Challenges for the implementation of the Care Network for Persons with Disabilities in a health region: a look from the dimensions policy, organization, and structure[1]

Desafios para a implementação da Rede de Cuidados à Pessoa com Deficiência em uma região de saúde: um olhar a partir das dimensões política, organização e estrutura

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Abstract

People with Disabilities (PWD) experience profound inequalities both social and in the access to health. The Care Network for Persons with Disabilities (*Rede de Cuidados à Pessoa com Deficiência*, RCPD) was established in 2012, with the goal of improving this access in an equitable and equal manner. This article aims to analyze the implementation and constraints of the implementation and the conditionings of the RCPD in the health region of São José do Rio Preto. This is an exploratory case study, of qualitative and quantitative approach, anchored in the instrumental of public policy analysis. The dimensions of policy, organization, and structure guided the analysis of results. Interviews were conducted with 37 key players from management, providers, and society. The Ministry of Health is considered the protagonist in defining policy and transferring financial resources. The state agency is the service provider and conciliator of municipal demands by the RCPD leading group. The lack of an assistance regulation system is an obstacle to the network organization. Contracted services decide who will have access to care, not respecting agreed flows. The structure of rehabilitation services, with the exception of the Specialized Rehabilitation Center, was not guided by health needs but by the existence of services in the territory. Barriers to guaranteeing the right to health are evident, perpetuating the inequalities experienced by the PWD.

Keywords: People with Disabilities; Health Policies; Healthcare Network; Inequality.

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Resumo

Pessoas com deficiência (PCD) vivenciam profundas desigualdades sociais e no acesso à saúde. A Rede de Cuidados à Pessoa com Deficiência (RCPD) foi instituída em 2012, com o objetivo de melhorar esse acesso de forma equânime e igualitária. O objetivo deste artigo é analisar a implementação e os condicionantes da RCPD na região de saúde de São José do Rio Preto. Este é um estudo de caso exploratório, de abordagem qualitativa e quantitativa, ancorado no instrumental de análise de políticas públicas. As dimensões política, organização e estrutura nortearam a análise dos resultados. Foram realizadas entrevistas com 37 atores-chave da gestão, prestadores e da sociedade. O Ministério da Saúde é considerado protagonista pela definição da política e repasse de recursos financeiros. O ente estadual é prestador de serviços e conciliador de demandas municipais através do grupo condutor da RCPD. A inexistência de um sistema de regulação assistencial é um entrave para a organização da rede. Serviços contratualizados decidem quem terá acesso a seu atendimento, não respeitando fluxos pactuados. A estrutura dos serviços de reabilitação, com exceção do Centro Especializado em Reabilitação, não foi orientada pelas necessidades de saúde, mas pela existência dos serviços no território. Evidenciam-se barreiras para a garantia do direito à saúde que perpetuam desigualdades vividas pelas PCD.

Palavras-chave: Pessoas com Deficiência; Política de Saúde; Redes de Atenção à Saúde; Desigualdade.

Introduction

As a historically neglected social group, people with disabilities (PWD) experience different social and economic barriers, added to hard access to education and health services, resulting in profound inequalities in relation to other social groups (WHO, 2011). The greater the inequalities experienced, the lower the level of social inclusion experienced by PWD (Cunha et al., 2022).

The significant incidence of disabled people in the Brazilian society turns the issue of disability into a social issue that demands the government to take actions to promote the citizenship rights of this population, either through social policies or other instruments that ensure justice (Santos, 2008).

Constitutional rights and laws have been proposed since the re-democratization, aiming to ensure the provision of services and social inclusion. In 2002, the National Policy for the Health of Persons with Disabilities was issued, establishing guidelines to drive the definition or readjustment of plans, programs, projects, and operational activities in the states and municipalities.

In 2012, the Ministry of Health (MoH) instituted Ordinance N° 793/2012 that implements the Care Network for Persons with Disabilities (RCPD), the health component of the National Plan for the Rights of the PWD - Living without Limits (*Plano Nacional dos Direitos da PCD - Viver sem Limite*). At the municipal level, the RCPD focuses on actions developed by Primary Health Care (PHC), such as early identification, welcoming, health education, promotion of inclusion, creation of lines of care and clinical protocols, home care, and adaptation of the school environment. Specialized Care (SC) would be provided in the territory of the health region through the implementation of Specialized Rehabilitation Centers (*Centros Especializados em Reabilitação*, CER) and Orthopedic Workshops (*Oficinas Ortopédicas*), establishing references for the territory that share care with the PHC, establishing continuous care flows, expansion and qualification of care and development of human resources. Hospital care should expand access to regulated rehabilitation beds (Brasil, 2012).

The RCPD was born in the context of the implementation of the model of Health Care

Networks (*Redes de Atenção à Saúde*, RAS). Recommended as an alternative to the fragmentation of healthcare systems, this model works through polyarchic organizations of sets of health services with common goals and cooperative action, being coordinated by the PHC (Mendes, 2011).

Among the challenges for the RAS to function, there is the need to establish institutional leaderships with capacity to coordinate the regional system, improve the information, communication, monitoring and evaluation systems of the networks, scale the network of services, improve care regulation strategies and increase the financing of the Brazilian National Health System (SUS) (Tofani et al., 2021).

Specifically about the RCPD, there are still few studies, but they have shown that, after 10 years of implementation, access barriers should be decreased, integration between network components should be favored, care flows defined, access expanded and accessibility improved (Dubow; Garcia; Krug, 2018; Machado et al., 2018). In order to fulfill its role, clear definitions must be established and the public should be aware about the caring mission of each point of care, as well as the flows between services (Magalhães Junior, 2014).

Implementing a public policy is a complex process. It involves design, situational diagnosis, applicability, motivations and incentives implied to the different actors, whether they are the policy-makers, the implementers or the stakeholders involved with the public policy in the process (Howlett; Ramesh; Perl, 2013).

Thus, this paper aims to review the implementation and conditioning factors of the Care Network for Persons with Disabilities in the health region of São José do Rio Preto.

Method

This is a case study of exploratory nature that uses a mixed approach, through quantitative and qualitative methods, and is anchored in the theoretical referential of public policy analysis (Donahue; Zeckhauser, 2008). Its use falls on the possibilities of studying the interactions between state bureaucracy (managers at different levels of government), street-level bureaucrats (service providers), society representatives, and the resources that these actors mobilize in policy design and its distributional outcomes (Viana et al., 2017).

This paper sought theoretical approximation with the study by Viana et al. (2017). The authors employ three dimensions to understand the RAS implementation process: Policy, Structure, and Organization. Together, they can explain, if not the whole, at least part of the implementation process of health care networks and the RCPD. The first dimension, Policy, seeks to identify: leadership roles in the decision-making process; negotiation and conflict; and the different forms of relationship between the State and society or between different governments, private sector actors, and members of the society. The Organization dimension was intended to identify the criteria for the RCPD conformation, planning, management, systemic integration among services, and care regulation. Structure translates the availability and sufficiency of human and physical resources, accessibility, and sanitary transportation. These dimensions have different degrees of autonomy and aspects of interdependence, and only an integrated view of the whole can identify which problems are more recurrent and how they can jointly interfere in the implementation of a health care network.

The case study was carried out in the health region called São José do Rio Preto (SJRP), state of São Paulo. It was elected because it brings together central elements for the analysis of the RCPD implementation. This health region is one of the 220 CERs qualified by the MoH. It has a rehabilitation service of the Lucy Montoro Rehabilitation Network (*Rede Lucy Montoro*, RLM), established through the partnership between the State Health Secretariat (*Secretaria Estadual de Saúde*, SES) and the São Paulo State Secretariat for the Rights of Persons with Disabilities. It also provides municipal specialty services, with rehabilitation actions and philanthropic services contracted by the Municipal Health Secretariats of the region and the SES. Allied to these factors are the population size of 732,845 inhabitants and 20.61% of PWD in the region, according to the 2010 Census. These data are similar to other health regions in the country, especially those with more than 400,000 inhabitants. Chart 1 brings more information about the health region under study.

Chart 1 - Socioeconomic characteristics of the health care structure in the health region of SJRP

		Source
Number of municipalities in the health region	20	Datasus
Population estimate (2019)	732845	TCU
People with Disabilities (2010)	20.61%	Census
GDP per capita (2019)	R$ 36,110.18	Seade Foundation
Average income per capita (2010)	R$ 990.66	Census
Illiterate population (2010)	4.20%	Census
Human Development Index (2010)	0.744	Census
Total public expense in health per inhab. (2020)	R$ 997.63	SIOPS
Number of Basic Healthcare Units (2020)	103	CNES
Number of specialties centers (2020)	40	CNES
Number of hospitals (2020)	12	CNES
Other services (2020)	21	CNES
Nurse/thousand inhab. (2020)	1.92	CNES
Physiotherapist/thousand inhab. (2020)	0.57	CNES
Speech therapist/thousand inhab. (2020)	0.16	CNES
Physician/thousand inhab. (2020)	3.01	CNES
Psychologist/thousand inhab. (2020)	0.35	CNES
Occupational therapist/thousand inhab. (2020)	0.11	CNES
Basic Care Coverage (2020)	54.02%	MS/SAPS
Family Health Strategy Coverage (2020)	34.46%	MS/SAPS
Healthcare plan beneficiaries (2020)	39.90%	ANS

ANS: Agência Nacional de Saúde Suplementar (National Health Agency); CNES: Cadastro Nacional de Estabelecimentos de Saúde (National Registry of Health Facilities); Datasus: Departamento de Informática do SUS (SUS IT Department); MoH: Ministry of Health; GDP: Gross Domestic Product; SAPS: Secretaria de Atenção Primária à Saúde (Primary Health Care Secretary); Seade: Sistema Estadual de Análise de Dados (State Data Analysis System); SIOPS: Sistema de Informações sobre Orçamentos Públicos em Saúde (Public Health Budget Information System);TCU: Tribunal de Contas da União (Union Accounts Court).

Aiming to better understand the specificities of management and services for PWD, the municipalities were the health region hub - São José do Rio Preto - and the two with the highest population rates of PWD for individuals with at least one of the disabilities investigated - Palestina (26.61%) and Mirassolândia (23.62%).

To answer the objectives of this study, semi-structured interviews were performed and questionnaires were applied to three categories of key players representing the state, regional and municipal levels: manager, provider and society. The Manager category (indicated by G) includes the professionals who work in the Municipal Health Secretariats, the State Health Secretariat, and the Regional Health Division. Provider (P) is the category that aggregates those responsible for the services that offer health care and professionals who deal directly with the public. The last category, Society (S), encompasses the social representatives within the municipal health councils (*Conselhos Municipais de Saúde*, CMS) and the PWD council. We did not intend to limit the study to directly administered services, but also interview actors linked to private contracted non-profit services.

To choose the services, all those that regardless of their level of complexity provided care to PWD were listed. It is understood that within a health care network PHC services are essential, since they must coordinate care and be the gateway to the system. For the selection of Basic Health Units (BHU), four units were selected in the hub city and one unit for each of the other cities.

All outpatient rehabilitation services, either provided directly or under contract, were incorporated to the list of respondents. This choice occurred due to the centrality of these services in the network. Finally, a single regional hospital service was selected, with the largest number of services available in rehabilitation, being also an important teaching hospital.

The questionnaires were double-typed. After typing consistency analysis, descriptive data analysis was performed using the IBM-SPSS-13 software. The results of Likert-type questions are presented as the mean resulting from the set of answers. For this, the possible answers were translated into numbers as follows: "very high - 5", "high - 4", "moderate - 3", "low - 2" and "very low - 1".

Semi-structured interviews were transcribed and analyzed using content analysis, which is one of the possibilities of interpreting data from a text or speech, adopting standards with the aim of extracting the thematic meaning or its significance. Content analysis aims to establish links between themes, words, and/or ideas, thus determining a way to weigh the extracted senses and meanings in order to reveal subtleties contained in the text (Bardin, 2015). Themes were organized by dimensions and conditioning factors of implementation, presented in the analytical scheme used as reference (Chart 2).

Fragments of the interviews and documents were used to exemplify the messages.

The research was submitted to the Research Ethics Committee and approved through opinion n° 3,441,243 dated July 5, 2019.

Chart 2 - Analytical model

Dimensions	Policy	Organization	Structure
Constraints	• Institutional leadership • Conflicts • Decision-making	• Planning • Integration • Care regulation	• Installed capacity • Labor force • Accessibility • Transport

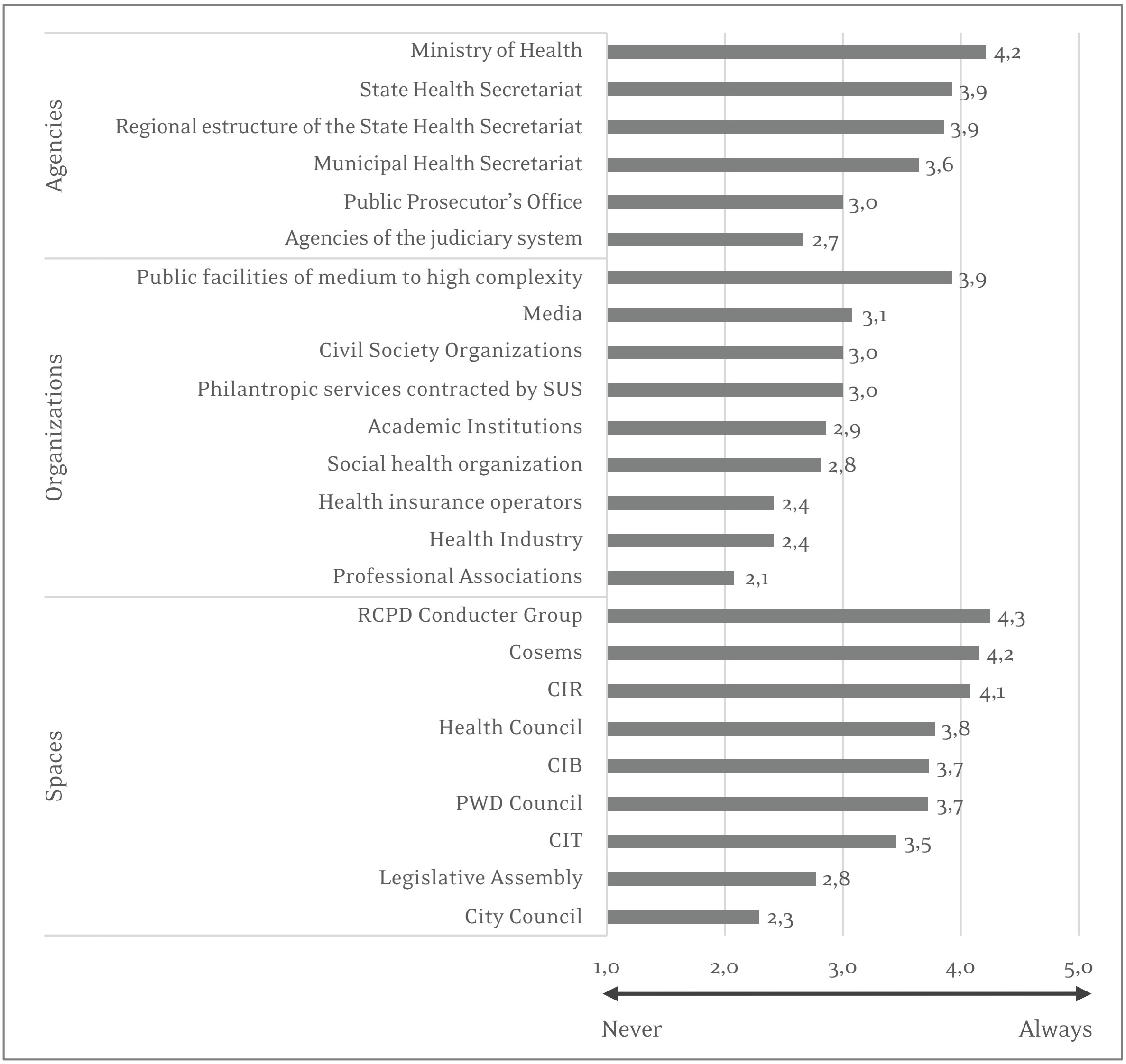
Results and discussion

A total of 37 individuals representing the state, regional, and municipal spheres were interviewed, divided into the categories of Manager (46.0%), Provider (40.5%), and Society (13.5%). One philanthropic institution refused to participate in the study. Respondents had been linked to their respective institutions of work/social representation position for an average of 11 years. Among these, 70.3% were female, with an average age of 45.2 years. Among the respondents, only two were PWD, both representing the PWD council of the municipality of São José do Rio Preto.

Policy

The leading role of the MoH since the beginning of the RCPD implementation process is evident, driving the actions performed by the other federative entities. On the importance for decision-making, the MoH is the main body (average 4.21); among the organizations, are the public facilities of medium and high complexity (3.92); and the decision-making spaces with the greatest prominence are: RCPD conductor group (4.25), Council of Municipal Health Secretaries (*Conselho dos Secretários Municipais de Saúde*, Cosems) (4.15) and Regional Interagency Commission (*Comissão Intergestores Regional*, CIR) (4.08) (Graph 1).

Graph 1 - Importance of decision-making agencies, organizations, and spaces in the RCPD, SJRP, 2019



CIB: Bipartite Interagency Commission (Comissão Intergestores Bipartite); CIR: Regional Inter-managers Commission (Comissão Intergestores Regional); CIT: Tripartite Inter-managers Commission (Comissão Intergestores Tripartite); Cosems: Council of Municipal Health Secretaries (Conselho dos Secretários Municipais de Saúde).

For Lima et al. (2017), the leading role of regional governance will be guided by those agencies, organizations, and spaces with greater capacity to influence the conduct and organization of the health system. The way governance is constituted is mirrored in the traits of these spaces, their scope, decisions, relationships between actors, and strategies and instruments used by them. In this sense, the emphasis attached to the steering group matches the attributions assigned to it by Ordinance No. 793/2012, namely: implement clinical guidelines and protocols; and monitor the actions of each component of the RCPD. Uchimura et al. (2017) state that the leading role in health regions is granted by the regional structure of the SES, as well as by the facilities that provide services.

The relations of the different levels of the state bureaucracy are essential for decision making; thus, the CIRs have a central role for being an "*official, elective space* [...] *where decisions must happen*" (G8). Such positioning is shared by Vargas et al. (2015).

Clashes and disputes between the federated entities are common in the Brazilian federalist logic, especially in the organization of assignments. For the respondents, the responsibility of the municipalities regarding the PHC is clear. For the SC, they say that responsibilities are shared, leading to overlapping actions or the non-compliance with previously agreed competencies.

There is additional difficulty in implementing the RAS, due to the low administrative capacity of the municipalities. Local policy makers and implementers show resistance and difficulty in accepting a supra-municipal level to monitor the management of the networks (Vargas et al., 2015).

In the case analyzed, the state sphere is presented as the responsible for formulating the regional plan and diagnosing the region together with the municipalities. Managers and providers understand that the SES stands out in the provision of services for the RCPD because of the RLM. The state entity is a protagonist in the leadership of the construction of the RCPD. Its role is prominent especially in the CIR: "[...] *who defines what has to be done, what will be agreed upon, is the CIR, with important action of the state*" (G1).

The states act in different ways in leading the process of building the RAS. States with weak leadership act directly as service providers, engaging less in the coordination of the networks. On the other hand, strong states guide the definition of services and patient flow between municipalities, perform monitoring and evaluation, and finance the networks and services (Vargas et al., 2015). A study by Roese, Gerhardt, and Miranda (2015), in Rio Grande do Sul, shows that although the state did not operate through financial incentives for adherence to programs and policies, it acted as facilitator and guarantor of the ministerial strategy, a posture similar to that found in this study.

Conflicts and the search for a leading role in decision-making are important elements in the analysis of the governance of a policy. The role of the state in this region was stabilized in two poles: as a provider of specialized services, through the RLM, and as a conciliator between municipal demands through the RCPD steering group. It is therefore a core actor for the network. At the local level, the network organization leadership is disputed between the RLM and the municipal health secretariats. The MoH has an ethereal presence, since its importance is signaled by the definition of policy and the transfer of resources, but it is absent in daily conflicts.

It is a consensus among the rehabilitation service providers that, if they were invited, they would participate in the discussions with the regional steering group about the organization of the network. The posture of not bringing the providers to the discussion table increases the fragmentation of services. This fragmentation can have a harmful effect on access and care due to the precariousness of the sector's management strategies, making the system inefficient and not very sustainable. Identifying, understanding and creating relationships between managers and providers would be an opportunity to put an end to this fragmentation process, and to optimize and improve service delivery (Santos; Campos, 2015).

The Council for the Rights of Persons with Disabilities (*Conselho de Direitos à Pessoa com Deficiência*, CDPCD) and the CMS presented averages of 3.79 and 3.67, respectively, regarding their importance in decision-making. A representative from society affirms he feels a greater need for integration between the CDPCD and public management. PWD do not appear in the speeches as representatives for the implementation of the policy, and do not participate in the spaces of negotiation and decision-making in the region.

Organization

Health policies in Brazil are largely elaborated by the MoH and implemented in the states and municipalities through mechanisms of financial incentive. It is up to the latter to organize the implementation processes, planning and necessary pacts. It is at this stage that they come to life and can produce effects different from those initially planned.

As for planning, managers state that, starting in 2012, the action plan was built at a time when "[...] *there were many financial resources and* *many qualifications*" (G6). Still, it was a process of "[...] *great difficulty in developing projects involving the micro-region, because of the limits imposed by the population size, the needs of each service and political interests*" (G8).

In the opinion of managers and providers, the Regional Action Plan for the RCPD does not make agreements on care flows, definition of vacancies, lines of care and priority flows for exams of users who are being followed up in rehabilitation. According to a manager, at the time of the diagnosis of the services capacity, some philanthropic institutions, even being points of care contracted by the municipalities of the region for the care of physical and intellectual PWD, were ignored for the composition and diagnosis of the Network.

Specifically for the access to rehabilitation services, the regulation centers serve as scheduling entities for the first evaluation conducted by the services providers. There are, therefore, two phases for care regulation: the first is done by the regulation centers, making vacancies available for screening. In this initial phase, there is no prioritization for users who need early rehabilitation. The second phase occurs within the services that remove patients from the regulatory center queues, perform individual assessments of cases according to the prioritization criteria of the institutions, and create waiting lines within the service.

Among those responsible for the municipal and regional regulation centers, it is a consensus that the scheduling of specialty and rehabilitation medical appointments for PWD always occurs after referral from the BHU, via the regulation center. They claim not to know the waiting time for scheduling the evaluation of services in rehabilitation, and the rates of absenteeism from services.

Providers stated that for cases in which early rehabilitation is prioritized (fractures, recent stroke, developmental delay, among others), the waiting time is no longer than one month. For chronic cases, it can be as long as six months. In this regard, literature presents discrepant data, with waits for chronic cases ranging from one to six months (Passalent; Landry; Cott, 2009).

Representatives of philanthropic institutions, in turn, stated that they have their own regulation system, independent from the ones used in the rest of the network. They reported that patients can be referred from the network, via BHU or the CER, but may arrive at the institution by referral from friends, school, and churches. These forms of referral are not agreed with the contracting secretariats, in which the need for the reference and counter-reference authorizations are regulated by the Regulatory Complexes. "*This logic causes problems for the organization of the network [...], since the philanthropic services are not integrated into the municipal and state regulation system. They are open-door services*" (G5).

The philanthropic services do not follow the pacts entered by the regional management instance, establishing links of service provision directly with the municipalities, including those from other health regions. There is a predominance of market logic, with a focus on production goals and absence of continuity of care and territorial responsibility for users. The state is unable to transpose these rules so that the services are properly inserted in the regional plan of care for PWD, making unfeasible the construction of a single protocol for access, i.e., an effective regulation.

Reis et al. (2017) state that it is necessary to settle philanthropic institutions under the subordination of regional management, through dynamic plans of regulation, evaluation and monitoring. Philanthropy should play a complementary role within the public health policies for people with disabilities, and should be subject to contracts with well-defined goals, accountability, transparency, and continuous evaluation process.

The process of care regulation will not provide equitable and full access while operating only with part of the public services and not acting on the interests of private services (Albuquerque et al., 2013). Matthews (2012) reveals this situation when dealing with the emptying of state actions resulting in the loss of control over public policies as a consequence of greater interactions between state actors, market and civil society. The lack of organizational structure of the care regulation processes leads to cases of occupation of care vacancies in two or more rehabilitation services by the same user at the same time, which limits the access of other users.

The main problem of network articulation is found in the lack of definition of the scope of action of each health service. This is a statement presented in chorus by the providers, who affirm the need to participate in negotiation forums, aiming to create service flows appropriate to the needs of the services and the population, as well as to define more precisely the scope of each service.

Despite the determination of comprehensive care to PWD, the failure to delimit the specific actions and competencies of the services, as well as the failure to work in a multi-professional way, implies in providing ineffective care to the user. Integrality of care and multiprofessional care end up being limited to an idealistic perspective (Machado et al., 2018).

Each point of care acts predominantly independently and disarticulated from the network. There are few spaces for discussion and integration of PHC teams with the SC, which occurs mainly in technical meetings in which "[...] *there is some time left*" (P2) to discuss specific cases of a few users.

The mechanisms used for systemic integration found are divided into two categories. The first occurs through formal mechanisms, such as reference and counter-reference forms and team meetings; and the second through informal processes. In this case integration occurs when the same health professional works in two different services and/or through personal contacts, by means of message applications. Integration depends on mutual efforts between the points of care and the efforts of the professionals (Vargas et al., 2015). These agents hold enough power to modulate the implementation of a public policy and, consequently, alter the outcomes for users (Lipsky, 1983). The following speech exemplifies the idea:

> *There is no integration that really works [...] it starts from primary care, we see is a primary care with support from the Núcleos Ampliados de Saúde da Família, NASF [Extended Family Health Centers], in which the professionals who are in NASF do the way they want to do and there is no person who can really coordinate the management in NASF to do it in a way that is equally and really coordinated with integration among all.* (P10)

Continuity of care, as a way to maximize health care through the link between user, professionals and services, is predominantly referred to as non-existent. This responsibility falls mostly on the user: "After discharge, we leave the door open for the physically disabled, we have workshops here for them, they are still here. But then he is no longer our [patient], he is not in our goals. He's using the space and that's it" (P9).

Another provider states that: "What happens is that we return to the PHC [the patients], so that they don't stay here in the service occupying the vacancy of those who could have greater benefit. But they end up coming back here. Nobody looks at them in PHC" (P10).

Lack of dialogue between providers and managers creates conflicts. These occur mainly with contracted philanthropic services, due to the rigid protocols they build to include users in the service. Philanthropic institutions that monitor users with physical disabilities try to define the profile of users served, not according to the health needs of the population, but around the historical construction of the service. An example of this emerges in the speech of a provider of these institutions in which he says that

> [...] *you have to have disability in the psychological evaluation scale, you have to have mild, moderate or severe disability, it is the first step, so if you within the scale have borderline level, not being considered disabled and not being considered normal, we no longer provide care* [...]. *To the institution we only bring people with neurological disability, he can have physical disability, there is no problem, but if he has physical disability and no neurological disability he does not come here, only neurological disability comes in, with physical or not, syndromes or not.* (P2)

Another service states that the profile of its services was not agreed upon with the municipalities that contracted it, leading to conflicts between municipal management and the entity.

> *The focus is on neurological patients. We don't provide care to patients with Down's syndrome, it does not correspond to the therapy; patient with autism, we have no experience* [...] *no matter how much you have physical disability, we do not have this experience, this expertise. It is clear for us, for the Health Secretariat I can't say* [...]. (P1)

Philanthropic institutions have their own rules for entry of users, as does the Lucy Montoro Network. The state does not manage to overcome these rules so that the services are contemplated within the regional plan of care to PWD, which hinders the construction of a single protocol for access, as the managers of the municipalities and the health region would like to see.

The existing logic for the construction of the RCPD in the health region of SJRP is built on the existing equipment and services, in their peculiarities and their own service flows. It is a model in which supply is structuring, and not the demand and health needs of PWD. The institutionalization of instruments for agreements, management contracts, and regional organization are necessary. It is essential to establish

> [...] *official regional instruments for agreements, including with the central municipality* [...]. *Officially, it does not have a systematic monitoring, it is dependent on the mobilization of the municipalities* [...]. *The manager can't understand that there is a merit on the part of the municipality in making the pact* [...] *can't understand the issues of building regional networks. They can't understand that it is a strategy to guarantee access to their population.* (G7)

The contractual agency of private facilities - and, as shown here also, of public establishments such as the RLM - for the provision of public services should require the guarantee of terms, i.e., the instruments of management and service provision should be consistent and coherent with the constitutional principles and guidelines of the current social contract and public policies. Otherwise, differences may appear when defining the modes of their operation, their service delivery, and their evaluation (Miranda, 2017).

Structure

The health region has only one CER qualified in physical and intellectual rehabilitation. When asked about the existence of demand for more CER, 86.67% of respondents answered positively. Among the services that make up the RCPD, only the specialized care in visual rehabilitation and the dental specialty centers were considered sufficient by more than 50% of respondents (Graph 2).

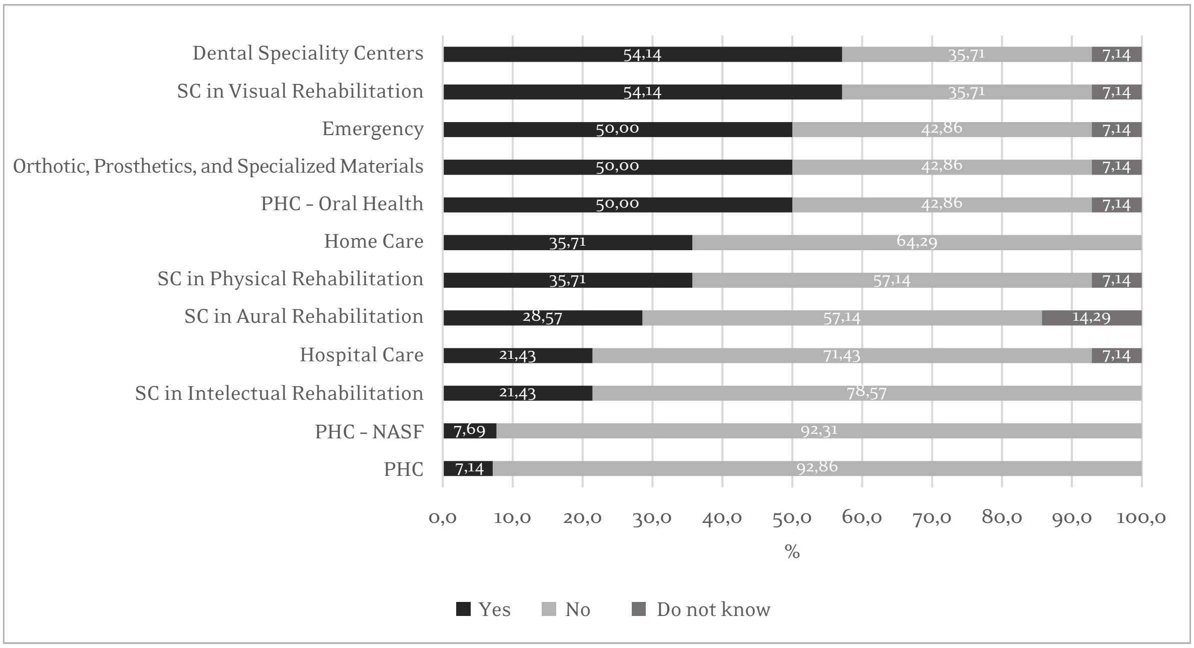
Representatives of the society state there is a need for more rehabilitation services in most municipalities. The smaller ones do not have services and few of these supply the demand through consortium or pacts with the hub municipality or the state. Porosities in services provision suggest problems in inter-municipal health care networks. Territorial inequalities in the supply of health services reflect discrepancies in the level of social and economic development, and point out to limitations in the planning of public policies and in the distribution of resources to the population (Rodrigues; Amaral; Simões, 2007).

Non-uniform territorial distribution among services, shortage of supply and concentration in hub cities of the health regions are reflected in territorial inequalities. These create a high degree of regional dependency in relation to hub municipalities, impact the distribution of power, and amplify intergovernmental conflicts and regional governance arrangements. Such factors would be exemplified through the dispute for human and financial resources, and the degree of influence of providers (Lima et al., 2017).

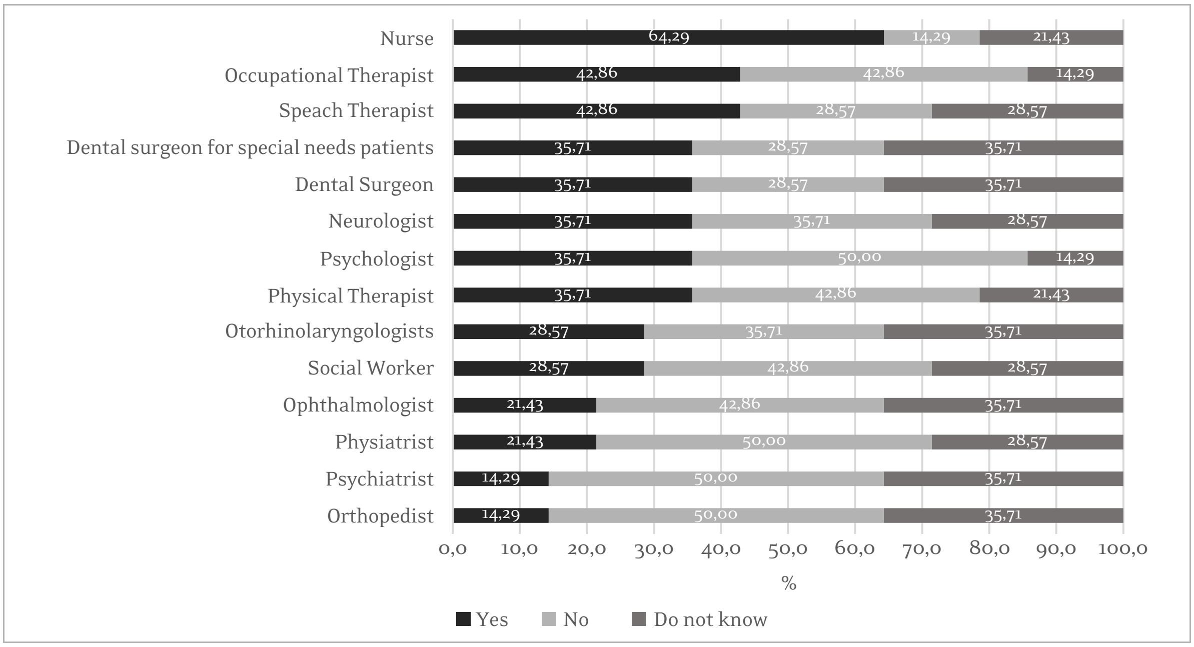
Rehabilitation centers are concentrated in urban areas, making access difficult for rural residents. The need to travel constantly to obtain rehabilitation treatments can be expensive, time-consuming, and strenuous, factors that are worsened by the lack of public transportation adaptation. The implementation of services in municipalities with low population density is hindered by the indispensability of some degree of technological density, which is concentrated in large cities. Still, the integration between PHC, SC and rehabilitation services, all near the user's residence, would enhance their recovery (WHO, 2011).

The low sufficiency of human resources is highlighted in Graph 3.

Graph 2 - Sufficiency of RCPD services, SJRP, 2019



Graph 3 - Sufficiency of professionals in RCPD, SJRP, 2019



Only nursing professionals were considered sufficient BY more than 50% of the respondents. It is also notable that up to 35.7% of respondents stated that they did not know how to answer the question. A study on the implementation of the RCPD in Rio Grande do Sul found a low number of professionals to serve this public, highlighting that hiring these professionals, especially in small municipalities, runs into state bureaucracy, lack of financial resources, and poor infrastructure (Dubow; Garcia; Krug, 2018). In Minas Gerais, 17.7% of health care facilities that provide specialized services for people with disabilities have a minimum adequate staff (Escarce et al., 2017).

Accessibility mechanisms are essential to allow PWD to participate and search for care. There is availability of materials in Braille for 25% of respondents, but audio description and Libras interpreter resources do not exist (58.3%). The municipality of São José do Rio Preto makes a Libras interpreter available for the deaf community in the follow-up of consultations and exams. According to a representative of the society, this monitoring is essential, since the language barrier is a recurring problem. They also state that when the interpreter cannot be present during consultations, calls are made by WhatsApp to facilitate communication. The municipality has also offered Libras training for health professionals, with the expectation that at least one professional per unit will be able to use this form of communication.

In relation to transportation, each municipality is independently responsible for the organization, without interference from the regional and state spheres. As the disabled user requires continuous, prolonged treatment, and usually more than once a week, this service is essential, especially with the concentration of health services in the region's hub municipality.

Managers say that in smaller cities there is no adapted car for wheelchair patients, so it is necessary to use the "ambulance-therapy". This is one of the ways found to travel long distances, especially to the region's hub or even to state references. The lack of health transportation can lead to missed appointments, delayed care, and difficulty in obtaining medications. This is a core barrier to accessing health services, especially for people with lower incomes and those with greater health needs. Such problems lead to worse chronic disease management (Syed; Gerber; Sharp, 2013).

Final considerations

The theoretical reference used makes it possible to understand the implementation of the RCPD with an expanded look. The overlapping of services of distinct agency - provision by philanthropic entities, private contracted companies, municipal and state public agencies -, coupled with the implementation of the CER and RLM, shapes a historical construction that can be extrapolated to part of the national territory (Miranda, 2017). These roughness carries historical legacies of past achievements and attests cultural, social, and economic marks, interconnecting the present and the past.

The results presented expose persistent problems in the implementation of the RCPD, which may manifest as an expression of the inequalities experienced by PWD and are consistent with other difficulties found in the literature such as: lack of consistent epidemiological data (WHO, 2011), low coverage of rehabilitation services (Kuper; Hanefeld, 2018), fragmentation and inefficient coordination of the health system, lack of continuity of care (Geberemichael et al., 2019), financial resources, workforce and professional training (Thomas; Tharion, 2019).

Although presented separately, the dimensions reviewed – Policy, Organization, and Structure – make up a triad of factors that only superimposed can present the challenges and conditioning factors for the implementation of the RCPD in the studied health region.

Philanthropic providers, due to their historical importance in the care of PWD, hold a considerable part of the physical and human resources for the provision of services, in addition to popular appreciation. These facts give them political and decisional power - not within the formal decision-making instances of the State, but in informal processes -, evidenced by the need to contract their services, and by exercising regulatory power of their actions independent of the agreed actions. Besides, they decide who can have access to their services, not respecting the existing flows.

The existence of different contracted public and philanthropic rehabilitation services in parallel places obstacles to the process of care regulation, and to the definition of the scope of each service. The lack of a single care regulation system for the RCPD is one of the main obstacles to the organization of services.

Care gaps are not only evidenced at the territorial level, they are also created by the specificity of each service. The structure of rehabilitation services of the RCPD, with the exception of the CER, was not built with a focus on meeting the needs of the population, but through the hiring of services available in the territory. Actions carried out by public services, with direct management or through social organizations, are oriented to fit within the system, even if in a poorly organized way.

Inequalities can be manifested in different ways; in this case, it starts by the lack of representation of PWD among the interviewees. When studying the case of the implementation of the RCPD in a health region, we chose to interview the individuals who occupy the positions within the analyzed categories. Although this is an important limitation of the study, not having PWD in decision-making positions is symptomatic of a policy that has difficulties to be materialized in real life. By not enabling the participation of this population in these decision-making spaces, their health needs cannot be guided and are not transformed into consistent policies.

New studies regarding the RCPD, aiming to deepen the understanding of the implementation and its effectiveness, are necessary. Nevertheless, the results presented make clear some of the challenges for the RCPD policy proposal to become effective.

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Mota and Bousquat participated equally in the preparation of the manuscript, which is the result of Mota's doctoral thesis at the PPG of Public Health at the Faculdade de Saúde Pública of USP.

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