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COMPREHENSIVENESS IN THE CARE NETWORK REGARDING THE CARE OF THE DISABLED PERSON

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ABSTRACT

Objective: to analyze the implications of the Care Network for the Disabled Person with Disabilities within the Unified Health System.

Method: it is a reflection study based on recent policies and literature related to the theme.

Results: the structural changes change the care flow, as well as point out abilities for the professionals who work in the care points. The articulation of these care points is considered the principle for the system to function in an integrated way, in order to ensure the comprehensiveness of the care provided for people with disabilities. On the other hand, in the fields of practice, the persistent disarticulation of these components is still observed because they are limited to caring for people with disabilities in their own areas of activity. It was based on the National Policy on the Health of People with Disabilities, guiding the institutional and home rehabilitation actions, which assures these people access to comprehensive, interdisciplinary and intersectoral care and assistance, essential to the process of rehabilitation and social inclusion.

Conclusion: it is concluded that this reflection represents a contribution so that the professionals who work in the area are better guided regarding their competencies, responsibilities and fundamental actions with the users of the network.

DESCRIPTORS: Primary health care. Disabled people. Rehabilitation services. Public health policies. Nursing care.

INTEGRALIDADE NA REDE DE CUIDADOS DA PESSOA COM DEFICIÊNCIA

RESUMO

Objetivo: analisar as implicações da Rede de Cuidados da Pessoa com Deficiência no âmbito do Sistema Único de Saúde.

Método: trata-se de um estudo de reflexão pautado nas políticas e literatura recente relacionada ao tema.

Resultados: as mudanças estruturais alteram o fluxo de atendimentos, bem como apontam competências para os profissionais que atuam nos pontos de atenção. Considera-se a articulação desses pontos de atenção como princípio para que o sistema funcione integrado, de forma a assegurar a integralidade do cuidado às pessoas com deficiência. Em contrapartida, nos campos de prática, ainda se observa a persistente desarticulação desses componentes por se limitarem a prestar cuidados às pessoas com deficiência isoladamente em seus espaços de atuação. Pautou-se na Política Nacional de Saúde da Pessoa com Deficiência, norteadora das ações de reabilitação institucional e domiciliar, que assegura a essas pessoas acesso a cuidados e assistência integral, interdisciplinar e intersetorial, essenciais ao processo de reabilitação e inclusão social.

Conclusão: conclui-se que essa reflexão representa uma contribuição para que os profissionais que atuam na área sejam melhor orientados sobre suas competências, responsabilidades e ações fundamentais junto aos usuários da rede.

DESCRIPTORIOS: Atenção primária à saúde. Pessoas com deficiência. Serviços de reabilitação. Políticas públicas de saúde. Cuidados de enfermagem.

INTEGRALIDAD EN LA RED DE CUIDADOS DE LA PERSONA CON DISCAPACIDAD

RESUMEN

Objetivo analizar las implicaciones de la Red de Cuidados de la Persona con discapacidad en el ámbito del Sistema Único de Salud.

Método se trata de un estudio de reflexión pautado en las políticas y literatura reciente relacionada al tema.

Resultados los cambios estructurales alteran el flujo de atención, así como apuntan competencias para los profesionales que actúan en los puntos de atención. Se considera la articulación de esos puntos de atención como principio para que el sistema funcione integrado, a fin de asegurar la integralidad del cuidado a las personas con discapacidad. En cambio, en los campos de práctica, aún se observa la persistente desarticulación de esos componentes por limitarse a prestar cuidados a las personas con discapacidad aisladamente en sus espacios de actuación. Se basó en la Política Nacional de Salud de la persona con discapacidad, orientadora de las acciones de rehabilitación institucional y domiciliar, que asegura a esas personas acceso a cuidados y asistencia integral, interdisciplinaria e intersectorial, esenciales al proceso de rehabilitación e inclusión social.

Conclusión se concluye que esa reflexión representa una contribución para que los profesionales que actúan en el área sean mejor orientados sobre sus competencias, responsabilidades y acciones fundamentales junto a los usuarios de la red.

DESCRIPTORES Atención primaria de salud. Personas con discapacidad. Servicios de rehabilitación. Políticas públicas de salud. Cuidados de enfermería.

INTRODUCTION

In Brazil, in 2010, the highest incidence of all types of disabilities was recorded in the population aged 65 years old or over, demonstrating the close relationship between the aging process and the consequent loss of functionality. This situation requires the implementation and subsequent expansion of the rehabilitation services network to meet the increasing demand of the Brazilian population, both for the elderly and people with some type of disability.¹

Given this scenario, 23.9% have at least one of the disabilities: visual, auditory, motor, mental or intellectual, being in the first place the visual disability, affecting 18.6%; in second place is the motor disability, occurring in 7.0%, followed by the hearing disability, in 5.10%; and the mental or intellectual disability, in 1.40%.²

Rehabilitation is the area responsible for enabling the training of new skills to the people who use them, making it possible to cope with everyday obstacles. It is to rehabilitate and enable someone again for something that has been lost, and for that, the work of a multidisciplinary team, involving professions from the most diverse areas - human, biological and exact - is essential.³

In the Brazilian reality, public health rehabilitation services are still characterized by the fragmentation and discontinuity of care. As a result of weaknesses in the articulation between the managing bodies of the system, the management of the services and the professional teams that work directly with the client,⁴ it is necessary to consider the urgency in the organization, planning and execution of interventions based on the guidelines of the care network.

Adverse reality to what was proclaimed in the Brazilian public health policies, considering the role of the Primary Health Care (PHC) as a gateway to the network system, coordinating interventions at the first level of care and proceeding to the other care points of the care network of the disabled person. Integration that will favor the coordinated management of care, promoting comprehensiveness to its users, articulation of health promotion actions and prevention, treatment and rehabilitation of diseases and injuries.⁵

In order to revert this fragmentation and discontinuity of the care and assistance provided to the population, the reorientation of the health care model in Brazil has as its main strategy the structuring of a primary care network based on the Family Health Strategy (FHS), which covers the population's health needs.⁶

According to the National Policy on the Health of People with Disabilities, the care provided to these people should be based on the assumption that, in addition to the need for specific health care due to their own condition, these individuals can also be affected by common diseases and injuries that are common to the others, needing, therefore, other types of services beyond those strictly related to their disability. Thus, the health care provided to the disabled person cannot only occur in specific rehabilitation institutions, it must be ensured throughout the Brazilian Unified Health System (*Sistema único de saúde-SUS*) service network.⁷

A study conducted in the United States⁸ pointed out guidelines offered by nurses to spinal cord injury patients and their families about home care, with a focus on the gradual functional autonomy for self-care and overcoming challenges for independent living.

The search for knowledge on the complexity that involves the care and the comprehensive assistance of the disabled person has been registered in several countries. In Germany⁹ a study was carried out to improve the instruments for the evaluation of the length of stay of patients with incapacitating neurological injury hospitalized in specialized hospitals with a view to referral to specialized rehabilitation services. Also relevant, a study aimed at identifying better interprofessional actions of rehabilitation teams was carried out in Canada,¹⁰ or a study aimed at evaluating the quality of health and primary care services carried out in five regions of Italy,¹¹ corroborate the need to increase the knowledge regarding the demand for care and rehabilitation of people with disabling neurological damage. These are examples of studies that confirm investigations with similar themes in the international academic community, focused on the care, assistance, rehabilitation and social inclusion of people with disabilities due to incapacitating neurological damages.

This article aims to reflect on the implications of the implementation of the Care Network of the Person with Disabilities in the scope of the Unified Health System, considering the structural changes that change the care flow and skills of the professionals who work in the care points,¹² which are: Barriers for the implementation of the Care Network for the Disabled Person; The (dis)articulation of the teams of the Primary Health Care with the Care Network for the Disabled Person; Barriers in the scope of the hospital network management and reflexes in the (dis)continuity of the care provided to the disabled person. Thus, each of them will be described below:

Barriers for the implementation of the Care Network for the Disabled Person

Among the guidelines defined in Article 2 of the ordinance 793/2012, emphasis is placed on section IV, in which the access and quality of services are guaranteed, offering comprehensive and multiprofessional care, under the interdisciplinary logic. It is frequent the debates among the Primary Care teams about the professional abilities that are necessary for people with disabilities to be guaranteed their access rights to these services with quality, above all, with regard to the interdisciplinary interface.¹²

Although approved after long discussions and agreements between managers and their representatives in the Municipal Interagency Committees, there is little repercussion in relation to the professional teams that work in the network's attention points. Despite the determination of comprehensive care to be provided to the disabled person, the

non-delimitation of professional competencies for this and failure to carry out multiprofessional work implies their non-fulfillment. As a result, those most affected will inevitably be the disabled people who are not even able to schedule a screening and users of rehabilitation programs. The comprehensive and multiprofessional care end up being limited to the theoretical-idealist-legal perspective.¹³

It is challenging what is pointed out in subsection III of Article 3 of the ordinance 793/2012, which defines the general objectives of the network, offering a guarantee of articulation and integration of the care points of the health networks in the territory, qualifying the care through the embracement and classification of risk. In a simple visit to the available care points, either as a user in search of service or as an observer of community associations, it is possible to see that their teams act (dis)articulated, and they do not even know about the existence of the network or other care points.¹³

At this pace, the integrated articulation of the health care points of the same area, in the scope of SUS, is definitely not happening, most likely due to the same difficulties mentioned above. Each care point acts exclusively in its space, as limited and isolated from the others. In addition, the health professionals who make up their teams do not interact with the other teams to care for the target population (people with disabilities) in relation to aspects that escape from what is usually conditioned by the routines of the sectors/services where they work.¹³

The expectation of public managers should be focused on the goal, which is to be able to structure a group dedicated to the care of the disabled person, to study the territory, involving health professionals, leaders and local residents. The invitation must be made through the explicit intention of knowing the place in order to better elaborate health actions, and their participation will certainly bring more acuity, adequacy and strength to future actions.¹⁴

The (dis)articulation of the teams of the Primary Health Care with the Care Network for the Disabled Person

Another point that needs further reflection is contained in items I and II, of Article 11, of the ordinance 793/12, which deals with the Care Network for the Disabled Person, which should be organized in the scope of Primary Care, Specialized Care in Auditory, Physical, Intellectual, Visual, Ostomy and Multiple Deficiency Rehabilitation, Hospital Care and Urgency and Emergency.¹²

The ordinance 4,279/2010 establishes guidelines for the organization of the Health Care Network (HCN) within the scope of SUS, and recognizes the undeniable and representative achievements of SUS in recent years. However, it is increasingly evident the difficulty of overcoming the intense fragmentation of health actions and services and qualifying the care management in the current context. In this ordinance, the HCN is defined as organizational arrangements of actions and health services, of different technological densities, which integrated through technical, logistical and management support systems, seek to guarantee the comprehensiveness of care.¹⁵

Therefore, it is important to point out that the organization of the HCN requires the definition of the health region, which implies the demarcation of the geographical limits and the population, as well as in the establishment of the set of actions and services that will be offered in the health region. The competencies and responsibilities of the care points in the comprehensive care are correlated with a population-based coverage, accessibility and scale for the formation of services. The proper definition of the regions coverage is essential to inform the organization strategies of the HCN, and the pacts between the State and the municipality must be observed for the process of regionalization and parameters of the scale and access.¹⁵

In addition, the ordinance 4,279/2010 discusses the community guidance, recommending that Primary Health Care use clinical, epidemiological, social and evaluative skills in order to complement the adjustments made in the programs so that they meet the specific health needs of the defined population. In order to do so, it is necessary to define and characterize the community, identify their health problems, modify programs to address these problems, and monitor the effectiveness of program modifications.¹⁵⁻¹⁶

From this point of view, it is important to point out that the primary care has emerged to respond to the broader vision of health needs. All the ethical problems and challenges emanate from the work processes and the organization of the system to respond to these needs in a particular territory and environment.¹⁷

At the juncture of the Pan American Health Organization, the PHC is a strategy to organize the Health Systems in order to provide universal access to services and comprehensive, systematic and articulated care over time. At this point, the universal access to services should be understood

as ensuring that people with disabilities will have comprehensive coverage, including comprehensive care, for their long-term care and care needs predictable in rehabilitation programs.¹⁶

The premise of the ordinance 4,279/2010 has emphasized the community guidance, however, it does not contemplate details so that the actions and services of the PHC provide valuable clarifications on accessibility, appropriateness of the environments, rehabilitation programs, protection, among other information that are relevant to people with disabilities or reduced mobility of their specific health regions. Therefore, a great opportunity to strengthen the HCN beyond the theoretical dimension is lost, at least as far as the topics of assistive technology are concerned and that are of great interest to this group of the population.¹⁵⁻¹⁸

On the other hand, the Family Health Support Centers (FHSC), in accordance with the ordinance 2,488/2011, were created with the objective of broadening the coverage of primary care actions, as well as their resolubility.¹⁹

It is known that the FHSC, in theory, has been considered a fundamental component to enhance the comprehensiveness of care, the resolubility of primary health care and also of SUS, intervening in the culture of unnecessary referrals, promoting the discussion about the training of health professionals. The FHSC should also contribute to evidence of bottlenecks in the health system. There is a contestation regarding the care points, since their teams are rarely integrated with the family health teams, besides not being integrated with the other teams that make up the Care Networks.²⁰

This is a distorted reality, since the FHSC professionals would effectively have to discuss cases, the joint care or not, interconsultation, joint construction of therapeutic projects, permanent education, interventions in the territory and health of population groups and the community. A set of intersectoral actions, actions of prevention and health promotion, discussion of the work process of the teams, among other functions. All the activities can be carried out in basic health units, health centers or in other parts of the territory.¹⁹⁻²¹

From this point of view, a simple supervision of managers to develop production reports at the care points of the Primary Care network, taking as a reference the activities developed by the FHSC teams, may be sufficient to reveal the lack of objectivity, lack of systematization, records, documentation and files of the cases served by the FHSC, as well as their

referral to other network teams so they can provide continuity of care and comprehensive assistance to the people in the community. It is suggested that the members of these teams have not yet understood exactly what is their role in the Primary Care scenario, due to the distance between the official guidelines and the demands presented by the people in the communities, however, it is evident the need to include these people in the area.

There are those who recommend the need for further studies on this reality for the improvement of the academic training and professional performance in the area, contributing to the implementation of the FHSC. Similarly, there are those who defend the thesis that there is a fragmentation of the work processes, the fragmentation of relations between different professional backgrounds, and the precarious formation of the different professional categories, which are generally distant from the debate and formulation of a health policy, as extensive problems in the different areas of the Brazilian public health.^{14,21-22}

There is no escape from the understanding of rehabilitation as a unique process, which seeks to develop people's potential and lead them to a life with health, well-being and a better level of autonomy. However, this comprehensive vision, which seeks to put together rehabilitation and quality of life, is relatively recent within the public health services. For a long time, rehabilitation and physiotherapy for both clients and managers were considered synonymous, and this contributed to the non-availability of other resources and therapeutic interventions. Currently, there is a more totalitarian view of the user of rehabilitation programs, associated with harmonious interdisciplinary work, which opens the way to a more comprehensive and favorable therapeutic response in the treatment of these people.²³

The coping with the sequelae imposed on people with acquired disabilities requires overcoming several aspects, starting with emotional, social, cultural, self-esteem, sexuality, body image, among others, causing the person to reflect on the true sense of existence itself. These are decisive moments for rehabilitation teams to implement therapeutic actions outside institutions, considering that they are people who demand long-term care at home.²⁴

Also relevant for the Network of Care Network for the Disabled Person, it is worth mentioning items I and II, of Article 1, of ordinance No. 963, of May 27, 2013, which define the scope of Home Care within SUS, through which it is possible to

form an idea about this new modality of professional performance. According to what is stated in item I, home care must be conceived as a new modality of health care, replacing or complementing those already existing, characterized by a set of actions to promote health, prevention, treatment of diseases and rehabilitation provided at home, with guarantee of continuity of care and integrated into health care networks.²⁵

In addition, the statement of item II, of the ordinance no. 963/2013,²⁵ clarifies that the Home Care Service (HCS) is a substitute or complementary service to the hospitalization or outpatient care, responsible for the management and operation of Multiprofessional Home Care Teams (MHCT) and Multiprofessional Support Teams (MST), being the MHCT classified into two types: type 1, which are those that make up the HCS in the municipalities >40 thousand inhabitants; and type 2 those that make up the HCS in municipalities with a population between 20 thousand and 40 thousand inhabitants.²³ It is worth remembering that Home Care is not explicitly included as a component of the Care Network for the Disabled Person according to the ordinance 793/2012, since this modality of complementary or substitutive service is included as a component of care of the Care Network to Urgencies and Emergencies defined in Article 4 of the ordinance No. 1,600 of July 7, 2011.²⁴

However, Article 3 of the ordinance 963/2013 defines that home care aims to reorganize the work of the teams responsible for home care, whether primary care, outpatient and emergency hospital services. The Article 5 of the same ordinance also establishes that these services should be structured in the perspective of the health care networks, with the primary care as the defining factor for care and territorial action.²⁵

Still on the actions of the Primary Care for people with disabilities, the SUS National Relation of Actions and Health Services points out that it is up to this level of attention, more specifically on the actions to be taken at the level of Home Care, actions and responsibilities that are characterized by promoting the adaptation of the patient to the use of orthoses/prostheses, tubes and ostomies. In addition to promoting the rehabilitation of people with permanent, transitional or continuous disability, until they are able to attend the rehabilitation services.^{12,26}

Barriers in the scope of the hospital network management and reflexes in the (dis)continuity of the care provided to the disabled person

By the way, the Hospital and the Urgency/Emergency Care, as part of the Care Network for the Disabled Person, needs to fit and demonstrate adherence to this program, considering the importance of its articulating role with the other care points of this Network, prioritizing the early intervention of people with incapacitating neurological damage in the Specialized Rehabilitation Centers, as defined by Article 22 of the ordinance 793/2012.¹²

Thus, the contribution of a study carried out with medical managers and nurses who work in a large hospital in the Zona da Mata Mineira in 2015, which identified their degree of lack of knowledge about the Care Network for the Disabled Person, making it difficult to prepare clients with disabling neurological damage and their referral for early interventions in Specialized Rehabilitation Centers.²⁷

Responsibilities and competencies to take on issues regarding the embracement, risk classification and care in emergency situations involving people with disabilities. Instituting reference teams in rehabilitation in emergency hospital settings linked to pre-disability action, in addition to expanding the access and qualifying the health care for people with disabilities in hospital rehabilitation beds.⁸ The hospitalization/rehabilitation dyad materializes as the professionals who structure and operationalize the care for patients with incapacitating neurological damage transcend the biomedical aspects and signal a practice oriented towards the health care model, which attempts to consolidate it. This model advocates the implementation of a complex chain of care and the vision of the extended clinic in the reach of the cure or in the conviviality with some type of limitation.²⁸

With the implementation of the Care Network for the Disabled Person and the complexity that involves the need for care of people with incapacitating neurological sequelae, the hospitalization/rehabilitation dyad must increasingly refine itself to the materialization of its noblest objective, which is to excel in the comprehensive care of these people, both in their environments and outside institutions.²⁷

Many factors can influence the quality of life after trauma, such as the quality of care offered by the health system, type and severity of injuries, number of surgical interventions, degree of sequelae, pain, access to rehabilitation and socioeconomic status, among others. That is why the preparation

of the hospital discharge of people with incapacitating neurological lesions needs to be more elaborate, planned, so that these people and their families can be adequately guided towards the continuity of the rehabilitation treatment, according to the complexity required by each specific case, in the various care points available in the network.²⁷⁻²⁸

Hospitals that offer programs for counseling and training of family members of people with disabling neurological injuries, even if they have serious functional limitations or the incidence of pressure injury that the person has acquired during the period of hospitalization in these institutions, are rare. Most of them do not even set up scripts for the hospital discharge planning. Thus, many people are discharged from hospital and given to their families without basic guidance on how to deal with home care needs, as well as the continuity of short, medium or long-term rehabilitation treatment to be performed by the teams which make up the care networks, out of the hospital context.²⁷

By the way, transformation processes within human resources are complex and also conflicting, and they may require a long time to be build. However, it is essential that health professionals perceive how their (dis)articulated activities jeopardize the process of rehabilitation of people, so they can take on the ethical commitment to perform their roles in harmony with the other services and care points of the network, prioritizing satisfactory goals for their clients, families, and community. In addition, the incidence of pressure injury in people with neurological sequelae hospitalized in the hospital network increases at an accelerated pace, causing delay in the entry of these individuals into Physical Rehabilitation Programs, as well as impose unforeseen expenditures on the treatment and home evaluation of these injuries, difficulty in accessing technical support, materials and specific guidelines.¹³

However, the Primary Care, more specifically the HCS and FHSC teams, should play an important role in the follow-up of those with physical disabilities, both in the prevention of pressure injury, as well as in the treatment of injuries²³ considering the need to minimize the complications resulting from these impairments.

Another worrying aspect, questionable for what it represents in practice, refers to the one described in Article 20 of the ordinance 793/2012, since the Dental Specialty Center (DSC) is understood as a health facility that offers specialized dental care. Emphasis is given to Article 21, which establishes that the DSCs should extend and quali-

fy the care provided to the specifics of the disabled person who needs dental care.¹²

It is important to emphasize that in the day to day many are the difficulties for the DSC teams to provide care of the disabled people in a satisfactory way, especially to those with severe neurological sequelae, who need dental treatment under general anesthesia. In the meantime, children, adolescents and adults with lesions due to cerebral palsy suffer from oral infection and gingival diseases, seriously compromising their teeth and oral health, due to the lack of adequate structure and access to provide the service to this population.²⁹ Therefore, since the structure of the DSC does not have highly complex equipment to meet such demand, it is more appropriate to refer them to hospital care teams, aiming at the intersectoral level resolution, as recommended by the Ministry of Health.²⁹

Thus, the lack of materials, equipment and structure for performing surgical interventions, as well as dental professionals qualified to attend this type of intervention, means that few units and teams of the Dentistry Specialty Centers offer highly complex care. Such deficiencies result in frustration for the families, care network teams, as well as a lot of wear and tear on people with disabilities, because it is exhausting to come and go without being able to do the dental treatment that they need so much.²⁹

An example of other conditions that require greater attention to the health of people with disabilities is the study carried out in public hospitals in Greater Florianópolis, which analyzes the assistance provided by health professionals throughout the amputation process. This study indicates that the rehabilitation process is enhanced by the multidisciplinary team, through which the acquisition of the prosthesis and the respective referral to care points should function articulated in a network, being standard in the care and in the way to be covered.³⁰ Also in a study carried out in a public teaching hospital in the southern region of Brazil, the multiprofessional care for the amputees,³⁰⁻³¹ in the process of rehabilitation of the ostomized person, it is emphasized the contributions with the objective of knowing the nursing care provided to the hospitalized people submitted to the intestinal stomial surgery, which concluded that the nursing professional training for the care of people with intestinal stomas happens in a broad way, restricted to the theory. Therefore, it is recommended the involvement of the family in the nursing care, through guidance, support and instrumentation for the long-term care that will be performed at home.³²

CONCLUSION

The Care Network for the Disabled Person is a public policy that was instituted in 2012, so it is understandable that its proposal of integration among the teams that work in the different care points is not yet articulated, which reveals a policy still lacking in attention and investments, both from the structural part, in the sense of better disposing technologies to provide adequate care to this target population, and in the instrumentalization of care professionals, providing training and knowledge about these disabilities.

In this sense, it is suggested a greater investment in the systematic dissemination of strategies involving public health managers, as well as the hospital management spheres, in order to align the discourse, seek cooperation, articulation and consensus, so that the therapeutic actions aimed at disabled clients can be effective elements for transforming the reality. Reality that lacks professionals and teams involved, capable of implementing instruments that can guarantee their access to comprehensive, interdisciplinary and intersectoral care and assistance, which are essential to the process of rehabilitation and social inclusion, for millions of Brazilians who need them.

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