

# $SUCCESSFUL\ EXPERIENCES\ IN\ THE\ RESTRUCTURING\ OF\ THE\ CARE\ NETWORK\ FOR\ PEOPLE\ WITH\ DISABILITIES:$ $EXPERIENCE\ REPORT$

# EXPERIENCIAS EXITOSAS EN LA REESTRUCTURACIÓN DE LA RED DE ATENCIÓN A PERSONAS CON DISCAPACIDAD: INFORME DE EXPERIENCIA

# EXPERIÊNCIAS EXITOSAS NA REESTRUTURAÇÃO DA REDE DE CUIDADOS À PESSOA COM DEFICIÊNCIA: RELATO DE EXPERIÊNCIA

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#### ABSTRACT

Introduction: Health Care Networks are organized through the integration of technologies, services, and health-related actions. The Care Network for People with Disabilities in a municipality of Minas Gerais faces challenges related to marginalization, invisibility, and financial and social difficulties of its users, which compromise access to comprehensive care, affecting their rehabilitation and social inclusion. This reality highlights the need for managerial interventions and approaches to promote effective improvements. Case Report (Results): This experience report addresses the restructuring of the Care Network for People with Disabilities, organized into five phases: starting point, initial questions, reconstruction of the lived process, in-depth reflection, and points of arrival. New services and patient regulation workflows were implemented, fostering multiprofessional and intersectoral articulation within the network. A return to basic premises recommended by regulations, but previously neglected in daily practice, was observed, resulting in better organization and efficiency in care delivery. Conclusion: Successful managerial actions promoted better network integration, enabling absorption of previously excluded demand. Active listening and collaboration with people with disabilities, their families, and healthcare professionals were essential for formulating more assertive measures and achieving success in the restructuring process.

**Keywords:** People with Disabilities; Health Services for People with Disabilities; Health Care; Health Management; Workflow.

#### RESUMEN

Introducción: Las Redes de Atención en Salud se organizan mediante la integración de tecnologías, servicios y acciones orientadas a la salud. La Red de Cuidados para Personas con Discapacidad en un municipio de Minas Gerais enfrenta desafíos relacionados con la marginalización, invisibilidad y dificultades financieras y sociales de sus usuarios, lo que compromete el acceso a una atención integral, afectando su rehabilitación e inclusión social. Esta realidad evidencia la necesidad de intervenciones y posturas gerenciales para promover mejoras efectivas. Relato del caso (Resultados): Este relato de experiencia aborda la reestructuración de la Red de Cuidados para Personas con Discapacidad, organizada en cinco fases: punto de partida, preguntas iniciales, recuperación del proceso vivido, reflexión profunda y puntos de llegada. Se implementaron nuevos servicios y flujos relacionados con la regulación de pacientes, que favorecieron la articulación multiprofesional e intersectorial dentro de la red. Se observó la retomada de premisas básicas recomendadas por las normativas, pero anteriormente desatendidas en la práctica cotidiana de los servicios, resultando en una mejor organización y eficiencia en la atención. Conclusión: Las acciones gerenciales exitosas promovieron una mejor integración de la red, permitiendo la absorción de la demanda previamente excluida. La escucha activa y la articulación con las personas con discapacidad, sus familiares y los profesionales de la salud fueron esenciales para la formulación de medidas más asertivas y para el éxito del proceso de reestructuración.

**Palaras clave:** Personas con Discapacidad; Servicios de Salud para Personas con Discapacidad; Atención en Salud; Gestión en Salud; Flujo de Trabajo.

#### **RESUMO**

Introdução: As Redes de Atenção à Saúde são organizadas pela integração de tecnologias, serviços e ações voltadas para a saúde. A Rede de Cuidados à Pessoa com Deficiência em um município de Minas Gerais enfrenta desafios relacionados à marginalização, invisibilidade e dificuldades financeiras e sociais dos usuários que comprometem o acesso a uma assistência integral, afetando sua reabilitação e inclusão social. Essa realidade evidencia a necessidade de intervenções e posturas gerenciais para promover melhorias efetivas. Relato do caso (Resultados): Este relato de experiência aborda a reestruturação da Rede de Cuidados à Pessoa com Deficiência, articulada em cinco fases: ponto de partida, perguntas iniciais, recuperação do processo vivido, reflexão de fundo e pontos de chegada. Foram implantados novos serviços e fluxos relacionados à regulação de pacientes que favoreceram a articulação multiprofissional e intersetorial da rede. Observou-se a retomada de premissas básicas recomendadas pelas normativas, porém negligenciadas na prática cotidiana dos serviços, resultando em maior organização e eficiência no atendimento. Conclusão: As ações gerenciais exitosas promoveram a melhor integração da rede, permitindo a absorção da demanda previamente excluída. A escuta ativa e a articulação com pessoas com deficiência, familiares e profissionais de saúde foram essenciais para a formulação de medidas mais assertivas e para o êxito do processo de reestruturação.

Palavras-chave: Pessoas com Deficiência; Serviços de Saúde para Pessoas com Deficiência; Atenção à Saúde; Gestão em Saúde; Fluxo de trabalho.



# INTRODUCTION

Health Care Networks (RAS) represent organizational arrangements structured through integration of different technologies, services, and actions aimed at health, intending guarantee comprehensive care. networks, supported by management systems, technical, and logistical support, aim to ensure qualified and continuous care, encompassing the three levels of healthcare: primary, secondary, tertiary<sup>(1)</sup>. and These organizational arrangements comprise the Unified Health System (SUS), which, upon its implementation, has ensured access to various health programs and thereby reduced mortality in Brazil<sup>(2)</sup>.

Among the various health networks in Brazil, this experience report focuses on the Care Network for People with Disabilities (RCPD), which was set up following the publication of MS/GM Ordinances No. 793/2012 and No. 835/2012. currently replaced by MS Consolidation Ordinances No. 3/2017 and No. 6/2017, respectively<sup>(1)</sup>. In the state of Minas Gerais, the RCPD was instituted by resolution of the Bipartite Interagency Commission of the State of Minas Gerais (CIB-SUS-MG) No. 1272/2012<sup>(3)</sup>. In Lagoa Santa, a municipality in Minas Gerais, the RCPD is governed by Municipal Decree No. 4.879 of April 13, 2023, which establishes the new Comprehensive Care Policy for People with Neurodevelopmental Disorders and/or Physical Disabilities in the Municipality<sup>(4)</sup>.

To establish an effective PCRD, it is essential to ensure coordination among the

components of healthcare, including primary care, specialized care, hospital care, and urgent and emergency care<sup>(1,4)</sup>. Although effective coordination is necessary, the Care Network for People with Disabilities (RCPD) in Brazil is fragmented, characterized by a lack of integration between services and the absence of specialized care. This configuration results in care gaps that are detrimental to people with disabilities<sup>(5-6)</sup>.

The lack of adequate provision of health services imposes constant worries and challenges on families, as well as significant financial pressure. People with disabilities face marginalization and invisibility, as well as economic and social difficulties and difficulties within the Disability Care Network itself. These conditions prevent access to comprehensive, interdisciplinary, intersectoral and compromising both their rehabilitation and social inclusion, which causes suffering for patients and their families $^{(5-6)}$ .

Thus, several factors have led to the need for urgent interventions and management positions to improve the RCPD in Lagoa Santa/MG, making it necessary to report on successful experiences in restructuring the RCPD. This allows for the dissemination of management measures that can contribute to improvements in the RCPD in other settings and locations.

# **OBJECTIVE**

This study aims to report on successful experiences in restructuring the Care Network



for People with Disabilities in the municipality of Lagoa Santa in Minas Gerais, Brazil.

#### MATERIAL AND METHOD

This is a descriptive experience report on the first phase of restructuring the RCDP in the municipality of Lagoa Santa, located in the Metropolitan Region of Belo Horizonte, Brazil, from September 2022 to April 2024. The actions reported took place within the scope of RCDP enrolled management, which serves an population of 2,091 individuals with disabilities registered with e-SUS Primary Health Care in 2024<sup>(7)</sup>. The services that make up the network in question are Family Health Team (ESF), multiprofessional extended clinic, Children and Youth Psychosocial Care Center (CAPSIJ), Rehabilitation Center (CREAB), Integrated Health Care Center (CAIS), and Association of Parents and Friends of the Exceptional (APAE).

This experience report was organized to produce relevant knowledge that can be applied in different contexts and is structured as follows: 1) Starting points; 2) Initial questions; 3) Recovery of the process experienced; 4) Background reflection; and 5) Points of arrival<sup>(8)</sup>. Based on this systematization, the experience report incorporates a detailed, critical, and reflective analysis of the practice carried out<sup>(8,9)</sup>.

In the context of systematizing experience, the starting point is the practical experience itself, whether it is an intervention, a project, or an activity carried out by a group or organization<sup>(8)</sup>. It is from this experience that the

systematization process begins, seeking to understand its elements, dynamics, and results. The initial questions are those that guide reflection on the lived experience and direct the systematization process. They can address aspects such as the objectives of the experience, the methods employed, the challenges encountered, the strategies implemented, and the outcomes achieved. These questions help guide the analysis and retrieval of relevant information<sup>(8)</sup>.

The recovery of the lived process refers to the stage in which the experience is reconstructed, revisiting the events, the stages, the decisions made and the actions carried out along the way by the protagonists, adopting the narrative textual type, without interpretative comments or explanations of the events that occurred. Background reflection is a deeper, more critical analysis of experience, seeking to understand its causes, impacts, and broader meanings. Involve the identification of trends, contradictions and learning that emerge from experience, as well as the connection with relevant theories, concepts and approaches<sup>(8)</sup>.

The end points are the conclusions and lessons learned from the systematization process. They represent the primary recommendations and lessons learned that can inform future practices, influence policies, or contribute to knowledge in a specific area. These endpoints are the result of analysis and reflection on the lived experience<sup>(8)</sup>.

This experience report was not submitted to the Research Ethics Committee, since no

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individual was approached as a research subject and only the management processes of the RCPD were described.

#### **RESULTS**

The starting point for the experience report was the lack of coordination between the points of care, which led to the need to establish and regulate care flows, build mechanisms that would provide epidemiological information on the region covered, promote inclusive practices for people with disabilities, guarantee new vacancies in specialized services, and resolve the pent-up demand that had existed for more than two years in the municipality of Lagoa Santa, Minas Gerais. When evaluating health services, it is essential to observe how they function and identify areas for improvement through their demands, work processes, and, above all, the results they produce. This enables improvement in the quality and effectiveness of care, ultimately leading to enhanced levels of well-being for the population.

The initial questions that will guide the discussions and provide a systematized structure for the process of restructuring the RCPD in the municipality of Lagoa Santa were: What management actions are needed to restructure the RCPD in the city? Which stakeholders could be involved in the process of restructuring the RCPD?

To reconstruct history and recover the process experienced in the management sphere, three fundamental actions were taken to

restructure the RCPD: 1) setting up a new health service to care for people with disabilities, 2) implementing flows/instruments to regulate cases for the new service, 3) adapting existing services in the network to follow the new restructured model.

The installation of a new health service for people with disabilities within the RCPD was the most urgent measure for restructuring the network. Therefore, CAIS was established to meet all the municipality's pent-up demand, which, at the time, in September 2022, was close to 200 referrals.

To set it up, it was necessary to define the relevant strategic planning, choose and adapt a building to house the service in question, obtain licenses and authorizations in accordance with legal requirements related to the provision of health services, allocate financial resources, necessary human resources, infrastructure/equipment, and finally define criteria and schedule evaluation and monitoring of the service's performance.

During the process of setting up the CAIS, we sought to comprehensively research and analyze the real needs of the target public. To this end, several meetings were held with people with disabilities and their families to listen to them and understand the barriers they face when accessing existing health services. Through this collaborative perspective, focused on the person rather than the disability, it was possible to establish an inclusive and sensitive health service, thereby offering equal access to quality care and humanized assistance at CAIS.

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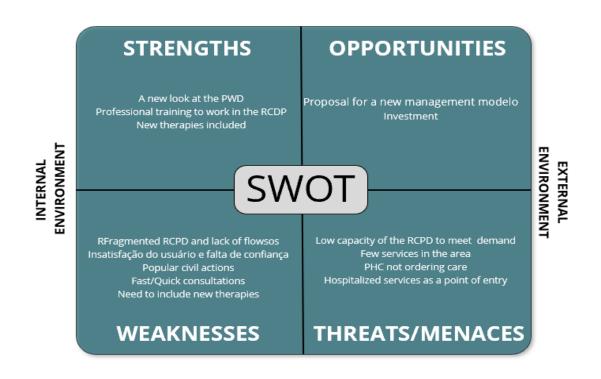


Then a Working Group (WG) was appointed to manage the installation of the CAIS, comprising a multidisciplinary team that enriched and consolidated the success of the work from different perspectives on the same object of study. Participating actively in the WG were the professionals who would take over the management of the new service (coordination and technical reference), the professionals selected to be part of the new service team, and the technical reference of the municipal policy for People with Disabilities. The professionals involved in the WG had extensive expertise in the RCPD or RAS (nurses, occupational therapists, social workers,

speech therapists, physiotherapists, doctors, psychologists, and psycho-pedagogues), as well as training or specialties in caring for people with disabilities. It should also be noted that two members of the WG are mothers of children with atypical needs and share their experiences as both managers and users of the RCPD.

After meetings with the families and the WG, the SWOT matrix was drawn up with a summary of the factors pointed out about the RCPD in terms of strengths, weaknesses, threats, and opportunities, considering the internal environment of the network and the external environment (Figure 1).

**Figure 1** - SWOT (Strengths, Weaknesses, Opportunities and Threats) – matrix to present the factors related to the internal and external environment of the Care Network for People with Disabilities, Minas Gerais, 2024.





## **DISCUSSION**

Living with a disability can be evaluated as an item of social exclusion and absence, be it from the family, the government, or rights. Terms such as people with disabilities, handicapped people, special people, people with special needs, incapable people, defective people, are used repeatedly as terms capable of labeling human beings in preconceived concepts over time<sup>(10)</sup>. The vocabulary used is more than just a means of communication; it influences the thoughts and conceptions of health professionals and society<sup>(10)</sup>. Through this language, it is possible to interpret the everyday problems faced by people with disabilities, who are marginalized and made impossible even in health services<sup>(11)</sup>.

The reorganization of the RCPD in the municipality of Lagoa Santa, in Minas Gerais, represents an integrated strategy to meet the historical and current demands of this group, in line with the principles that guide the Brazilian Unified Health System (SUS). Universality, one of the doctrinal pillars of the SUS, aims to guarantee unrestricted access to all citizens, including people with disabilities. However, practical implementation faces considerable challenges, because although the incorporation of the needs of this population has undergone some progress in public policies, practice still has significant gaps in terms of the integrality and equity of care<sup>(11)</sup>.

Over time, it becomes apparent that the SUS was not designed with the needs of the disabled population in mind, and that this group may not have had a voice in planning services

that were equitable to society<sup>(6)</sup>. It's worth noting that the lack of participation by all actors in the decision-making processes prevents their potential and weaknesses from being discussed and addressed from the various perspectives of a healthcare network<sup>(6)</sup>. Studies conducted in different regions of Brazil yield converging results, suggesting that Care Networks for People with Disabilities are unable to fully comply with current regulations<sup>(5,6)</sup>.

Therefore, in Lagoa Santa/MG, there was a need to implement current public policies that establish guidelines for the care of this specific population, in addition to strategies aimed at establishing effective communication between the services in the network, and consequently, humanized and qualified care within the municipality's RCPD.

The Health Care Networks, in their organizational structure. must necessarily support care for people with disabilities, integrating this care consistently into Network's own structures, considering different regional and territorial situations, and aiming to ensure that each reality guides healthcare and prioritizes individualized therapeutic projects. In this way, it is possible to promote equity, comprehensive care and the characteristics and challenges of each territory<sup>(12-)</sup> 14)

During the process of setting up the new service, we tried to shed light on users' experiences and perceptions of the quality of care received at the RCPD, intending to minimize the main challenges reported, such as



the difficulty of access related to the waiting time to start rehabilitation, fragmentation of care, lack of preparation of professionals, and scarcity of information.

Studies indicate that the main criticisms from users are the difficulty of accessing specialized services, the fragmentation of care. which compromises the continuity effectiveness of treatment, as well as the lack of training among professionals. These authors, corroborating the scenario in the municipality in question, suggest that to improve the quality of care, it is necessary to strengthen integration between the different levels of care and promote continuous training of the professionals involved, to ensure that care for people with disabilities meets their needs in a comprehensive and resolutive manner<sup>(14)</sup>.

Care for people with physical disorders or disabilities in the municipality of Lagoa Santa provided **ESF** by the teams, Multiprofessional Extended Clinic, the Child and Youth **Psychosocial** Care Center. Rehabilitation Center, and the CAIS, as well as by other services in the municipal network. Today, the Association of Parents and Friends of the Exceptional (APAE, acronym in Portuguese) is part of the network, responsible for the **Specialized** Rehabilitation Service for Intellectual Disability (SERDI, acronym in Portuguese) and the Advanced Early Intervention Program (PIPA, acronym Portuguese)<sup>(4)</sup>. The new CAIS service has applied to be qualified as a Specialized Rehabilitation Center (CER, acronym in Portuguese) in its Health Microregion and is awaiting the outcome of the process.

Setting up quality rehabilitation services requires careful planning and attention to a range of factors. The creation of CERs is a significant initiative aimed at improving access to and the quality of services. These centers offer diagnosis, treatment, and rehabilitation in multiple modalities (hearing, physical, intellectual, and visual), meeting a considerable demand from the population. According to the Ministry of Health, new centers are being established with significant investments to serve a larger number of people with disabilities<sup>(12,13)</sup>.

The CERs have proved successful in offering comprehensive and specialized care. However, these centers must be part of an articulated care network, guaranteeing continuity and integrality of care. The management of these services must consider the specificity of each rehabilitation modality and the needs of patients, promoting social inclusion and quality of life<sup>(12,13)</sup>. In Brazil, the rehabilitation services that comprise the RCPD face significant challenges, particularly in terms of providing quality services and ensuring the appropriate training and distribution of professionals. Recent studies have shown that continuous training and capacity building are essential for delivering high-quality care and ensuring patient satisfaction. Rehabilitation professionals must have a combination of technical skills and interpersonal skills. **Empathy** and communication skills are fundamental humanized care, as is ongoing training through



continuing education programs and in-service training<sup>(11)</sup>. In the management and implementation of rehabilitation services, efforts must continue and be collaborative among the government, health management professionals, professionals from RCPD services, as well as with the strong participation of civil society.

The study, entitled "Rehabilitation in South India", evaluated the rehabilitation scenario in South India, highlighting the challenges and advances in this field. The authors analyzed the interplay between cultural, social, and economic factors that influence access to and quality of rehabilitation in the region. The study addresses how inequalities in the distribution of resources and the lack of specialized professionals affect the effectiveness of health services for people with disabilities. Finally, the authors suggest that rehabilitation in India can benefit from greater policy attention and targeted investments, especially populations in rural and marginalized areas. The research concludes that to ensure equity in access to rehabilitation care, structural reforms and more investments in infrastructure and training are needed. This reality has also been observed and reported by studies carried out in Brazil<sup>(15)</sup>.

The successful experiences presented in this study can contribute to the literature by improving the implementation of the RCPD in other scenarios, as they describe actions and decision-making processes involved in implementing and restructuring the RCPD within the municipality.

Literature enables us to observe the face of inequality experienced by people with disabilities in their daily lives. This is evident in the precarious scenario of the RCPDs studied, characterized lack by a of coherent epidemiological data, low coverage of rehabilitation services, care fragmentation, a failing health system, diminishing financial resources, limited human resources, and inadequate professional training<sup>(15)</sup>.

It was found that managerial efforts aimed at implementing or restructuring a quality PCRD must be based on a patient-centered and integrated approach, adapting in an essential way to the specific needs of everyone. In addition to physical infrastructure, ongoing training and continuing education for professionals are also necessary. Aiming for humanized care, technical competence, and effective communication between the network's points of care.

## FINAL CONSIDERATIONS

The RCPD in the municipality of Lagoa Santa/MG (Minas Gerais) had weaknesses that led to the need for coordination between health services to meet the growing demand for people with special needs on the margins of the SUS. Thus, the successful implementation of management actions led to better coordination of the network and the absorption of all surplus demand that had previously been excluded. To achieve success in the actions carried out, articulating and listening to the wishes of the PCD, as well as their families and the health

professionals who provide direct assistance to users, has led to the development of more assertive measures in this process.

Among the management measures taken were the creation of a new specialized service for the RCPD, the implementation of an assessment tool that allowed for more targeted referrals to the PCD's demands, and investment in more open and permanent channels for actively listening to the needs of users and their families. This report makes a significant contribution to the practice of managing Care Networks for People with Disabilities, since it a parameter of successful serve as experiences that have contributed to restructuring of a previously fragmented network, pointing to paths and directions that can be followed for equal access to health for a population that is constantly marginalized.

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# **Authorship Criteria (Author Contributions)**

Amanda Rezende Silva de Oliveira and Maithê de Carvalho e Lemos Goulart contributed substantially to all stages of the study, including: (1) study conception and/or planning; (2) data collection, analysis, and/or interpretation; (3) writing the manuscript, critically reviewing it for relevant content, and final approval of the version to be published. The remaining authors participated in the discussion of the results, contributed to the critical review of the content, and approved the final version of the manuscript.

# **Conflict of Interest Statement**

Nothing to declare. The authors declare no financial, political, institutional, or other conflicts of interest related to this study.

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