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An Analysis of the Intentions of a Chilean Disability Policy Through the Lens of the Capability Approach

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ABSTRACT *This article sheds light on the public policy situation for persons with severe disabilities in Chile by analyzing the Ministry of Health “Home-Based Care Program for Persons with Severe Disabilities.” The article further advocates for the relevance of the Capability Approach (CA) in the assessment of public policy for persons with disabilities and intends to illustrate a link between a real policy and basic concepts of the CA providing a model of content analysis for public policy through the lens of the CA. We present a content analysis, focused on underlying intentions of agency, freedom, well-being, and achievement based in the official text of the Chilean program. Then we examine this content under original categories and matrices based on the work of Sen, to ultimately reveal how a current Chilean policy falls short of fully addressing the diagnosed situation of its target population and highlights areas for improvement. Not only does the program lack coherence and compliance with Chilean laws and international standards, but it also lacks connections with important concepts for persons in situations of dependency such as agency and freedom.*

KEYWORDS: Disability, Dependency, Public policy, Chile, Capability Approach, Content analysis

1. Introduction

Disability is a multifaceted, complex concept. Internationally, the most widely accepted and recognized definition of disability for public policy is provided by the United Nations’ Convention on the Rights of Persons with Disabilities (CRPD). The CRPD defines disability as an evolving concept that, “results from the interaction between persons with long-term physical, mental, intellectual or sensory impairments and the environmental barriers that hinder their full and effective participation in society” (UN 2007). This definition illustrates how a disability is often due to prejudice and the inaccessibility of an environment, instead of people’s physical differences or medical issues (Ablon 2010).

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This new perspective shifts away from attributing a disability solely to an individual, and recognizes how environments can disable. Globally, changes in public policy are critical in order to decrease the barriers to inclusion that persons with disabilities currently face and provide them with their rights to social protections (UN 2007, Art. 28). Poverty is all too often an obstacle for many people with disabilities. So much so that, Sen (2009) deems disability and poverty as inextricably linked. Out of the one billion people in the world estimated to be living with a disability, approximately 80% live in developing countries (WHO-World Bank 2011).

In 2004, the First National Survey of Disability (ENDISC)¹ conducted in Chile found that 12.9% of the population has some form of disability. The survey also revealed that 1 in 5 people who live in the lowest socioeconomic group of society has a disability (FONADIS 2006), while the rates are 1 in 8 for the middle group of society and 1 in 21 for the highest socioeconomic group of society (FONADIS-INE 2004).

Furthermore, the survey found that 2.5% of the Chilean population has a severe disability; that is, more than 400 000 people are “severely impaired and unable to function in their daily life without the care or support of a third party, and cannot manage to overcome their surrounding barriers alone, or do so with great difficulty,” most of them living in the lowest socioeconomic group (FONADIS-INE 2004).

For the purposes of this article, our focus is on persons with severe disabilities (PWSD) in “situations of dependency,” defined as “a specific type of disability in which two elements are present: a limitation of the individual to perform a specified activity, and the interaction of certain environmental factors related to personal and/or technical support,” (Querejeta González 2004a, 27, 2004b, 349–350). It is also necessary to note that currently there is no existing data that relate type of disability to the respective situation of dependency besides the 2004 ENDISC (Díaz 2013).

The policy of the Ministry of Health (Ministerio de Salud, MINSAL) that is analyzed in this article is one of the few Chilean policies that target persons with disabilities in situations of dependency or bedridden. The purpose of this article is to utilize the Capability Approach (CA) to create a new model for the content analysis that permits an examination of a current Chilean public policy.

1.1. Public Policy and Dependency in Chile

The 2010 Chilean Law No. 20.422 (Ley No. 20.422 2010) derived from Chile’s ratification of the CRPD in 2008 and established “Norms on Equal Opportunities and Social Inclusion of People with Disabilities,” updating Chilean concepts of disability and inclusion to those established internationally and giving way to more active governmental engagement in terms of equal opportunities initiatives and more concrete actions for persons with disabilities.

Despite these advances, a great weakness remains in Chile’s social protection system for adults (18–60 years old) with disabilities (Sánchez 2013). Public services in Chile mainly cover attention, care, and response for children and adolescents (0–24 years old)² or seniors (over 60 years old). This creates a significant void of support for adults with disabilities between the ages of 24 and 60 years. Even though a person with a disability could be living in a “situation of dependency,” because of their age they are considered “independent” in the eyes of the law.

For this article, “independence” is the power to do something without the help of a third party and “personal autonomy” is a person’s ability to self-govern, “administer or manage their dependency” (Querejeta Gonzalez 2004a, 36, 2004b, 353; Le Gall

and Ruet 1996). Living in a situation of dependency may or may not result in the loss or diminution of personal autonomy. If a person living in a situation of dependency can administer and manage their dependency, they would preserve the power to decide what, how, and when to perform an action, which should be the ultimate goal. However, in Chile it is found that in situations of dependency, often autonomy is diminished (Díaz 2013).

1.2. Disability and the CA

Originally, Sen did not develop the CA to specifically address disability; rather disability was used to illustrate what the approach proposed (Mitra 2006).³ However, many scholars of the CA have explored disability within this framework and find that “the capability approach has significant strengths in addressing disability issues,” (Qizilbash 2006, 3) since it considers the multiple dimensions of a disability, such as the social and economic statuses of individuals. In *The Idea of Justice*, Sen himself states that, “the relevance of disability in the understanding of deprivation in the world is often underestimated, and this can be one of the most important arguments for paying attention to the capability perspective” (2009, 258).

While viewing disability through the lens of the CA, “the idea of equality is confronted by two kinds of diversity: (1) the basic heterogeneity of human beings, and (2) the multiplicity of variables in terms of which equality can be judged” (Sen 1992, 1). Deficiency of the body and/or the mind is only one among many variables that interact with a person’s social, economic, and physical environment to produce a range of advantages or disadvantages, “disability is therefore a particular form of the general phenomenon of capability–poverty” (Burchardt 2004, 746).

Additionally, the CA takes into account the choices available to an individual. It emphasizes not only what a person is or does, their “functionings,” but also the range of capabilities which they can choose from, that is the “set of capabilities” that a person can freely act upon. This perspective captures a person’s relationship with their surrounding environment, as well as the available societal opportunities. Due to its comprehensiveness, the CA is believed to complement and exceed other disability models (Trani and Bakhshi 2009), which made it crucial to this analysis.

2. Fundamentals of Analysis

The analysis looked for conditions that created and/or enhanced a person’s capabilities and their ability to act autonomously by searching for intentions of agency, freedom, well-being, and achievement present in the text of MINSAL’s “Home-Based Care Program for Persons with Severe Disabilities.” Ultimately, this analysis introduces a model for future content analyses of public policy through the lens of the CA. Due to the importance of freedom and agency⁴ to the CA, we saw it as opportune and critical to select a government program aimed at addressing the needs of persons in situations of dependency since the ability to act autonomously, and the freedom to choose from a set of capabilities, is especially fragile for those living in situations of dependency.

In the Chilean context, an analysis of actions targeted at persons in situations of dependency acquires a special relevance due to the collectivist nature of society. Collectivism is a, “strong interdependence among members,” where, “the interest of the group supersedes the interest of individuals, and becomes comprehensive to identity” (Marfull-Jensen and Flanagan 2014, 1). Collectivism in itself is not problematic, but becomes problematic in Chile

because it creates a system heavily reliant on familial support and care for success. Furthermore, a collectivist mentality contrasts with the goals of autonomy and independence as outlined in the CRPD and Law No. 20.422, yet, as we will show, it continues to be reflected in public policies targeting persons with disabilities.

The following sections provide the various concepts that are critical for understanding and interpreting our analysis, results, and conclusions. It should be noted that the following analysis is far from a traditional analysis of public policy and constitutes an exploration within a methodology specifically crafted to analyze this type of social policy. Furthermore, the analysis was only performed on the official text of the selected relatively young program and cannot provide information on the program's implementation due to the absence of available data.

2.1. Basic Concepts

Utilizing the CA in public policy is not novel (Nussbaum 1997). The United Nations' Human Development Reports and the Sarkozy Commission are just a few examples of current policy initiatives that utilized the CA as a theoretical framework (Goerne 2010). For the purposes of this article, we assume that human flourishing is the end goal of any political activity, which means that the, "expan[sion] of freedom is both the primary end, and principal means of public policy: consequently, public policy should focus on removing barriers to freedom that leave people with little choice to exercise their reasoned agency" (Ruger 2009, 2).

According to Sen (1992), the achievement of equality should be evaluated in terms of the life that a person is capable of living. That is to say that equality should be measured by a person's freedom and agency—what they can actually say, be, and do in their lives. "Freedom is one of the most powerful social ideas and its relevance to the analysis of equality and justice is far reaching and strong" (96). More specifically, a close examination should be given to a person's rights, freedoms, and real opportunity. This is because equality "may be better represented by the freedom that the person has, and not by, or at least entirely by, what the person achieves—in well-being or in terms of agency—on the basis of that freedom" (Sen 1987a, 1987b, 47). Examples of this kind of examination are assessing whether a person can, "live longer, escape from avoidable causes of death, is well nourished, able to read, write, communicate and participate in science and literary tasks, etc." (Acosta 2011, 192). Arguably, "the creation of social opportunities makes a direct contribution to the expansion of human capabilities and quality of life" (Sen 1999, 144). The CA is a powerful tool that can help enhance citizens' lives through social opportunity, but "functionings and capabilities also need direct policy support" (Burchardt 2005, 369).

Typically within public policy, "equal opportunity" is understood as a person's disposition to a particular resource, barrier, or restriction. Within the CA, "equal opportunity" refers to the equality of capability, or the elimination of blatant inequality of capability, so that

societal arrangements, involving many institutions (the state, the market, the legal system, political parties, the media, public interest groups and public discussion forums, among others) are investigated in terms of their contribution to enhancing and guaranteeing the substantive freedoms of individuals, seen as active agents of change, rather than as passive recipients of dispensed benefits. (Sen 1999, xii–xiii)

Sen (1993) indicates that it is possible to establish four points of interest when assessing human advantage, based on two different distinctions:

- (1) First distinction:
 - (a) The promotion of the person's well-being;
 - (b) The search for the goals of the person's agency (what a person can say, be, and do), which may include goals other than the person's well-being.
- (2) Second distinction:
 - (a) Achievement, as in what a person actually reaches or performs;
 - (b) Freedom or real opportunity to choose and achieve a valued goal.

When considering both distinctions together four concepts emerge: (1) "achievement of well-being," (2) "achievement of agency," (3) "freedom of wellbeing," and (4) "agency of freedom." Originally, Sen conceived of agency and well-being as distinct, but interconnected, aspects of the human life that command both respect and attention. As a result, agency and well-being have two dimensions: actual achievements and freedom of those achievements (Crocker 2006). To fulfill these dimensions,

the ethically-sensitive analyst evaluates development policies and practices in the light of the extent to which they promote, protect, and restore human agency rather than merely the good or bad things that happen to people. (Crocker 2006, 298)

2.1.1. Well-being. Well-being can simply be defined as a person's achieved goals, but it more specifically pertains to evaluating a person's achievements in relation to their desired functionings. However, opportunities (functionings) are not weighted and valued solely by achieved goals (well-being); it is possible to have a real advantage and waste it, to sacrifice one's own well-being for the goals of another, or to not make use of the freedom to achieve a greater well-being (Sen 1987a, 1987b).

Well-being is of great importance to the analysis of social inequality and the assessment of public policy. Societies may accept the responsibility to help with their citizen's well-being, especially when there is some danger or vulnerability; for example, if someone is dying of hunger or cannot obtain adequate medical treatment. Providing a social service does not necessarily interfere with the citizen's other agency objectives (Sen 1992).

Within the context of public policy, well-being comprises the relevant functionings that every person, regardless of socioeconomic status, recognizes the worth of even if not prioritized by the individual (Burchardt 2005; Sen 1985). This is because, "problems of social injustice and inequity between different classes and groups relate strongly to extensive disparities in wellbeing—including the freedom that we respectively enjoy to achieve well-being" (Sen 1992, 72).

2.1.2. Agency. Agency refers to, "what a person is free to do and achieve in pursuit of whatever goal or values he or she regards as important" (Sen 1985, 203). Although agency is likely to overlap with and influence well-being, "since most people wish to promote their own well-being," (Burchardt 2005, 295) it is neither limited to well-being nor suggests a direct relationship between the two (Sen 1985). The "achievement of agency" is the successful completion of a person's valued goals and objectives, regardless of well-being (Sen 1992). This is because, at times, "[a]n expansion of freedom of agency can go with a reduction in actual well-being" (Sen 1985, 207). For example, someone can choose not to pursue their well-being, or engage in prejudicial actions towards their own well-being such as a person who drowns trying to save someone else's life (Burchardt 2005).

Moreover, attention needs to be given to the differences between agency and well-being in regard to freedom. "Freedom of agency" is, "one's freedom to bring about the achievements one values and which one attempts to produce" (Sen 1992, 57). Furthermore, it is the

freedom to choose and achieve one's desires, free from external coercion or internal compulsion (Crocker 2006, 297). While "freedom of wellbeing" refers to "one's freedom to achieve those things that are constitutive of one's wellbeing" (Sen 1992, 57).

Finally, it is possible to distinguish between: (1) the "success of achieved agency," which is the occurrence of something that a person values independent of her role at the time of realization and (2) the "success of instrumental agency," which is the occurrence of such things by one's own effort, or where one has played an active role in its execution (Sen 1992, 56).

2.2. MINSAL: Home-Based Care Program for Persons with Severe Disability

There are only two policies in Chile directed at persons in situations of dependency: (1) SENADIS⁵ "Promotion of the Autonomy and Attention to Dependency" and (2) MINSAL's "Home-Based Care Program for Persons with Severe Disabilities." With an estimated 2014 budget of 7500 million CLP⁶ (12 million USD), MINSAL's program is the largest in terms of history, coverage, and financial resources, and for those reasons it was the policy selected for this analysis. Furthermore, SENADIS' policy is still in its piloting stages with a budget a tenth of the size of MINSAL's.

MINSAL established the Home-Based Care Program for Persons with Severe Disabilities in 2006 during President Michelle Bachelet's first term. The program provides detailed guidelines for the support of the elderly or other bedridden individuals as well as their caregivers. Moreover, the policy has two core components: one linked to in-home care services, and the other is more subsidiary, consisting of a monthly cash transfer of 22 000 CLP (40 USD), which is less than 10% of the average minimum wage salary in Chile (about 450 USD).

Overall, the intention of the program is, "to give the person with a severe disability, their caregivers, and family members, comprehensive in-home care in physical, emotional, and social ways that improve quality of life, thus enhancing recovery and/or autonomy" (MINSAL 2011, 5). At its simplest, this program is a health-care strategy or handbook implemented at the national level. Its success is highly dependent upon local administrations and health services utilizing their public health networks to extend coverage families and PWS in situations of dependency. People with severe physical, mental or even multiple disabilities are especially vulnerable and in need of coverage since they frequently fall within the ranges of legal poverty (Sánchez 2013).

3. Methodology

The purpose for analyzing MINSAL's "Home-Based Care Program for Persons with Severe Disabilities" is to better understand the "underlying" (Bardin 1996, 104) Chilean interest in disability through the lens of the CA since the CA aligns with the program's goals of enhancing quality of life and personal autonomy. To do so, we performed a content analysis that searched for CA concepts and analyzed for intentions underlying the social practice and material surface of the text (Piñuel Raigada 2002). More specifically, our analysis looked for the presence of concepts and intentions related to the creation and/or enhancement of the capabilities of persons in situations of dependency, such as intentions of agency, freedom, well-being, and achievement (Holsti 1968). For this purpose, a series of matrices were developed with our categories and conceptual analysis.

A structural analysis was also performed. Units of diagnosis,⁷ objectives, and components of the program were separated and analyzed in order to determine that our resulting categories were consistent, that is, if what was found in the structural analysis was also

present in the objectives and components of our content analysis as well. Fundamentally, the unit of study in the analysis is a group of words, such as sentences or paragraphs, in the program that referenced the promotion, development, and/or strengthening of a person's capability (Bardin 1996).

The content analysis consisted of four initial steps: (1) the identification of a benefit, incentive, or action in the program, (2) evaluating its objectives, (3) breaking down its components, and (4) analyzing its indicators. These steps allowed us to assess internal consistency and identify underlying implications of program initiatives. Finally, we concluded whether each of the four steps promoted agency, well-being, freedom, and achievement. We made use of the Technical Standard (MINSAL 2006) as an auxiliary for interpretation of the text of the program when additional clarification was needed. No other texts were used to conduct the analysis.

Operationally the analysis used the following steps:

- Recognizing groupings in the text that referenced benefits, incentives, or actions that enhance capability. Only those groups of words that dealt directly with people with disabilities were considered and were distinguished in the text by expressions such as: "provide persons with disabilities," "the person with disabilities develop," "person's with a disability will receive" and other similar phrases. Additionally, we analyzed sets of words that referred to social structures, in terms of conversion factors that strived to create and enhance persons' capabilities (Goerne 2010).
- Semantically categorizing the data (Bardin 1996): related to agency, well-being, freedom, and achievement to decipher whether or not the program encourages the development of these concepts.

The analysis utilized simple matrices (Strauss and Corbin 2008) to consolidate our findings and separate the most important variables. The following divisions were established:

- Dimension: the identified goal of the Chilean state's action.
- Category: the type of services offered by the program to achieve said goal, taking into account how persons with disabilities receive them.
- Quotations: corresponds to actual phrasings that reveal the contents of the category in each stage of policy design (diagnosis, objectives, components, and indicators). Multiple phrasings can reference the same category.
- Elements of analysis: Are the theoretical contents of agency, well-being, freedom, and achievement there in the program? These are indicated by the mere presence, positive or negative, or absence of such content and were grouped as follows:
 - o Presence with positive effect (encourages its development): ✓
 - o Presence with negative effect (encourages that does not develop): X
 - o Absence (the item was not found): ∅

4. Results

Our overall analysis revealed that MINSAL's policy has two principal goals or dimensions: in-home care for PWSD, and additional benefits that help provide more comprehensive care to PWSD. Furthermore, each dimension contains two distinct categories, or types of services, that we utilized to create our matrices (see Tables 1–4) for content analysis: "Direct Services Matrix," "Indirect Services Matrix," "Transfers Matrix," and "Networks Matrix". These four categories resulted from our assessment of all direct and indirect

services with the objective of impacting the quality of life of PWSD, and were independently analyzed for intentions of: agency, well-being, freedom, and achievement. The detailed results of our analysis are broken down by matrix⁸ category in the following subsections. Additionally, we use both “persons in situations of dependency” and “persons with severe disabilities” as interchangeable terms that reference the program’s recipients or target population. Each matrix represents an action of MINSAL’s program, which was analyzed by the intentions of: agency, well-being, freedom, and achievement.

4.1. Direct Services Matrix

The Direct Services Matrix (see [Table 1](#)) is part of the “in-home care for PWSD” policy dimension because it pertains to the services provided by the primary health teams in the homes of PWSD. These benefits are direct actions with economic costs (either in inputs, human resources, etc.) that exclusively target PWSD actions, but exclude direct transfers of cash.

The diagnosed problem of “direct services” is a need/demand for comprehensive care services for PWSD in Chile, which it attempts to address with the act of in-home care visits. However, in the text of MINSAL’s policy there is a lack of explanation of what actions must be performed and why during those visits, instead these details are provided separately in the policy’s Technical Standard (MINSAL 2006), making the actual text of the policy ambiguous and incomplete. The Technical Standard additionally provides a clearer definition of program’s recipients, stating its target population as PWSD who “suffer” from severe dependence and require support, guidance and supervision in all daily activities, such as bathing, dressing, going to the bathroom, relocating, and eating. Additionally, the Technical Standard is the first direct reference to persons who are bedridden (MINSAL 2006, 8). During the in-home care visits, health officials are supposed to comply with specified procedures, diagnose, and intervene based on mobility/disability of PWSD, aid with their daily activities, and conduct training sessions with caregivers to enhance awareness and knowledge.

Overall, direct services focus on the support of PWSD in situations of dependency. That support does lead to some achievement of well-being for the individual since the program helps the person to complete various personal needs, such as bathing, dressing, going to the bathroom, relocating, feeding, etc., but these personal needs represent the scope of well-being targeted.

Underlying the Technical Standard, we found an intention of freedom, since persons in situations of dependency can utilize the services provided to enhance their capability sets and access previously unattainable capabilities. It is important to note that the actual presence of freedom is contingent upon the recipient valuing those new capabilities. The content analysis found, that it was not possible to determine if in fact the associated capabilities were prioritized by the recipients.

Ultimately, the analysis found no intentions of agency associated with direct services. Rather, it can be argued that the individual’s agency is violated since the objectives listed in the text of the program are to “take care” and “provide” for said person, and furthermore “intervene” and “transmit”, as stated in the Technical Standard. Both documents define the health team as the central actors and the person in a situation of dependency as acted upon. There are no references to recipient’s personal goals or if the newly attainable capabilities are those that the person values.

Even though the need for comprehensive care and services is stated in the original diagnosis for direct services, the text of the program never provides evidence to support these assertions and the established procedures of in-home care visits, such as research on what

Table 1. Direct Services Matrix.

Dimension	In-home care for PWSB			
Category: Direct services	Benefits that are directly aimed at PWSB. These services involve direct actions with economic costs (either in inputs, human resources, etc.), but are not direct transfers of cash			
	Diagnosis	Objectives	Components	Indicators
Process of analysis	<p>“Must provide comprehensive services to individuals (and families), and even more so in segments of greater economic and social vulnerability”</p> <p>“The importance of primary care health teams ... who must provide care for people who have some degree of disability”</p> <p>“They must provide services according to their needs”</p> <p>“This segment demand services and therefore, the existence of devices in their network to respond to those needs”</p> <p>“75.7% (of the population) receive attention and demand services in the public sector”</p>	<p>“Provide comprehensive care for people who have severe disabilities, considering the psychosocial needs of the patient and his family”</p>	<p>Provide homecare to address health needs of the PWSB</p> <p>Address health care holistically and look at biological as well as psychological needs of the PWSB and their family</p>	<ol style="list-style-type: none"> 1. Number of PWSB served organized by sex and age 2. Number of visits per-patient in comparison to number of scheduled visits 3. Percentage of patients with bedsores
Intentions of agency	X	X	X	X
Intentions of well-being	✓	✓	✓	✓
Intentions of freedom	∅	∅	∅	∅
Intentions of achievement	✓	✓	✓	✓
Internal coherence	<ul style="list-style-type: none"> • The program indicates the importance of providing care to all people with a disability. However, this program is exclusively for PWSB in situations of dependency who are bedridden since an indicator of quality of service is the percentage of patients with bedsores. • Emphasis is placed on “comprehensive care” and “quality of life” for persons with disabilities, but indicators only reveal coverage, which does not measure quality of care or even what types of services were provided. 			

specific supports PWSD in Chile lack. The absence of evidence for direct services coupled with the lack of consideration of the recipient's agency led to weak objectives, and subsequently indicators that cannot definitively determine if the program's goals of autonomy and quality of life enhancement are achieved.

4.2. Indirect Services Matrix

The Indirect Services Matrix (see Table 2) is part of the "in-home care for PWSD" dimension because it pertains to the services provided by the primary health teams in the homes of PWSD, but these actions or benefits target caregivers or those related to PWSD. Like direct services, indirect services involve actions with economic cost (in inputs, human resources, etc.), but are not direct transfers of cash.

The analysis found that "indirect services" primarily refer to the achievement of well-being as well but actions categorized in this matrix target the well-being of the family or caregivers, thus indirectly affect the care recipient. The objective of this training is to provide caregivers with necessary tools to facilitate their work and overcome environmental challenges (MINSAL 2006, 7). This component of the program strives to improve the family's quality of life as well as the quality of care provided, since families are typically the main providers of care in Chile. Freedom is weakly present in the training's objectives since caregivers could further develop their capabilities to provide quality care to PWSD, but again, the analysis found no intentions of agency.

First, it is unclear whether the training is actually desired by the family members, and second whether the preferences and goals of the family members' align with those of the training program. Additionally, the program proclaims that it is based on the "shared responsibility of the family group," which implies that familial care ultimately is an obligation rather than a choice. Furthermore, PWSD do not qualify for the program without familial care, making the family's participation mandatory, which is problematic for more reasons than just agency. In the program's objectives, this obligation is downplayed; it is presented mildly as a combined strategy. However, it is very significant because without a family, a PWSD does not qualify for the program's support.

4.3. Transfers Matrix

The Transfers Matrix (see Table 3) is classified in the "additional benefits that help to provide more comprehensive care for PWSD" dimension. This dimension includes benefits that are not overt acts of care, and are not confined to the homes of PWSD. Furthermore, these are economic benefits that qualifying PWSD receive indirectly by the direct transfer of cash to caregivers.

The analysis found intentions of well-being present in the "Transfers Matrix." The program diagnosed the need for monetary support based on the statistic that one in five persons with a disability in Chile lives in the lowest socioeconomic sector of society. Again, this action is an indirect benefit to persons in a situation of dependency since the monetary payment is directly given to the caregivers. The primary goal of this monetary transfer is to help foster the well-being of the caregivers. This enhancement of financial resources is weakly freedom in the sense that it can permit the family to develop other capabilities that were previously inaccessible due to their need to work, but the monetary amount is meager and not supported in the text by evidence. Additionally, it could allow the caregiver to, "exert greater control over the who, how and when of the assistance they need" Burchardt (2005, 748), but this support does not necessarily yield the achievement of any given functioning.

Table 2. Indirect Services Matrix.

Dimension	In-home care for PWSD			
Category:	Actions or benefits aimed at caregivers or those related to PWSD. These indirect services involve an action with economic cost (either in inputs, human resources, etc.), but are not direct transfers of cash			
Indirect services	Diagnosis	Objectives	Components	Indicators
Process of analysis	<p>“Must provide comprehensive services to individuals (and families), and even more so in segments of greater economic and social vulnerability”</p> <p>“It is based on the shared responsibility that the family must assume in the care and attention of people with disabilities, because of this, the health team must deliver necessary tools to families, for the care of patients, and to engage the family in this process”</p>	<p>“Prepare the families who care for such patients, delivering holistic service with emphasis on the person, his family and their environment”</p> <p>“Give caregivers and families the necessary tools to provide comprehensive care for persons with severe disabilities”</p>	Provide necessary tools and training to families and the PWSD surrounding environment	<p>1. Trained and paid caregivers</p> <p>(number of trained caregivers who receive payment / total number of caregivers who receive payment)</p>
Intentions of agency	X	X	∅	X
Intentions of well-being	✓	✓	∅	✓
Intentions of freedom	∅	✓	∅	∅
Intentions of achievement	✓	✓	∅	X
Internal coherence	<ul style="list-style-type: none"> While there is coherence between the diagnosis and its objectives, there is a lack of consistency between components and indicators. The single component we have listed is, “provide necessary tools and training,” but the measurement of that is payment to caregivers, which does not accurately measure the goal of learning techniques or actions that increase the quality of life of the person. This payment refers to the monetary benefits, which is not necessarily a tool and does not develop the skills or competencies of the caregivers that will improve the well-being of the PWSD. 			

Table 3. Transfers Matrix.

Dimension	Additional benefits that help provide more comprehensive care to PWSD ⁹			
Category:	Indirect economic benefits for qualifying PWSD via their caregiver(s)			
Money transfers	Diagnosis	Objectives	Components	Indicators
Process of analysis	“The study points out that for people living with a disability in Chile one of every five live in low socioeconomic status; one in eight people live in the middle socioeconomic status, and one person with a disability out of every 21 are of high socioeconomic status”	“To recognize the work of the caregivers of persons with severe disabilities, and provide training and monetary support if they fulfill the qualifying criteria”	<p>Monetary support to the care providers of PWSD especially those in the range of poverty</p> <p>Recognize the work of these care providers by a set annual payment</p> <p>To receive payment, the recipient must be enrolled in their government health center, be a beneficiary of FONASA or of any government program, be classed as poor, destitute or not indigent through a social assessment by a social worker or application of tab CAS II team by the Social Assistance of the municipality.</p>	<p>1. Trained and paid caregivers</p> <p>(number of trained caregivers who receive payment / total number of caregivers who receive payment)</p>
Intentions of agency	∅	∅	X	∅
Intentions of well-being	✓	✓	✓	✓
Intentions of freedom	∅	✓	✓	∅
Intentions of achievement	∅	∅	∅	∅
Internal coherence	<ul style="list-style-type: none"> • The text assumes that caregivers are part of the family and live in house or nearby. It also assumes that the socioeconomic conditions families are similar to those who care for the PWSD. • This monetary support is more like a reward for ‘good behavior’ or participation, which does not necessarily result in better care for the PWSD, or increase their capabilities since it is a set amount of money and not assessed by the varying situations and needs of PWSD. • The indicator is not clear about what exactly is measured. It illustrates how many caregivers receive payment but not the quality of life or effective capacity building that result from this payment. 			

While the intent of well-being is evident throughout the various elements of the analysis, the intention of freedom is not as apparent in the program's diagnosis or indicators. Moreover, intentions of agency are missing from this action of the program and are arguably jeopardized. For example, the support could arguably incentivize social immobility since caregivers must maintain an indigent living situation in order to continue qualifying for monetary support.

4.4. Networks Matrix

The Networks Matrix (see [Table 4](#)) is included in the “additional benefits that help to provide more comprehensive care for PWSD” dimension since these benefits are not overt acts of care, and are not confined to the home of PWSD. Specifically, this matrix refers to direct or indirect societal benefit(s) for PWSD that result from the effective coordination between the government, private sector, agencies, families, and PWSD.

This category refers mainly to the achievement of well-being for persons in situations of dependency and their families. The emphasis placed on networks of (public, private, and social) support strives to improve quality of life, opportunity, and the continuation of health care for persons in situations of dependency. There is an achievement of well-being in regard to the concentration on the health of PWSD. However, the lack of coherence between the objectives stated in the diagnosis and its indicators does not allow the achievement of well-being to develop fully.

The analysis revealed a slight development of agency detailed in these program objectives, since the recipients have the opportunity to change health programs if they need to do so. Since this could be a desired goal of the person in a situation of dependency, it makes it an opportunity for agency exertion. However, it is important to emphasize that health care itself is not a final goal, but rather a means to obtain a goal or capability like health (Sen 1992, 36), so this does not ensure an enhancement in overall quality of life. Finally, there were no present indicators for the development of freedom, which would promote the development of capabilities or real opportunities.

5. Overall Findings

Ultimately, the content analysis concluded that the MINSAL program lacks coherence and does not ensure solutions to the problems of dependency it proclaims to address in its initial diagnosis. The program's declared intention is, “to give the person with a severe disability, their caregivers, and family members, comprehensive care at home in physical, emotional, and social ways aimed at improving quality of life, thus enhancing recovery and/or autonomy” (MINSAL 2011, 5). These shortcomings are to the detriment of the well-being, agency, freedom, and achievement of PWSD in situations of dependency.

5.1. Lack of Internal Consistency

The content analysis revealed a serious deficiency in the soundness of the MINSAL program. The text loses coherence between its components, so much so that the problem identified in the diagnosis is not fully addressed in by components or measured by indicators. Due to this, the program's objectives and components have the intentions to resolve targeted issues, but do not necessarily guarantee that the problem will be tackled. Additionally, the indicators do not take into account all the actions of the program's components, which prevents an evaluator from effectively assessing the program's impact. For example, an indicator of success for in-home care is a reduction in the percentage of PWSD

Table 4. Networks Matrix.

Dimension	Additional benefits that help provide more comprehensive care to PWSD.			
Category:	Perceived direct or indirect societal benefit(s) for PWSD that result from the effective coordination between the government, private sector, agencies, families, and PWSD			
Networks	Diagnosis	Objectives	Components	Indicators
Process of analysis	<p>“This segment demand services and therefore, the existence of devices in their network to respond to their needs”</p> <p>“It is essential to integrate the work of institutions dealing with the issue of disability, since they must provide critical services to individuals and families, even more so in sectors of greater economic and social vulnerability”</p> <p>“The development of networking strategies is essential, by which, ministries, services, and municipalities, as the civil society, must plan activities that aim to improve the quality of life of the person with disabilities and their families”</p> <p>“75.7% (of the population) receive attention and demand services in the public sector”</p>	<p>“Safeguard the continuity and timeliness of a health-care network, making appropriate arrangements in the event that these services are needed”</p> <p>“Maintain updated database of persons with severe disabilities on a web page”</p>	<p>Each health facility must inform the Secretary of Care in the Ministry of Health, about implementing a program</p> <p>Follow the process of registry on the webpage and enter their Record Monthly Statistical REM</p>	<p>Updated Record in web page</p> <p>(No of Quotas used by the Health Service, registered in the web worksheet, estimated to complete year/No. of quotas committed by the Health Service)</p>
Intentions of agency	∅	✓—∅	∅	X
Intentions of well-being	✓	✓	∅	X
Intentions of freedom	∅	∅	∅	X
Intentions of achievement	✓	✓	∅	X
Internal coherence	<ul style="list-style-type: none"> • There is a consensus across categories to address the need for integrated networks of services for PWSD, but it lacks an indicator. • There are specific activities listed in the text (p. 10), indicating that the health-care team should incorporate community resources such as volunteers, monitors, NGOs, or others, to create a larger network that can help perform follow-up efforts, develop care plans, and monitor records. • Although the maintenance of records is necessary in order to provide adequate services, it is an administrative action that does not necessarily provide a benefit to the PWSD, their caregivers, or improve their quality of life. 			

with bedsores, but this indicator has neither a meaning for non-bedridden PWSH nor ensures the enhancement of quality of life and autonomy

5.2. Categories of Analysis Concerning the CA

The analysis discovered that intentions of freedom and agency are virtually absent and that there is at present a bias towards achievement and well-being. The program's components target caregivers instead of persons in situations of dependency, who are supposed to be the program's beneficiaries. Ultimately, persons in situations of dependency primarily indirectly benefit from the program, and their caregivers are those who truly receive direct benefits. This attests to the collectivist nature of Chilean society and its continual presence in policies despite contradiction to the CRPD and Law No. 20.422.

Furthermore, our analysis concluded that the program is fundamentally collectivistic (Marfull-Jensen and Flanagan 2014) since it attributes the role of primary caregivers to the family. The program was written in such a way that persons in situations of dependency and their caregivers are conceived as a single unit. Primarily families, rather than persons in situations of dependency, are the direct actors and beneficiaries of the program; two integral components of the MINSAL policy, training and the stipend, are exclusively offered to families. In the context of this policy, the collectivist mentality assumes that the benefit to one would be of benefit to the other; this occurrence cannot easily be controlled, especially since our analysis found weak, incoherent indicators, and virtually no oversight due to the absence of established follow-up mediations to ensure continuous benefit for persons in situations of dependency. As a result, the infiltration of collectivism and lack of coherence between the program's diagnoses, components, and indicators, discard the agency, autonomy, and functionings of persons in situations of dependency and ultimately impair the program from assuring the enhancement of the autonomy and quality of life for persons in situations of dependency.

Ultimately, the program does not deliver solutions to the problems of dependency it proclaims to address in its initial diagnosis. The program's declared intention is, "to give the person with a severe disability, their caregivers, and family members, comprehensive care at home in physical, emotional, and social ways aimed at improving quality of life, thus enhancing recovery and/or autonomy" (MINSAL 2011, 5). Truly, as we have shown, the family/caregivers are the direct beneficiaries of this program, and the agency, autonomy, and functionings of the person in a situation of dependency are not considered.

6. Discussion

Currently, disability is not integrated into the Chilean social protection system. Instead, there are various social services available to persons with disabilities, such as pensions, forms of technical assistance, and other monetary supports. Even it was not until MINSAL's Home-Based Care Program for Persons with Severe Disabilities in 2006 that the Chilean government recognized and attempted to provide support to persons in situations of dependency. Even though the MINSAL's program is a relatively new policy, a content analysis of this program suggests that it fails to fully address the diagnosed situation. In order to truly achieve its goal of enhancing the autonomy and well-being of persons in situations of dependency, the policy requires redesign, scheduled implementation, and furthermore, the political will to position this issue on the policy agenda and advance it in the realm of social protection.

Overall, in order to foster well-being and promote the autonomy of this population, a reform of public policy is critical and necessary within the framework and understanding

of the CA. The well-being of persons in situations of dependency, and even the current success of the MINSAL's policy, rests problematically upon families and diminishes the autonomy of its target population in various ways. Although it provides some necessary supports that may enhance persons' capability sets, such as assistance with bathroom and mobility, it is uncertain whether these supports actually increase well-being, and the indicators fail to measure impact as well. Unintentionally, this renders the policy vulnerable to maintaining persons in situations of dependency in disabling environments where capabilities and functionings are impaired (Burchardt 2004; Mitra 2006). The valued functionings of persons in situations of dependency are not considered, which prevents persons from exercising their agency, becoming more autonomous, and even assessing the state of their personal well-being. In order to more securely achieve the enhancement of well-being and autonomy for persons with disabilities, future policies must give special attention to the concepts of agency and freedom, which are virtually absent from MINSAL's policy. Due to its collectivist influences MINSAL's policy lacked agreement with both national and international laws.

The challenge seems to lie in the lack of political and technical awareness of these established laws and the need to develop policies that promote the personal autonomy and agency of persons in situations of dependency. Visions of assistance and charity permeate the language and practice of public policy for this population, which further goes against what is promoted in Law No. 20.422 and the CRPD. Furthermore, it seems important to teach policy-makers to view persons with disabilities, whether mild or severe, as autonomous, valid subjects in the decision-making process in order to guarantee their agency and self-determination with choices that affect their quality of life and well-being.

Additionally, consideration needs to be given to the freedom of persons in situations of dependency in order to ensure respect of the actions that recipients' value, and to diminish the decision-making power that caregivers currently possess. Even though freedom, autonomy, and agency can appear problematic within the context of people who are to some degree dependent upon their caregivers, it is achievable and needs to be protected and promoted by policy (Burchardt 2005). The necessity of this redesign is made apparent when adults with disability and dependency "find themselves in a situation of exception to their originally projected lifecycle [... and], the protection and assurance of those individuals rests essentially on the family" (Sánchez 2013, 95). What happens when there is no family, either because of abandonment, or because the individual has outlived them? These "exceptions" are excluded from the support of the MINSAL's policy, but most likely are in dire need.

Disclosure statement

No potential conflict of interest was reported by the authors.

Notes

1. At the time this article was written this was the most current national data.
2. People with disabilities in Chile can remain in the school system until the age of 24.
3. For examples see: Sen (1987a, 1987b, 1992, 1999, 2004a, 2004b, 2004c, 2004d, 2009) and Nussbaum (2000, 2003, 2006, 2011).
4. Additionally, the two programs selected are the only ones dedicated to adults with disabilities, regardless of age group.
5. *Servicio Nacional de la Discapacidad*, National Service for Disability.
6. Chilean Pesos.
7. Diagnosis in public policy analysis must be understood as the way to identify elements and relationships for analysis (Sabatier 2007; Dunn 2008).

8. With the matrices, the reader must consider the description of elements provided in the last paragraph of the previous section.
9. Unlike the dimension of services, public benefits are passive in that they do not represent overt actions of care for people with disabilities; examples are tax rebates on certain goods, preferential access to subsidies, transfers, pensions, bonds, etc.

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