# Continuous Cash Benefit (BCP) for disabled individuals: access barriers and intersectoral gaps

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> **Abstract** The 1988 Constitution approved the Continuous Cash Benefit (BCP) directed to elders and disabled persons with a household per capita income of 25% of the minimum wage, and around 4 million people received this benefit in 2015. The design of BPC for disabled persons involves organizations of social security, social welfare and health. This paper discusses how some intersectoral coordination mechanisms gaps between these areas produce access barriers to potential beneficiaries. Results stem from a qualitative study performed with physicians, administrative staff and social workers from the National Institute of Social Security (INSS) and of the Social Welfare Reference Center (CRAS) in three municipalities of different Brazilian regions. Intersectoral coordination and cooperation are more structured at the Federal level. At the local level, they rely on informal and horizontal initiatives, which produce immediate but discontinuous solutions. The role of the CRAS remains contingent on the implementation. The need to establish institutionalized mechanisms for coordination and cooperation between social welfare, health and social insurance to improve the implementation and reduce barriers to access to the BCP is apparent. Key words Continuous Cash Benefit, Implemen-

tation, Access barriers, intersectoriality, cooperation, Coordination

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## Introduction

The Continuous Cash Benefit (BPC) is a welfare right guaranteed by the 1988 Federal Constitution to elderly persons aged 65 years and over and to persons with disabilities whose family income is up to 1/4 of the minimum wage. With amount equivalent to one minimum wage, it benefited about 4 million people in 2015. Its implementation involves organizations from three social sectors: social security, social welfare and healthcare. In the case of people with physical or mental disability, several barriers hinder access to benefit. Some of them are the result of the poor coordination and cooperation mechanisms between health services, social welfare and social security.

The Ministry of Social and Agrarian Development (MDSA) is responsible for managing, coordinating, regulating, financing, monitoring and evaluating the Benefit, while the INSS is responsible for its operationalization, including recognition of the right and concession, based on medical and social assessments.

In this paper, we discuss how some access barriers faced by people with disabilities in the benefit application process are related to gaps in the coordination and cooperation mechanisms between social security, social welfare and health care. As other social policies, the intersectoral nature of BPC stems from the adoption of advanced normative principles in its design and formulation, but which were not followed in management by coordination mechanisms that enable intersectoral cooperation in the implementation.

The paper is divided into five sections, in addition to this Introduction. In the first, we describe the characteristics of BPC for people with disabilities; then we show the methodology of the research that originated this paper; in the third, we discuss the analytical categories related to the theme; in the fourth, we show some results and, finally, we submit the final considerations.

## BPC for persons with disabilities

Since 1988, definitions of disability for granting the BPC have undergone several positive changes. Until 2007, the concept of disability inscribed in the law was strictly biomedical. Eligibility criteria were based on the concept of disability as an incapacity for independent living and work resulting from bodily anomalies / injuries. Resulting from a strong questioning of the

biomedical model of disability, involving social movements, civil society organizations and international organizations, a new disability assessment model for BPC eligibility was established in 20071 and implemented in 2009. Based on the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF), this new model has considered deficiencies as problems in bodily functions or structures, but within a social and personal context. Functionality and incapacity began to be seen because of the interaction between health states, environmental and socio-familiar contexts and participation in society. Persons with a disability are eligible for the benefit if they have (in addition to a per capita household income of 1/4 the minimum wage) "long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may obstruct their full and effective participation in society on an equal basis with other persons"2. As a criterion of long-term impediment, the law considers the minimum period of two years.

Thus, the evaluation of the applicant for purposes of granting the benefit, in addition to medical examination, incorporated the social assessment carried out by social workers, also from the National Social Security Institute (INSS). It is incumbent upon social workers to assess the component environmental factors - physical and social environment and attitudes - that are barriers to the participation of persons with disabilities in society and some realms of the activities and participation component. The bodily functions component, some realms of the activities and participation component, specific aspects of unfavorable prognosis, impairment of body structure and long-term impairments are assessed by medical expertise.

Despite advances in the conception and operationalization of the evaluation, the granting of the benefit still relies quite a lot on the subjective character implicit in any judgment. It is difficult to define uniform parameters<sup>3</sup> or clear criteria so that each individual is treated in the same way in the application process<sup>4</sup>. This extends to the characterization of the disability degree of the disabled person. The expert evaluation should consider both the severity and its persistence over time, which is fundamental for the granting of benefit and that is not necessarily a concern of the physician who attended that person.

The evaluation also depends on the values, perceptions and even professional bias of those involved in the various stages of the granting process. Diverse values, especially those related to different professional cultures, can hinder communication or involve divergent conceptions about disability. Health professionals involved in the diagnosis of disability, independent living and participation have different understandings, especially when it comes to people with some physical or mental disability<sup>5,6</sup>. There are also differences between medical professionals and social workers. While physicians recognize the importance of social assessment in the granting process, they express greater resistance to this partnership, as well as with regard to BPC objectives<sup>5,7</sup>.

# Research methodology

Data were collected in the second half of 2015 from institutions and stakeholders involved in the formulation and granting process: INSS and MDS national managers, professionals – administrative technicians; INSS medical experts and social workers - and potential beneficiaries, that is, BPC applicants. Although not necessarily participating in the granting process, which is operationalized by the INSS at the local level, social workers of the Social Welfare Reference Center (CRAS) – the municipal unit that is the gateway to the population service - may also have an important role in the referral of potential beneficiaries to the INSS. In order to verify intersectoral coordination/cooperation at the local level, we interviewed a social worker in each selected municipality.

Three medium-sized municipalities (Southeast, Northeast and North) were intentionally selected. Data were collected in agencies with a significant number of professionals working in the granting process and in the high frequency of beneficiaries and granting profiles, indicated by the research contractor. The semi-structured interviews sought to understand, according to the specificity of each segment, perceptions and positions regarding the access barriers related to the study components. INSS professionals and applicants were interviewed at INSS agencies on the days scheduled for the social and/or medical evaluation of the elderly and people with disabilities. CRAS social workers were interviewed at CRAS headquarters. National managers were interviewed via Skype. We interviewed 30 applicants, 15 professionals and 5 national managers.

### Analysis categories

In order to discuss the extent to which access barriers to BPC may be related to cooperation and coordination gaps, we briefly define these categories as they guided data analysis.

### Access

As an analytical category, access has already been widely studied and applied in the areas of health and education, but little in social security and welfare. In social security, access is regulated by participation in the contributory structure. Thus, access problems are more investigated regarding entry in the service, that is, difficulties and facilities that individuals face while requesting a given benefit. In welfare, due to the characteristics of its target population, the investigation of access implies understanding not only aspects related to the moment of application, but also those related to restrictions that precede and involve this request, such as information about the benefit, conditions to request and access the implementing agencies, as well as the values and attitudes of the professionals responsible for the various stages of the evaluation. In the case of people with disabilities, it is important to understand how the relationships between the three sectors involved can facilitate or hinder access.

Access to services involves cultural, geographic, economic, organizational and individual characteristics. In our study, we took access as accessibility – that is, the components that facilitate or hinder access to the care service<sup>8-10</sup>. Accessibility is related to the characteristics of the services that allow their achievement and use, such as organization, geographic availability, ability to pay and acceptability<sup>8</sup>. In addition, access influencing factors are age, gender and values; conditions for arriving at and entering services; needs perceived by the patient or diagnosed<sup>11</sup>.

These factors and realms, originally analyzed for access to health services, can be applied to other social services where there is an explicit need of the individual, as is the case of persons with disabilities who access the BPC. In the research, they were classified into three main components of access: the individual component, the socio-familiar member and the organizational component. In this paper, we specifically discuss the barriers to access to BPC produced by the organizational component. We introduced the

discussion related to intersectoral coordination and cooperation gaps among organizations from different sectors involved in the implementation.

# Intersectoral cooperation and coordination

The establishment of actions to achieve a public policy objective is addressed by political science as a collective action issue<sup>12-14</sup>. This implies that the provision of a public good does not occur voluntarily, but depends on cooperation and coordination mechanisms, without which it is unlikely to achieve sustainable results<sup>15,16</sup>.

In the case of policies or programs with interfaces in different sectors, coordination and cooperation are even more crucial for achieving results<sup>17</sup>. Peters<sup>17</sup> defines coordination as the need to ensure that the various organizations involved in providing some public service together do not produce redundancies or gaps. Coordination levels can be minimal or maximal. At the minimum levels, organizations simply know the activities of everyone involved and try not to duplicate or interfere. At the maximum levels, there are stricter controls over the activities of organizations and means to fill in service gaps<sup>17</sup>. Coordination mechanisms allow the adjustment of intersectoral policies and programs to increase their horizontal interconnections, with the possible sharing of financial sources18,19.

Cooperation is the joint action of a group of individuals to achieve a common goal<sup>14</sup>. It is an interaction between sectors to achieve greater efficiency in their actions, involving the optimization of resources while establishing formalities in labor relationships. Information sharing is the first step for cooperation<sup>18,19</sup>.

Although within a legal – normative – framework, activities related to the implementation of a policy can be organized in different ways. The mechanisms and processes can form different arrangements depending on the local context<sup>15,20</sup>. The way stakeholders engage and create solutions from the rules produces the local forms of implementation.

While dependent on top-down relationships that follow sectoral hierarchies, the implementation of intersectoral policies at the local level may, to a greater or lesser extent, approach horizontal management forms, whose coordination may be more or less loose, and cooperation transcends the boundaries between bodies and organizations. Particularly at the local level, horizontal relationships are responses to implementation processes in which the citizen has to relate

to bodies from different social sectors. Hopkins et al.21 argue that, while diffuse, horizontal management can be a crucial means of managing crosscutting issues related to certain policies or the provision of some services. They may include different types of linkages between stakeholders and organizations involved: informal links facilitating mutual exchanges; coordination to reduce or eliminate overlap and duplication and collaboration through resources, work or decision-making processes are integrated into all organizations involved. Inadequate management mechanisms produce significant barriers, while more appropriate initiatives produce synergies and lessen implementation problems, favoring both implementing agencies and applicants. The following results show barriers to access to BPC related to intersectoral cooperation / coordination gaps.

#### Results

The intersectoral coordination and cooperation gaps will be discussed focusing on the relationships between a) the INSS and welfare and b) the INSS and health.

a) Relationships between the INSS and welfare

Relationships between the social security and the welfare sector can take place within the same federative level, for example between the MDS and the INSS, in the commissions and meetings to address national benefit management; between different federal levels, between INSS national managers and municipal welfare administrators and managers; within the same municipality, between INSS local agencies and CRAS.

More structured intersectoral coordination and cooperation occur at the federal level, between INSS and MDS. Several joint initiatives have been taken in different areas related to the implementation of the BPC, such as in regulation, budget, elaboration of the new evaluation model, in the training of INSS staff and in relationships with the CRAS. As a formal coordination body, a BPC Steering Committee was set up with the participation of MDS and INSS to discuss management problems, decision-making and referral of decisions to technical groups.

The creation of the Monitoring Group for Disability and Incapacity Level Assessment (GMADI) in 2010, made up of MDS and INSS technicians involved in the definition, implementation and monitoring of the BPC grant assessment model, sought to coordinate this area for the implementation of the BPC. The changes in the conception of the evaluation were made in a working group composed by professionals from the MDS and INSS.

MDS normative acts are in place to guide interaction between the INSS and the municipal management in relation to the concession process, but more structured forms of cooperation in the municipalities end up depending on the initiatives of the INSS local agencies' management. Cooperation is usually contingent and not formalized, although attempts have been made to establish covenants by agreement, a process that has not gone forward.

Despite being agreed in the three spheres as part of the decentralized design of social policies, cooperation between the INSS and the socio-welfare network relies very much on the political relationships of the federal government with the municipal government and municipal or even state management. There is no formal instance or legal instrument defining the tasks with the objective of establishing cooperation mechanisms. The interactions and cooperation are informal and the responsibility for this interface is incumbent upon INSS' social service.

Some places have partnered, even without having a formal institutional direction ... [...] So the INSS [...] the agencies talk to the social workers of the CRAS and the municipality. Social workers have a fundamental role in this process and they seek this.... Last year, the MDS made several regional meetings seeking both the INSS and municipal and state servants, etc. Thus, the need for these partnerships was unison [...] However, some municipalities do not want to do that, they do not adhere. 'No, this benefit is from the federal government, and so forth'... and ends with ...'But most certainly want to; we at INSS want to, as it is important for us, because we improve our work, our flow (professional from national management).

Each of the 5,570 Brazilian municipalities is free to adhere to joint management tools and mechanisms among the different federative levels. The party realm, especially when there is no monetary incentive to adhere to federal policies, can be an important barrier to interfederative cooperation. In addition, not all municipalities have INSS facilities, and applicants have to go to other municipalities to apply for the benefit, involving a greater number of stakeholders in intersectoral relationships. In small municipalities, it is easier for INSS and CRAS social workers to cooperate to solve certain issues. This is more complicated

in larger municipalities, also due to problems of staff turnover and greater difficulty in contacting the socio-welfare network.

The need to establish cooperation – generally referred to as "partnerships" or "collaboration" – is consensual between national managers and among the various categories of professionals interviewed in the municipalities. Problems that could be alleviated if INSS and CRAS local agencies cooperated in a more structured way were pointed out by the professionals involved in the implementation of the BPC.

# **Entry information**

The gateway to the request is scheduling for qualification at the social security agency by dialing number 135, a call-center service that provides the first official information on the benefit. Ignoring the rules may be the first barrier. On the day scheduled for the request, the applicant must provide the INSS agency with the documentation of all members of his/her family group to prove income and family composition. However, the family composition adopted by the benefit is not necessarily the same as that of the applicant. Oftentimes, the information given by number 135 is not even understood to allow the applicant to ask questions.

Applicants do not need to go through a CRAS before the first visit to the INSS. However, if they do so, they can receive the proper information. However, not always do CRAS social workers themselves know all the rules. Since CRAS has no formal role or authority in the application and benefit decision process and social workers are often overwhelmed with many other demands; they clarify, refer, and even provide assistance during the application, but this is not a regular initiative. The application process only begins, in fact, at the INSS agency.

Several respondents suggest that CRAS could have some registration mechanism before applicants arrive at the INSS agency. This is because if applicants do not carry the complete documentation when they file the application, they have 30 days to return with requirements met, or the process is rejected. Considering that applicants are people with disabilities, in addition to social and economic vulnerability and that most live far from the centers where the agencies are located, the financial and emotional cost of travel is high.

Both from the point of view of the INSS and the applicant, time and resources are wasted because the organizations involved cannot establish strong inter-organizational cooperation mechanisms. Other coordination mechanisms would be necessary by higher instances besides already existing ones to make this happen.

In the face of lack of information, vulnerability, fear of facing red tape, resorting to an intermediary becomes a solution at hand for applicants. INSS servants have little ability to interfere with intermediaries, because they cannot prevent an applicant from being accompanied by another person, who is not placed as an intermediary, but as a "friend", "neighbor" or "some acquaintance".

The administrative staff complain a lot about intermediaries, to whom applicants must pay if the benefit is granted. They also point out CRAS potential to guide applicants as a way to alleviate this issue. The widely accepted view among INSS professionals is that the role of intermediaries would be greatly diminished if there were an articulated network between INSS and CRAS.

#### Social evaluation

Once the application has been approved, social evaluation and medical examinations are scheduled. The social evaluation consists of an interview with the social worker of the INSS, who has full autonomy to score the requirements of the social form, which, together with the medical examination form, make up a sum of points that establishes the approval of the application. The social evaluation process done at the INSS agency is highly criticized. The fact that the CRAS social workers do not participate in the evaluation process, nor that their opinion is taken into account in the process was seen by a respondent as a serious flaw in the system.

There are no formalized arrangements or any social information system about the applicant shared between INSS and CRAS. There is a form, namely, Social Information System (SIS), which, when in doubt, the INSS social worker completes and forwards through the applicant to the CRAS social worker to complete with some information. However, the applicant himself must take the form and bring it back completed, which makes the process quite random and slow.

Contacts between CRAS and INSS are individual initiatives and are limited by the deadlines and goals established by the very INSS, since no servants are available for a permanent coordination with the CRAS. INSS organizational planning does not cover relationships with the CRAS and individualized actions can delay agency service deadlines and threaten performance goals.

The institutional and personal performance of INSS servants is evaluated and measured half-yearly from an annual action plan, with the average service time being monitored by local management. INSS-CRAS cooperation is local and informal initiative, producing horizontal management forms. However, individual efforts and informal ties allow for mutual exchanges prevail over institutionalized actions.

As the coordination between the local agencies of the INSS and the CRAS is poor or non-existent, nor is there a regular follow-up of the rejected applicants by CRAS on the result of the application. The welfare department is not aware of cases referred and rejected, nor of the reason for the denial. Knowledge about the outcome of the processes could prevent further referrals to INSS agencies from ineligible persons, as well as favoring support for incorrect dismissals.

Oftentimes, the benefit is denied due to a small excess income or, in the case of the disabled person, if there is already another disabled person benefiting from the BPC in the same family. While not eligible, these are vulnerable and have difficult access to income. At the time of the survey, a national INSS manager informed that they were working together with the MDS in order to refer the rejected applicants to another policy instead of just leaving them there without any further assistance.

In this process, the relationships built depend on the local context and the involvement of professionals in cooperation initiatives. In one of the agencies, after the introduction of social assessment, one respondent said there was an internal agreement to search for the social support network in the municipalities and areas covered by the INSS agencies. This initiative allowed the establishment of linkages with research institutions, the establishment of working groups on specific regional problems, the dissemination of tools and greater discussion within INSS agencies and integration with commissions and councils.

# b) INSS-SUS relationships

Coordination and cooperation between INSS and SUS bring issues of another nature. There is a greater interaction between the INSS and mental health professionals, with more frequent meetings between social workers from the INSS and SUS from the area of mental health to explain changes, exchange experiences and seek solutions.

Regarding physical disabilities or chronic diseases, applicants have to submit medical reports for expert evaluation and there is no mechanism for coordination or cooperation with the SUS, at least at the locations of this study.

The medical examination carried out at the INSS consists of an examination that verifies the medical report submitted by the applicant and assesses whether the health condition attested by the SUS is an impediment to independent living and work for at least two years. In addition to not knowing that the patient needs the report to apply for the BPC, SUS physicians do not even know what BPC is and therefore do not put into the report information that would be relevant to the social security medical examiner. The medical documentation that the INSS expert receives from SUS is often incomplete. The expert has to assess the applicant's clinical condition at the time of the examination and to check long-term compromised functions. This procedure requires access to certain exams and some detailed information, which the applicant does not always provide in his documents. The expert may issue a Request for Information to the Assistant Physician (SIMA), an application that he prints requesting the physician or health professional, psychologist, speech therapist, etc. to provide the missing information. The applicant himself must submit the SIMA to the attending physician, or someone else attending him/her to fill in data; he/she may also ask for a copy of the medical record at the health center or the hospital where he/she received treatment, which he/she cannot always provide on time.

So there is this difficulty with the applicant, who sometimes lives in (another municipality) and until he/she goes there and manages it, he/she depends on third parties to bring it back .... Then, they often know of this difficulty, and the applicant himself says: 'It will take me three months to get this consultation'... Then, we evaluate based on that document and he/she will lose out on this... In the part of the bodily function, we have to follow the medical documentation, so this is a barrier. (Medical expert)

There is no institutional communication mechanism, systems do not intersect and communicate. The medical evaluation or even the social evaluation are pending and the applicant must return within 30 days, otherwise the benefit is denied.

As the impact on independent living and work over the next two years should be assessed, rehabilitation generally depends on the health care network. One expert says that the main difficulties are related to functionalities, which do not need to be related to a disability, but may also

be associated with some chronic illness, such as heart disease, diabetes and that has repercussions on the function and living and working conditions. The role of the health network is therefore crucial for the provision of information:

Because here we do not do health care, we do expert medical care ... So it is the recognition of the right based on information that is technically and documental-wise proven. (Medical expert)

The medical evaluation depends not only on the set of documents or reports of the SUS, but also on person's proof that he/she sought assistance and that he/she is under medical treatment for the condition that would generate the benefit. That is, he/she cannot claim a condition that he/she has never tried to solve somehow, which implies in proving with appropriate reports and exams of the SUS.

The lack of examinations and the need to return to the SUS to obtain a new report or an examination would be an avoidable cost if the physicians of SUS network already knew what documents the patient needs in order to file the application. With more knowledge about BPC, SUS physicians could support access when they identify BPC eligible patients. Thus, they would need to know, have contact with the benefit and the medical evaluation; or else, this could be through the intermediary of a health social worker. The lack of information that is a barrier is not only on the part of the applicant, but also on the part of the health professional.

Several applicants interviewed learned about the existence of BPC at the health facility. In fact, some health professionals know the benefit a little and indicate to the patients, but as an individual initiative. Social workers already include BPC in their professional practice, but they do not always know the benefit well and not all patients are attended by the social service department of facilities.

As for the synergistic initiatives, a pilot of the INSS communication program with the health system was developed in one of the agencies, with the construction of a form and the referral through the social worker to try to solve health care issues that prevented the applicant's recovery and kept him/her in the BPC. An inter-organizational cooperation between social workers and medical experts, as well as an inter-sectoral cooperation between INSS and SUS was established, which eventually died out, according to the respondent, due to lack of adequate support. It was a local, horizontal initiative that did not achieve sustainability.

### Final considerations

The need to establish institutionalized coordination and cooperation mechanisms with the social welfare and health care sectors that can improve implementation processes and lower barriers to access PCBs was clear. Federal administration managed to establish intersectoral coordination and cooperation tools and seeks to extend similar mechanisms to local levels, where the policy is implemented. However, these are slower processes because they rely on inter- and intra-federative agreements involving a greater number of instances and stakeholders.

The BPC is a welfare benefit, but as it is implemented by the INSS, the role of the CRAS remains contingent. Since INSS is the gateway, the application process can be entirely isolated from the care network. This refers to the design of the BPC. A welfare benefit granted by social security is a contradiction that expresses a viable design to be implemented at first, but that with the construction of SUAS seems dysfunctional.

Institutionalized coordination and cooperation mechanisms between local INSS agencies and the CRAS could improve the implementation process in a number of ways. The first would be to avoid scheduling ineligible persons, improving flows and shortening applicants' waiting time at agencies. The second would be to improve public information, a crucial problem for the PCB.

On the other hand, one must also acknowledge that the BPC is a rather complex benefit with rules that are difficult to understand and over which applicants have no control. The vulnerability of applicants increases the barriers produced by the lack of information, because they are unsure about the roles of each institution and often not even what benefit they are requesting. The role of CRAS could also reduce the role of intermediaries, which have become a solution from the viewpoint of the vulnerable, uninformed applicant, who feels supported to deal with red tape with which he is unfamiliar.

The introduction of social assessment in the granting process in 2009 and the interview with

social workers at the social security allowed a greater approximation with the needs of the beneficiaries, which stimulated the network of protection through referrals to other services and rights. However, they are also criticized by the professionals themselves, since social assessments are made at INSS agencies.

Some processes related to BPC medical examination that extrapolate the governance of the INSS local agencies and that depend on the communication with the SUS network. Such mechanisms, however, even when built by local initiatives, to ensure their sustainability, rely on coordination mechanisms and incentives at the central levels.

At the local level, several identified problems are sometimes solved by horizontal initiatives, but would probably be more effectively addressed by institutionalized arrangements between the INSS, CRAS and the SUS, which in turn depends on vertical relationships with central decision-making levels.

The gaps observed and the solutions to the problems involving the different institutions depend on informal linkages and relationships, which is a characteristic of horizontal and diffuse forms of management. The problem of the various positive and synergistic intersectoral actions from the local level is that they are not usually sustainable. Local initiatives are more agile and unbureaucratized and depend on individual actions, but are discontinuous and random. This is evident in the initiatives taken by some local agencies that were later discontinued. There are in fact contradictions between the individual unbureaucratized initiatives at the far end and the hierarchical structure of the INSS. Horizontal dynamics have not replaced the vertical rationale of federal policies and programs. To fulfill all the functions claimed for the improvement of the BPC implementation, the CRAS must be better structured and recognized as participants in the decision-making process on the granting of the benefit.

This article did not incorporate the amendments made by the federal government from July 2016 to access to the BCP.

# Collaborations

J Vaitsman and LVC Lobato contributed equally to the paper.

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