now I will reach 80% at least." He was then rated and obtained 1 point less than he did earlier. He exclaimed, "But how can this be! If I could drive before and now, I'm all broken." (T.GD.m.8)

Therefore, a significant percentage of the population is being deprived of inclusion guarantees that would allow them to access the solidary income. They are not granted this income because they are not considered to have severe or serious disabilities; nevertheless, they are not able to access the labor market, where jobs are primarily taken by their relatives, spouses, and/or guardians:

People they rate as having severe or serious disabilities are paid in this country. Sadly, they must be 25%, but there is another group of people who are rated between 49% and 30%, who are

considered to have moderate or mild disabilities, and receive hardly any care. (T.GD.m.8)

Moreover, besides the rate tightening, it is known that conducting work or education activities may decrease the percentage or rate of recognized disability. Consequently, some PWD decide to stop working to achieve a higher disability rate:

There were people who said that if they worked, they would be given a lower rate. Then, they preferred to stop working. We kept our jobs because achieving inclusion is no easy task, and suddenly, after such a decision, they stop working so they can obtain higher rates. Because if they are working, the rate will be low, and they are not working, the rate will be higher. (T.GD.w.1)

If you are studying, your rate will be lower. If you do daily life activities, the rate will be lower. And if you work, your rate will also be lower. (T.GD.w.7)

In conclusion, we observed several methods through which the impact of the legislation has been limited and where compliance with the law implies restraining the rights of its recipients. This situation has been noted in various areas and explained by our key informants.

Discussion

This study analyzed the legislative development of the rights of PWD in Bolivia and its social and labor impact on inclusion. The study suggests that the legislative evolution in Bolivia has promoted a notable increase in social awareness regarding people living with disabilities and a higher recognition of the collective, which favors social inclusion. Similarly, the importance of social movements and the mobilization of the collective's representative institutions, as well as the recognition of disabilities, are among the primary forces behind the acknowledgment and progress made toward recognizing the rights of PWD.

However, a significant disconnect has been observed between the national policy discourse and the implementation of the policies. Despite the social movements and the creation of inclusive policies, significant limitations have been noted in the implementation of specific actions regarding access to resources. The study participants highlighted key obstacles, such as the negative effect of including relatives and legal guardians as recipients of employment policies and the promotion of economic aid, which are incompatible with the legislation's intended educational and labor objectives.

In terms of the legislative progress, informants referred to the self-organization power of PWD as a (new) social movement in Bolivia. During the 1990s, PWD gathered to demand specific changes in civil rights. Based on classical

analyses by Barnes et al. (1997) and Shakespeare (2008), direct associative actions taken by PWD have several crucial elements: raising awareness in government and administrations, and building a political powerbase that can play a role in the design and implementation of public policies. Direct action also ensures that this awareness can reach public spaces and penetrate popular opinion. The national march promoted by the Federation of People with Disabilities in Bolivia is considered the march with the highest impact and influence on the recognition of their rights, as well as the first one where all disabilities were represented.

In addition, the key informants noted that people with intellectual disabilities had the smallest representation in those marches and protests, despite the participation of their relatives. In economically more developed countries located in the Global North, people with intellectual disabilities are more targeted by more conservative approaches (Capri et al., 2018). This collective requires guardianship, primarily by relatives, thus leading to two crucial issues. On one hand, the majority of people with intellectual disabilities are represented by their relatives, thus their public participation is lower than other collectives with disabilities. On the other hand, representative guardianship may cause contrary interests between families and PWD themselves. These factors lead to far more complications in terms of the inclusion of people with intellectual disabilities in debates and public actions that affect their lives directly (Rodríguez-Medina et al., 2018).

One of the primary findings of this study shows the importance of the process of recognizing disability as a condition and considering the collective as people with rights. The registry for disability in Bolivia, which functions through the institutions created to that effect (CONALPEDIS and CODEPEDIS), was the driving force for the recognition of disabilities. For the first time, a registry acknowledged the importance of raising awareness regarding the status of PWD and establishing a rating and classifying process that would enable this collective to access a network of specific services and benefits.

The recognition of citizenship implies regarding disability as a regulatory and ideological subject. This process poses a complex scenario wherein the conditions of PWD must be recognized to be politically visible. However, this institutional dynamic (re)builds nonpositive identities and biases. Arrieta (2017) noted that the articulation of this phenomenon is based on achieving a balance between the social recognition of the difference without losing the common identity of the idea of dignity, which is intrinsic to all human beings.

Some authors, such as Aparicio (2016), have suggested that the administrative process required to alter disability swiftly from a private to a public matter risks treating and seeing PWD as objects defined by classifications, labels,

types, degrees, and levels that allow them to access different types of goods and services. Contrary to the optimistic approach of our informants on the classification of disability in Bolivia, some social analysts, such as Barroso (2018), have warned against the negative sociopsychological consequences of such classifications on the collective. This is primarily due to them being the subjects of a damaged construction of their identities, which is characterized by objectification and stigmatization that further complicate their goal of self-fulfillment.

Regarding the challenges hindering the rights of PWD, this study reflected on the limited access of this collective to employment and public aid funds. According to the legislation in Bolivia, employment for PWD is considered a key component for their inclusion. However, policies promoting access to employment do not have the positive impact that this collective has demanded. The lack of institutional information makes it difficult to compare employment opportunities with the participation of people with and without disabilities in the labor market. The Organización Iberoamericana de Seguridad Social (OISS, 2014) addressed this matter from a wider geographical perspective, but it is useful to examine specific data. For instance, approximately 31% of PWD over 15 years are employed in Latin America and the Caribbean compared with 58% of people without disabilities. In Bolivia, only 15% of PWD between 15 and 55 years old are employed and most of them are self-employed (OISS, 2014).

PWD experience increased difficulties when looking for employment opportunities and their inclusion in the labor market. Thus, it is important to discuss the low participation of PWD in the labor market from the perspective of socio-educational gaps. Esponda et al. (2017) noted in a report conducted by United Nations Educational, Scientific and Cultural Organization (UNESCO) that, although updated information was not available, it is estimated that in Bolivia, approximately half of the PWD above 5 years old are illiterate. Conversely, the UNESCO (2015) report indicated that the illiteracy rate in Bolivia in the general population is 7.54%. Therefore, this leads to a problem in the initial stages of the education system, which is then transferred to the upper stages, thus exponentially limiting access to higher level education among PWD.

The second major factor regarding limitations to employment opportunities is linked to basic infrastructure itself. The lack of access to employment information, architectural barriers, and the lack of technical support or support personnel act as instruments that discourage the recruitment of PWD. These structural barriers exacerbate the employability gap of PWD and also undermine the motivation of this population as it pertains to seeking training and employment (Comisión Económica para América Latina y el Caribe, 2017).

The third factor that hinders the inclusion of PWD in the labor market is a negative perception that views PWD as

being less capable and valuable in a business-oriented system. Despite the particularities of disability in countries in the Global South (Meekosha, 2011), the hegemonic neoliberal capitalist model imported from the Global North has remained predominant. This system significantly impacts the various phenomena that occur in peripheral territories. Globalized societies categorize PWD as “redundant,” “useless,” and “unproductive” because they do not fulfill the structural requirements of the social and economic machine (Ferreira, 2008). Within the capitalist system’s paradigm, PWD are considered unable to produce or generate less production expenses than potential contributions to future profits (Russell, 2008). This insufficient recognition of their abilities leads to strategies (very often unconscious) that reduce the impact of inclusive policies and the rights recognized by them.

These factors limit social and labor inclusion opportunities for PWD in favor of their relatives. The recruitment of relatives of PWD is the primary strategy used to fulfill the legal quota of the percentage of personnel with disabilities within the public administration in Bolivia. Therefore, responses to disability are obstructed by the socioeconomic context, wherein it is more important to ensure an income for the family unit instead of fighting for the productive identity of PWD. This indicates how this collective is undervalued and how relatives and public institutions perform guardianship. This situation relegates PWD to passive, unproductive, and dependent roles. They depend on their relatives and family, who, through public measures, design the well-being of PWD. Thus, the archetype wherein PWD are not self-sufficient in creating their life projects—in this case, through employment—is hence (re)built.

This approach contradicts theoretical postulates and scientific evidence from the international movements that promote the independent lives of PWD (Barton, 2006). Furthermore, it infringes on the International Convention on the Rights of Persons with Disabilities (United Nations, 2006), which was approved and ratified by Bolivia. The convention emphasizes the self-determination of PWD as an essential element for them to choose their destiny and participate in all areas of life, under equal conditions, as the rest of the population. According to a comprehensive revision conducted by Algozzine et al. (2001), self-determination refers to an individual’s total being. This involves making decisions, choosing how to live one’s life, and taking responsibility for it. At a social level, it also involves contributing to the community by determining one’s political and self-governance status.

This analysis coincides with that of Pastor (2019), who noted that the ongoing use of these models leads to society not recognizing PWD as subjects with full rights. In particular, he suggests that actions taken by governments to implement the UN Convention do not consider PWD as direct and immediate beneficiaries. From this perspective, Meekosha

and Soldatic (2011) highlighted the limitations of public policies for transforming the reality of PWD in peripheral or Global South countries. Particularly in the Bolivian context, Buell (2013) and Barroso (2018) refer to the existing distance between legislative discourse and the lived experience of PWD. It is suggested that, among the different factors that explain this situation, the aforementioned contradiction may be the result of distortion between the measures of positive action implemented by governments and the negative practices that society exerts on PWD.

Furthermore, the Bolivian government encourages the funding of economic aid conditioned by the educational and labor inactivity of PWD. Such aid is incompatible with employment and necessitates the recipient be certified with a high degree of disability (>50%), thus leading to perverse effects. On one hand, it encourages PWD to be inactive and decide not to work to receive higher disability benefits. It also reduces the collective pressure needed to ensure the necessary changes in the social structure, which hinders the inclusion of PWD in the labor market. On the other hand, public institutions increased the requirements for recipients to reach the necessary degree of disability to be provided this aid. This leads to strengthening the aforementioned situation, wherein PWD decide to reduce their labor and education activities to be recognized as having a higher degree of disability.

This substantial modification of the criteria to access disability benefits conceals an intangible sociopolitical mechanism that limits not only the living conditions of PWD but also their identities. The degree of disability, which forms a significant portion of the identity of every person with a disability, depends on the political and economic interests of the context wherein it occurs. Therefore, how the social dimension determines the concept of disability is reflected (Oliver, 1996).

The international legal framework established by the UN Convention on the Rights of Persons with Disabilities (2006) foresees the obligation to adopt all necessary measures to ensure the labor inclusion of PWD. However, this convention has limited impact on recognizing the value and abilities of PWD and their economic production. Therefore, public administrations and private institutions tend to demonstrate their commitment based on the minimum legal requirements but without committing to promoting the full participation of PWD. Changing this dynamic requires specific actions aimed at raising awareness regarding the importance of employment as a socializing agent and a bridge to achieve inclusion in other social spheres (leisure, culture, social, and political engagement). Similarly, based on evidence from other contexts with no international legal regulations (Mukhopadhyay & Moswela, 2019), although PWD are unable to exercise their rights fully, ensuring their formal recognition helps them to become aware of their rights and demand to be able to exercise them thoroughly.

Limitations

Some research limitations must be considered regarding the interpretation of this study. The methodology used allowed us to fulfill the study purposes, which enabled a deep exploration of the legislative development on the social and labor inclusion of PWD in Bolivia. A wider sample may favor a higher profile in the population's discourses.

Finally, after analyzing the data of the focus group, a predominance of statements by male informants was noted, despite the higher female representation in this study. In Bolivia, women have a higher representation in social areas than men, but a significant predominance of male leadership was noted in the discussions and reflections on the topic in question, thus proving the prevalence of a gender-based social gap. The omission of women with disabilities from the discourse may have limited the visibility of intersectional discrimination experiences related to gender, as well as the role played by societal and educational policies as instruments for minimizing women's impact. Future research may consider these questions to broaden the existing knowledge and further analyze the topics discussed in this study.

Conclusion

As shown in the analysis conducted in this study, PWD and their relatives have been the driving force toward societal changes regarding the recognition of diversity and the implementation of measures in favor of inclusion. Despite the existing stigmatizing and discriminatory realities, the protests and marches conducted and led by the collective of PWD have yielded progressively positive results. However, there is a collective lack of cohesion within the group of people with functional disabilities, where there exists a certain corporate doctrine between the different types of disabilities. This lack of cohesion limited the changes achieved to date because there is not a single and strong voice aimed toward the state. This situation requires awareness-raising actions regarding functional diversity as well as cohesion measures.

Despite the legislative and social changes achieved, which indicate the recognition of diverse abilities, insufficient follow-up and assessment measures were observed. Consequently, the impact of policies was lower than expected and desired, thereby leading to a gap between the objectives pursued and the ones achieved. The need to reflect on and reformulate the rating system of PWD is one of the primary demands for improvement, which suffers from low reliability, thus ensuring that PWD are more vulnerable and subject to the assessment of rating teams.

We confirm the coherence of all the statements of the participants, which presented parallel lines of arguments with relation to the meaningful progress made

by the classification of disabilities in Bolivia. However, a difference of opinion was noted between the statements made by key informants in the focus group and the analytical perspectives of researchers. Theoretical analysts warn about the potential negative effects of any classification system because this establishes nonhomogeneous citizenship categories and rights linked to a specific situation (i.e., disability/population, type, and degree). However, the focus group informants were not categorically against these disability classification systems.

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