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Children's health care in the care network for people with disabilities in Brazil: a multicenter study

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Abstract The aim of this study was to identify factors associated with early identification of disabilities and developmental follow-up of children in primary health care (PHC) services under the Care Network for People with Disabilities (RCPCD). We conducted a cross-sectional study using data from a multicenter study undertaken in eight states. The data were collected using a structured questionnaire answered by PHC professionals with degree-level qualifications selected using random sampling and stratified by state and municipality. Poisson regression with robust variance was performed for the two outcomes. Of the 1,488 workers in the final sample, 63.6% performed early identification of disabilities and 49% provided developmental follow-up. Family health teams performed early identification of disabilities and follow-up more than traditional model teams, and expanded family health teams provided developmental follow-up more than both these teams. The factors that showed the strongest association with identification and developmental follow-up were profession, working in a family health team and knowledge of the RCPCD.

Key words Primary health care, Disabled children, Health services for persons with disabilities

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Introduction

Historically, health care for children with disabilities in Brazil began with the organization of philanthropic services from a moral and charitable perspective. This model prevailed until the creation of the 1988 Federal Constitution and advent of the country's public health system, o Sistema Único de Saúde (SUS) or Unified Health System, when, albeit fragmented, complementary laws and actions emerged to guarantee access to health care for children and adolescents¹⁻³.

Guided by discussions about care models, the Ministry of Health created priority health care networks with the aim of addressing the fragmentation of care. Many of the key actions directed at child health were assigned to the Rede Cegonha (Stork Network), today called the Maternal and Child Health Care Network. Specific actions directed at care for children with disabilities were tasked to the Care Network for People with Disabilities (RCPCD)4,5.

Actions to promote early identification and intervention for disabilities developed by the RCPCD consist of, among other activities, screening and follow-up of babies and young children according to the 2016 Early Stimulation Guidelines and the normative instrument regulating the RCPCD issued in 2020. These documents state that early identification and developmental follow-up of children are duties of the state and should include the analysis of motor, cognitive, sensory, linguistic and socio-emotional aspects, enabling timely referral irrespective of diagnosis. As a component of the RCPCD, primary health care (PHC) services are tasked with the early identification of disabilities through the provision of good quality antenatal and early childhood care and follow-up of high-risk newborns during the first two years of life^{4,6,7}.

Few qualitative studies or experience reports addressing the follow-up and care of children with disabilities in PHC have been produced in recent years. This reveals a scarcity of information about actions, especially those geared towards the different dimensions of child development, and potential factors associated with the provision of this aspect of care in the care network8,9.

This study therefore aims to identify factors associated with the early identification of disabilities and developmental follow-up of children in PHC in Brazil.

The findings of this study can contribute to improving surveillance by PHC teams to identify changes in neuropsychomotor development and the need for ongoing follow-up by specialists, minimizing the risk of functional impairment among these children6.

Methods

We conducted an analytical cross-sectional study using data from the multicenter study "Avaliação da Implantação da Rede de Cuidados Integral à Pessoa com Deficiência no SUS - Redecin-Brasil" (Evaluation of the Implementation of the Care Network for People with Disabilities in the SUS - Redecin-Brasil)10.

The Redecin-Brasil study was undertaken in eight states representing Brazil's five regions: Paraíba (PB) and Bahia (BA), in the Northeast; Amazonas (AM), in the North; Mato Grosso do Sul (MS), in the Midwest; São Paulo (SP), Minas Gerais (MG) and Espírito Santo (ES), in the Southeast; and Rio Grande do Sul (RS), in the South.

Three health regions/macro regions with different levels of implementation of the RCPCD were selected in each state, based on the suggestions of state managers of the RCPCD: advanced, moderate and in the early stages. For each region/macro region, state managers were asked to inform a municipality with a large number of RCPCD facilities and one with a small number of facilities, totaling 49 municipalities¹⁰.

The study population consisted of PHC professionals with degree-level qualifications. The professionals were selected and stratified by state and municipality using random sampling in a number proportional to the total number of doctors, nurses and dentists working in expanded family and primary care (NASF-AB)/multiprofessional teams, considering the prevailing PHC organizational models. The ideal sample size was calculated to be 1,709, considering the number of professionals and population of each participating municipality and adopting a margin of error of 1.8% and 95% confidence level.

The following dependent variables were used: (1) early identification of disabilities during antenatal and early childhood care; and (2) developmental follow-up of high-risk newborns during the first two years of life. Using a semi-structured questionnaire, the professionals were asked whether they performed early identification of disabilities using the question "Do you perform early identification of disabilities during antenatal and early childhood care?". Developmental follow-up of children was assessed using the question "Do you monitor high-risk newborns up to two years of age, provide adequate treatment for diagnosed children and support families according to their needs?" The replies "never" and "rarely" were deemed to indicate failure to identify disabilities or follow-up, while the answers "most of the time" and "always" were deemed to indicate identification or follow-up. The questionnaire was prepared based on the Ministerial Order 793/2012 (Ministry of Health) regulating the RCPCD⁴.

The independent variables were personal and professional characteristics (including age, sex and length of time working in PHC in years), permanent education and state. The PHC teams were as follows: 1) Traditional (encompassing traditional model primary care teams, oral health teams, community health workers, mobile clinic teams, multidisciplinary indigenous health teams and others); 2) Family Health Strategy (including family health teams, riverine family health teams and river family health teams); 3) NASF-AB, including expanded teams. Professions were grouped as follows based on the World Health Organization Guide for Rehabilitation Workforce Evaluation, adapted to PHC in Brazil¹¹: nursing/ medical; rehabilitation (including physiotherapists, speech therapists, occupational therapists and psychologists); and others (including dental surgeons, nutritionists, social workers, physical educators and others).

The states were the eight states included in the Redecin-Brasil study. The variable permanent education was assessed using the following parameters: knowledge of the RCPCD in the municipality of work and knowledge of Ministry of Health recommendations to support health professionals in caring for people with disabilities.

The categorical variables are presented using absolute and relative frequencies (%) and the continuous variables are described using medians and interquartile ranges, calculated using the Kolmogorov-Smirnov normality test. We also calculated percentages and confidence intervals for early identification of disabilities and developmental follow-up of children. Poisson regression with robust variance was performed for the following outcomes: (1) early identification of disabilities, and (2) follow-up of high-risk newborns during the first two years of life. To this end, we performed bivariate regression with the variables of interest to calculate crude prevalence ratios (PR) and their respective 95% confidence intervals. Variables that obtained a p-value of < 0.20 in the bivariate analysis were retained in the multivariate model. The input method used was backward stepwise regression. Statistically significant variables (p < 0.05) with the best fit to the model (AIC measure) for each outcome were retained in the final model.

The study protocol was approved by the research ethics committee of the Center for Health Sciences, Federal University of Paraíba (code number CAAE 13083519.3.1001.5188) and other ethics committees from participating institutions in the states.

Results

Only 1,555 PHC workers participated in the study due to logistical difficulties during data collection. There were missing data for certain variables, resulting in a total of 1,488 individuals for the final analysis. Most of the participants were women and the median age was 38 years. The median length of time working in PHC was six years. Table 1 shows the personal and professional characteristics of the PHC workers. Most of the professionals worked in family health teams and were nurses or doctors.

Figure 1 shows the percentage of professionals who reported performing early identification of disabilities and developmental follow-up of children and the respective confidence intervals. The findings show that most workers did not perform follow-up and a large percentage (approximately 36%) reported that they did not carry out early identification. The results also show that not all the professionals who performed identification provided follow-up.

Table 2 presents the data on factors associated with early identification of disabilities in PHC. The results show that the following professionals showed a positive association with early identification of disabilities: those working in family health teams (PR: 1.12; 95%CI: 1.02-1.22), those who provided developmental follow-up (PR: 1.79; 1.63-1.95) and those with knowledge of the RCPCD (PR: 1.09; 1.02-1.16). Rehabilitation professionals (PR: 0.77; 0.61-0.97) and other professionals from multiprofessional teams (PR: 0.52; 0.45-0.60) perform identification of disabilities less than nursing and medical professionals. No association was found between age and years of professional experience and identification of disabilities.

No significant differences in percentages of professionals reporting the identification of dis-

Table 1. Personal and professional characteristics of the PHC workers. Redecin, 2020.

Personal and professional characteristics	n	%	
Age			
< 38 years	756	50.8	
38 years and over	732	49.2	
Sex			
Female	1163	70	
Male	391	30	
Time working in PHC			
< 6 years	778	51.4	
6 years or more	753	48.6	
PHC team			
Traditional model	406	26.3	
Family health	941	61.1	
NASF-AB	195	12.6	
Profession			
Nurse/doctor	984	63.8	
Rehabilitation	125	8.1	
Other	433	28.1	
Identification of disabilities			
Yes	988	63.6	
No	566	36.4	
Developmental follow-up			
Yes	762	49	
No	793	51	
Knowledge of RCPD			
Yes	688	44.5	
No	856	55.5	
Knowledge of Ministry of			
Health recommendations			
Yes	601	38.7	
No	953	61.3	
State			
AM	209	13.6	
BA	297	19.3	
ES	70	4.5	
MG	221	14.3	
MS	174	11.3	
PB	137	8.9	
RS	140	9.1	
SP	294	19.1	

PHC: primary health care. NASF-AB: expanded family and primary care/multiprofessional teams. RCPCD: Care Network for People with Disabilities, AM: Amazonas, BA: Bahia; ES: Espírito Santo, MS: Mato Grosso do Sul, MG: Minas Gerais, PB: Paraíba. RS: Rio Grande do Sul. SP: São Paulo.

Source: Authors.

abilities and developmental follow-up of children were found across states, showing that this variable did not have a direct influence on the outcomes.

Table 3 presents the results of bivariate and multivariate regression performed to assess the factors that influence follow-up of high-risk newborns during the first two years of life. Prevalence of follow-up was lower in the older age group (PR: 0.88; 95%CI: 0.80-0.96) than in the younger age group, and in rehabilitation professionals (PR: 0.71; 0.56-0.80) and other professionals (PR: 0.67; 0.56-0.93) than in nurses and doctors. Family health (PR: 1.47; 1.27-1.71) and NASF-AB/ expanded teams (PR: 1.61; 1.27-2.98) and professionals who perform identification of disabilities (PR: 3.36; 2.72-4.17) and have knowledge of the RCPCD (PR: 1.13; 1.03-1.24) and Ministry of Health recommendations (PR: 1.29; 1.09-13.2) provide developmental follow-up more than traditional model teams and professionals who do not perform identification of disabilities and do not have knowledge of the RCPCD and Ministry of Health recommendations.

Discussion

Overall, the percentage of respondents who reported performing early identification of disabilities (63%) and developmental follow-up (49%) is below expectations, bearing in mind that these interventions are set out in the core strategy Promotion and Follow-up of Growth and Comprehensive Development of the National Child Health Care Policy¹². The results of the National Program for Improving Primary Care Access and Quality (PMAQ-AB) show that developmental follow-up rates in PHC services in Brazil in 2012, 2014 and 2017/18 were 77%, 76% and 87%, respectively¹³. However, these results refer to follow-up of all children, not just children with disabilities or developmental abnormalities. The follow-up prevalence rates found in the present study therefore seem plausible. These rates are inconsistent with the recommendations in the children's care guidelines for the RCPCD, normative instrument and Early Stimulation Guidelines, which emphasize that one of the roles and responsibilities of PHC is developmental follow-up of children. In addition, health professionals and PHC teams should provide surveillance and children's care, which involves monitoring growth and development and promoting the early identification of situations that need ongoing systematic follow-up^{4,6,7}. Is was therefore expected that the vast majority of PHC workers would have been qualified and perform early identification and developmental follow-up.

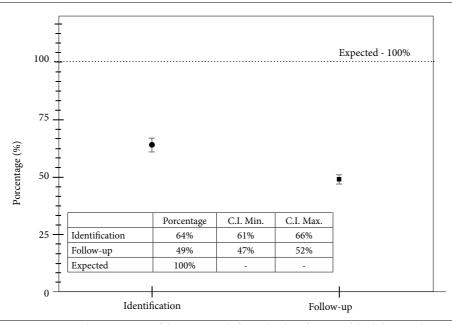


Figure 1. Percentages and respective confidence intervals for early identification of disabilities and developmental follow-up of children.

Source: Authors.

International studies have stressed the importance of early identification of disabilities and developmental follow-up, especially among babies at risk, such as those born preterm or requiring neonatal intensive care, those who suffered hypoxia or anoxia and those with risk of genetic or neurological abnormalities. Early identification of developmental delay in this group is critical and should be performed with all babies at risk, using standardized assessment instruments, such as the Hammersmith Infant Neurological Examination (HINE) and Bayley Scales of Infant and Toddler Development, third edition. The studies recommend comprehensive assessment of child development to identify potential abnormalities and enable early intervention14-16.

With regard to PHC teams, it is important to consider that children's care flows involve initial contact with the family health team or traditional team, and when the need for multiprofessional support is identified the child is referred to the NASF-AB for follow-up⁹. Our findings show that the team that performs developmental follow-up most is the NASF-AB, with a prevalence rate that is 61% higher than that of the traditional team. The NASF-AB plays an extremely important role in PHC, being made up of other profession-

als besides the minimum team, including social workers, physiotherapists, speech therapists and occupational therapists. The work of these professionals focuses on matrix support for specific interventions – consisting of technical-pedagogical and clinical-care support – and collective actions and care coordination. According to the NASF guidance documents, teams perform rehabilitation and disability prevention interventions and provide developmental follow-up of children¹⁷.

In contrast, the prevalence of identification of disabilities is lower in the NASF-AB than in family health teams. This is understandable given that the monitoring of child growth and development in PHC is generally performed by professionals belonging to the minimum team, particularly nurses. A study by Figueiras et al. showed that, in general, the level of knowledge about child development among doctors and nurses from family health teams was unsatisfactory and that they did not use assessment methods to screen for neuropsychomotor problems18. Along the same lines, studies by Van Schaik et al.19 and Gubert et al.20 reported that professionals tend focus on children's height or classic more severe signs of developmental abnormalities, overlooking mod-

Table 2. Factors associated with early identification of disabilities in primary health care services. REDECIN,

Variables	Prevalence I		Bivariate model		Multivariate model*		
	(%)	PR	(95%CI)	р	PR	(95%CI)	р
Age				0.048			
< 38 years	65.9	1					
38 years and over	60.9	0.93	(0.86-0.99)				
Time working in PHC				0.01			
< 6 years	66.6	1					
6 years or more	60.3	0.91	(0.84-0.98)				
PHC team				< 0.001			0.008
NASF	38.5	0.78	(0.64-0.95)	0.02	0.86	(0.70 - 1.08)	0.19
Family health	74.8	1.52	(1.36-1.68)	< 0.001	1.12	(1.02-1.22)	0.02
Traditional model	49.4	1			1		
Profession				< 0.001			< 0.001
Nurse/doctor	80.0	1			1		
Rehabilitation	45.6	0.57	(0.47-0.69)	< 0.001	0.77	(0.61-0.97)	0.03
Other	31.3	0.39	(0.34-0.45)	< 0.001	0.52	(0.45-0.60)	< 0.001
Developmental follow-up	88.6	2.24	(2.05-2.45)	< 0.001	1.79	(1.63-1.95)	< 0.001
Knowledge of RCPCD	68.1	1.14	(1.05-1.22)	0.001	1.09	(1.02-1.16)	0.008
Knowledge of Ministry of	69.6	1.16	(1.08-1.25)	< 0.001			
Health recommendations							
State				0.12			
AM	68.9	1					
BA	60.1	0.87	(0.77 - 0.99)	0.04			
ES	70.4	1.02	(0.86-1.22)	0.81			
MG	59.5	0.86	(0.75-0.99)	0.04			
MS	57.7	0.84	(0.72 - 0.98)	0.03			
PB	64.2	0.93	(0.80-1.09)	0.37			
RS	67.4	0.98	(0.85-1.13)	0.76			
SP	66.1	0.96	(0.85-1.08)	0.51			

^{*} Poisson regression with robust variance. Final model using the backward stepwise method; variables with p < 0.05 were retained. ned in the model. Statistical significance (p < 0.05) in bold. PR: prevalence ratio; PHC: primary health care; NASF-AB: expanded family and primary care/multiprofessional teams; RCPCD: Care Network for People with Disabilities. AM: Amazonas. BA: Bahia; ES: Espírito Santo. MS: Mato Grosso do Sul. MG: Minas Gerais. PB: Paraíba. RS: Rio Grande do Sul. SP: São Paulo.

Source: Authors.

erate or mild cases, which are likely to have high success rates if identified early and in a timely manner. Gubert et al.20 highlight that anthropometric measurements and filling in charts alone are not sufficient for effective child monitoring. This is because, besides the need for a broader perspective of the development process, it is important to consider the educational nature of appointments and communication with the family, which require multiple types of knowledge and multiprofessional teams and are key factors in health promotion.

The findings show that the prevalence of identification of disabilities and follow-up is 23% and 29% lower in rehabilitation professionals (physiotherapists, speech therapists, occupational therapists and psychologists) than among doctors and nurses. This may be explained by traditional practices linked to the biomedical model of health care, in which the identification and follow-up of children is part of care for child development. The latter is limited, for pragmatic reasons, to the follow-up of growth, to the detriment of the observation of the multiple dimensions of development outlined in child health care guidelines, such as motor, cognitive, sensory, linguistic and socio-emotional development²¹.

According to the World Health Organization¹¹, rehabilitation professionals assist people with disabilities to optimize functioning, modifying the patient's home according to their needs and using assistive products or physical, psychological, cognitive and sensory rehabilitation therapies. These workers should therefore

Table 3. Factors associated with follow-up of high-risk newborns during the first 2 years of life. Redecin, 2020.

Variables	Prevalence	Bivariate model		del	Multivariate model		
	(%)	RP	(95%CI)	р	RP	(95%CI)	р
Age				< 0.001			0.004
< 38 years	54.5	1			1		
38 years and over	43.5	0.80	(0.72 - 0.89)		0.88	(0.80 - 0.96)	
Time working in PHC				0.02			
< 6 years	51.9	1					
6 years or more	45.9	0.88	(0.80 - 0.98)				
PHC team				< 0.001			< 0.001
NASF	34.9	1.23	(0.97-1.58)	0.09	1.61	(1.25-2.08)	< 0.001
Family health	60.6	2.14	(1.82-2.52)	< 0.001	1.47	(1.27-1.71)	< 0.001
Traditional model	28.3	1			1		
Profession				< 0.001			< 0.001
Nurse/doctor	61.7	1			1		
Rehabilitation	36.8	0.60	(0.47 - 0.75)	< 0.001	0.71	(0.56-0.80)	< 0.001
Outros	23.4	0.38	(0.32 - 0.45)	< 0.001	0.67	(0.54 - 0.93)	0.01
Identification of disabilities	68.2	4.44	(3.64-5.41)	< 0.001	3.36	(2.72-4.17)	< 0.001
Knowledge of RCPD	55.9	1.29	(1.16-1.42)	< 0.001	1.13	(1.03-1.24)	0.01
Knowledge of Ministry of Health recommendations	59.6	1.41	(1.27-1.55)	< 0.001	1.20	(1.09-1.32)	< 0.001
State				0.03			
AM	49.5	1.00					
BA	41.5	0.84	(0.69-1.02)	0.07			
ES	53.5	1.08	(0.84-1.40)	0.55			
MG	51.4	1.04	(0.86-1.25)	0.70			
MS	45.1	0.91	(0.74-1.13)	0.39			
PB	44.5	0.90	(0.71-1.13)	0.37			
RS	54.2	1.09	(0.89-1.34)	0.39			
SP	55.3	1	(0.94-1.32)	0.21			

^{*} Poisson regression with robust variance. Final model using the backward stepwise method; variables with p < 0.05 were retained in the model. Statistical significance (p < 0.05) in bold. PR: prevalence ratio; PHC: primary health care; NASF-AB: expanded family and primary care/multiprofessional teams; RCPCD: Care Network for People with Disabilities. AM: Amazonas. BA: Bahia; ES: Espírito Santo. MS: Mato Grosso do Sul. MG: Minas Gerais. PB: Paraíba. RS: Rio Grande do Sul. SP: São Paulo.

Source: Authors.

have specific competencies to adequately assess needs²² for early identification of disabilities and follow-up of babies at risk, when compared to other professionals, with the exception of doctors and nurses (minimum team).

Indeed, there is consensus that neglecting the various dimensions of child development encompassed by multidisciplinary care can lead to gaps in the identification of numerous abnormalities that lead to neuromotor and/or neurobehavioral impairments²³. In the same vein, antenatal care provided by the SUS plays a central role in follow-up maternal and children's care and should be delivered by a multidisciplinary team. Follow-up is provided to ensure the prevention or

early detection of neonatal and maternal complications and abnormal fetal development, reduce preterm births, and facilitate intrauterine interventions and other timely interventions²⁴.

In addition to primary issues directly related to child health, gaps in early identification of disabilities, and consequently in the detection of abnormal child growth and development, compromise information and data generation, which help guide the formulation or strengthening of public policies to minimize impairments and health-related problems in children. The failure to identify and monitor disabilities therefore undermines the formulation of public policies, affecting functioning among people with disabil-

ities and generating unnecessary direct and indirect disability-related expenses^{25,26}.

The mitigation of problems and disabilities through timely identification facilitates inclusion at school and in the labor market, directly impacting the quality of life of people with disabilities as they are able to contribute to the economy and society. Ahmed Shahat et al.27 highlight that "the economic burden is shared by the family of the disabled child, public health services and society".

Knowledge of the RCPCD showed a significant association with both identification of disabilities and follow-up. This may be explained by the assumption that when professionals have knowledge of normative instruments and actions in the RCPCD they are more likely to have information about care flows and procedures, coordination, matrix support, and deficiency prevention and identification actions. This information can support work processes, optimizing children's care actions in accordance with prevailing norms and standards and ministerial orders, which is potentially associated with training received due to the efforts and initiative of individual professionals or teams21. The findings also show that prevalence of follow-up was higher among professionals from the younger age group (under 38 years). According to Santos et al.28, younger professionals are more likely to provide developmental follow-up because their training, including professional development and access to children's care guidelines, is more recent. The authors defend that permanent and continuous education is key to improving the quality of care delivered by PHC services.

One of the limitations of this study is the lack of alignment on concepts among researchers and some respondents. However, to mitigate any possible effects of this limitation, the study adopted the standard terms used in the normative instruments that regulate the RCPCD issued by the Ministry of Health and the main concepts were presented in the introductions to the questions. In addition, patient information could be incorporated into the study to provide a broader insight into the problem. However, the study encompassed all five of Brazil's regions using representative samples from each municipality involved and first-hand accounts from professionals working with children's care. Furthermore, it is the first study of its kind to consider aspects related to the identification of disabilities and developmental follow-up of children in PHC.

Overall, considering the importance of timely intervention in situations that require early stimulation and rehabilitation, the results show that PHC teams need to increase the adoption of strategies to identify disabilities and ensure developmental follow-up of children. Doctors and nurses working in family health teams who have knowledge of Ministry of Health recommendations stood out from other professionals in multiprofessional teams. Knowledge of Ministry of Health recommendations to support health professionals in caring for people with disabilities had a positive influence on identification and follow-up. In this respect, it is important to highlight the important role played by the NASF-AB and multiprofessional teams in ensuring the delivery of comprehensive children's health care in primary care services. Finally, future research should explore in detail the work processes involved in the delivery of child health care in primary care services under the RCPCD in order to identify possibilities, actions and strategies that enhance the early identification of disabilities and developmental follow-up of children, and ensure early intervention.

Collaborations

ASGB Mendonça, BLL Oliveira, TG Fernandes and ACB Schmitt worked on the conception and design, analysis and interpretation of data, writing of the article, critical review and approved the version to be published. RB Barroso worked on the analysis and interpretation of the data, writing the article, critical review and approved the version to be published. KSQ Ribeiro worked on data analysis and interpretation, critical review and approved the version to be published.

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