Autonomy and Care Work in Swiss Social Policy: The Case of the Personal Assistance Allowance of the Invalidity Insurance

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Abstract

The Swiss personal assistance allowance, introduced in 2012 under the Federal Law on Invalidity Insurance (LAI), aids disabled individuals requiring assistance with daily tasks. Despite its significance, it remains relatively unknown, prompting an analysis of its features and implementation challenges. This article adopts a socio-legal approach to explore this social service's political motives, unique characteristics, and implementation issues. Drawing from interdisciplinary research conducted between 2022 and 2024, including legal analysis and ethnographic study in the Canton of Vaud, the article examines the personal assistance allowance's role in promoting autonomy and empowerment for disabled individuals. It also delves into the implications of establishing beneficiaries as employers. While the Swiss personal assistance allowance reflects a broader shift towards recognizing and supporting the autonomy of disabled individuals, its implementation reveals complexities and tensions inherent in navigating legal obligations and ensuring effective support. In this context, the issue of informal caregivers presents a tension between the recognition of autonomy through contractualization and the practical burdens imposed on caregivers, leading to a shift of responsibilities from care tasks to administrative duties.

Keywords: Swiss personal assistance allowance, invalidity insurance, autonomy, informal caregivers, contract

Introduction: A Socio-Legal Approach to The Swiss Personal Assistance Allowance

Introduced in 2012, the Swiss personal assistance allowance under the Federal Law on Invalidity Insurance (LAI) is the most recent of the instruments introduced by this law. It is designed to help people with disabilities who are in receipt of a helplessness allowance to remain at home

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or return to it, and who therefore requires direct assistance with certain day-to-day tasks. In line with cash-for-care schemes (Ungerson/Yeandle 2007; Le Bihan, Da Roit/Sopadzhiyan 2019), the Swiss personal assistance allowance makes it possible to contract out a number of care tasks performed by home helpers, known as assistants, such as daily living, housework, childcare, support with work, training or leisure activities, or night watches (art. 39c RAI).

If certain benefits of the swiss disability insurance have been subject to various publications - notably the disability pension, auxiliary aids - the personal assistance allowance remains largely unknown to the public, sometimes even to its recipients. This benefit, having celebrated its ten years of existence, allowing for some perspective on its implementation, necessitated an overview of some of its features.

This new benefit appears to be an essential and indispensable aid to home living for a whole category of people with disabilities, embodying, in a Swiss variant, the concept of "independent living" promoted by the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD 2007). It meets some of the needs of beneficiaries, while at the same time giving recognition to care work that has hitherto been invisible. However, initial evaluations of this social service point to a high level of non-use: some beneficiaries do not make use of it, and those who do use it do so only partially (Guggisberg/Bischof 2020). While, as we shall see, the Swiss personal assistance allowance responds both to identified needs and to the demands of those concerned, this non-use raises a number of questions that are at the root of our reflections.

The aim of this article is therefore to use a socio-legal approach to discuss the form of this benefit, which is both emblematic of the shift towards recognition and self-determination of beneficiaries in the field of disability, and original in terms of its specific features. To this end, we will look at the different levels of analysis in order to understand the political project behind this Swiss personal assistance allowance, the benefit itself, and the issues it raises in its implementation.

The data used here is the result of interdisciplinary socio-legal research combining different sources and methods of data collection between 2022 and 2024[3] . On the one hand, we analysed legal texts and institutional documents. On the other hand, we conducted an ethnographic study (Cefaï 2010) in the Canton of Vaud, within an association that supports people with disabilities and helps them to set up the benefit. This choice of fieldwork was guided by the importance of the role played by the associations in implementing this social policy: the invalidity insurance recognises this role by mandating them and funding - at least in part - this support work. This recognition is enshrined directly in art. 39j RAI[4], which provides for the funding of counselling services provided by a third party, at the expense of the AI office[5]. It therefore seemed essential to study the implementation of the Swiss personal assistance allowance from the point of view of the work and experience of the assistance counsellors in an association supporting people with disabilities.

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[3] Research entitled "Aux frontières du care : une approche sociojuridique de la contribution d'assistance de l'assurance-invalidité" ("At the frontiers of care: a socio-legal approach to the Swiss personal assistance allowance") conducted at the Haute école de travail social et de la santé Lausanne (HETSL | HES-SO) by the authors and funded by the HES-SO's Social Work Department.

[4] The RAI is the regulation that complements and clarifies the LAI.

[5] The AI office is the state service responsible for ruling on benefit claims based on the LAI and the RAI.

In this context, we carried out direct observations (Arborio/Fournier 2005) of counselling meetings between professionals and beneficiaries, comprehensive interviews (Kaufmann 2011) with beneficiaries, and focus groups (Kitzinger 1994) with professionals from the association. Interviews were also conducted with a specialist in the provision of this social service at the Federal Social Insurance Office (OFAS/BSV). The perspective adopted, involving a complementarity of data, thus makes it possible to analyse the political and institutional point of view in order to understand the development of this social service, but also the point of view of the beneficiaries and the professionals who support them in order to grasp the issues involved in its implementation on the basis of the lived experience of the people concerned.

The Swiss personal assistance allowance and its implementation raise important issues, both from a legal and sociological point of view, in relation to two legal constraints that underpin its specific nature. On the one hand, it implies the conclusion of an employment contract (within the meaning of the Code of Obligations and standard employment contracts) between the disabled beneficiary and the assistants he or she hires to help him or her. In this sense, it establishes the disabled person as an employer, with the legal rights and obligations that this entails. At the same time, it reverses the asymmetry of the aid relationship (Meigniez 2018), between carer and cared-for, by creating a working relationship between employer and employee. Furthermore, this social benefit only allows assistants to be hired outside the family circle: relatives in the ascending and descending lines, husbands and wives, and cohabitees are excluded (art. 42quinquies let. b LAI). In this way, it goes against the grain of other Swiss services in the debate on recognition of informal caregivers, which aim to relieve these caregivers of the burden by outsourcing care work.

The aim of this article is to show the extent to which the disability insurance contribution is emblematic of the new approach in Swiss disability policy, presented in this paper, and also how its specific features affect the people concerned and the professionals who work with them. On the one hand, we will examine the issues and paradoxes of this social benefit in terms of autonomy and empowerment. Secondly, we will discuss the recognition of the care work at the heart of this service. Firstly, we will look back at the history and context of the Swiss personal assistance allowance in order to understand the political issues behind it. Secondly, we will discuss the implementation of this benefit in relation to its two specific features, based on the point of view of people with disabilities, their families and the professionals from the associations that support them. We will then discuss the implications of contractualising assistance. Finally, we will look again at the place of family members in this model of assistance.

Empowerment at the Heart of the Swiss Personal Assistance Allowance Policy

When it introduced the Swiss personal assistance allowance as a disability insurance measure, the Federal Social Insurance Office (OFAS/BSV) presented the new benefit in the following terms: "the introduction of a benefit enabling people with disabilities to lead an independent and responsible life" (OFAS/BSV 2011: 2)6. The emphasis placed on the "independent and

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[6] All quotes have been translated by the authors.

responsible life" of beneficiaries makes this the culmination of the paradigm shift that began with the 4th revision of the LAI and was largely reinforced by the 5th and 6th from which the Swiss personal assistance allowance emerged. While this shift in Swiss disability policy towards greater responsibility and empowerment is part of a logic of activation (Rosenstein 2012), it also reflects the emancipation movements of people with disabilities, which have led them to be considered as subjects of action, and no longer just objects of care. In these transformations we find the two sides of the notion of responsibility, both emancipating and carrying the potential risk of over-responsibilisation (Genard 1999).

From Stakeholder Demands to the Swiss Personal Assistance Allowance

The empowerment of beneficiaries is thus at the heart of the political project for the Swiss personal assistance allowance (art. 29 LPGA[7]), giving concrete form to article 19 UN CRPD[8], hich establishes freedom of choice of place of residence and the idea of independent living. As with all social insurance schemes in Switzerland, even before they become recipients of the benefit, individuals are called upon to position themselves as autonomous, since they have to apply for the benefit themselves, as entitlement to the benefit is not examined automatically by the disability insurance bodies that deal with the cases. Even if the benefit is only available to recipients of the helplessness allowance, this does not automatically mean that entitlement to the Swiss personal assistance allowance is assessed. In addition, the free choice of the disabled person to hire carers meets the imperative of self-determination. One of the arguments in favour of the form chosen for this new service is that the beneficiary himself can choose and recruit his assistants, thereby anchoring his autonomy. Finally, empowerment is embodied in the rejection of any logic of guardianship - a strong criticism at the origin of the principle of independent living - by establishing beneficiaries directly as employers; it is not possible to go through a third party (institution or service company) to hire staff: art. 24 quinquies let. a LAI provides for the hiring of an assistant by the insured person directly or by his or her legal representative.

The Federal Council defended this choice of restriction in the light of the general objective of the 6th revision of invalidity insurance - like the 4th and 5th revisions - to place the emphasis on the autonomy and responsibility of people receiving assistance: "in accordance with the purpose of AI/IV (art. 1a LAI), the aim is to promote autonomy and responsibility: these competencies must therefore be assumed by the insured person himself and must not be relegated to third parties (guardian, parents, organisations)" (Federal Council 2010: 1692). This same principle is reflected in the UN's recommendations on the implementation of the UN CRPD, in particular in General Comment No. 5 on independent living and inclusion in society, which states, with regard to personal assistance, that "the funds allocated should be managed by the person with disabilities receiving the assistance and should be used to pay for any assistance required" (UN CRPD 2017).

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[7] Loi fédérale sur la partie générale du droit des assurances sociales: Federal Act on the General Part of Social Insurance Law.

[8] United Nations Convention on the Rights of Persons with Disabilities.

The general objective of empowering beneficiaries corresponds more broadly to what Genard (2013; 2007) refers to as a major anthropological shift in social policy, which emphasises the empowerment of recipients of social benefits. For Genard (2013), the transition to an active welfare state is part of this anthropological shift, with all its ambivalence, since we are witnessing both a recognition of the subject in the person being helped, and the risk that the burden of responsibility will be shifted onto the beneficiaries. This paradox can also be seen in social work clients, who are configured and recognised as autonomous and responsible individuals (Breviglieri 2008; Pattaroni 2007).

As far as disability policy is concerned - in Switzerland as elsewhere - this shift has been largely influenced by movements to support and defend the rights of people with disabilities to autonomy and self-determination (Ravaud 2001). In this sense, the development of the Swiss personal assistance allowance responds to the demands of civil society and specialist circles in particular. While, as we suggested in the introduction, associations play an important role in delivering these services, they also have a role to play in shaping social policy. Since the 1990s, these movements have made themselves heard in Switzerland, particularly in the German-speaking part of the country. Numerous demonstrations, the most high-profile of which was the occupation of the park next to the Federal Social Insurance Office (OFAS/BSV) in 1997, raised the debate and opened up discussions on the development of personal assistance (Tschanz 2018).

On the other hand, while the development of a new disability insurance benefit to finance home care tasks does indeed correspond to the demands of the groups concerned, the form that the Swiss personal assistance allowance ultimately took also responds to other issues and constraints. The Swiss personal assistance allowance follows on from a pilot project known as the "assistance budget", which tested different models promoted by movements for people with disabilities. After examining different variants, the central objective retained for making a choice was also financial: "cost neutrality" (Federal Council 2010: 1699).

As a result, the solution adopted - the Swiss personal assistance allowance - only partially meets these initial demands, in particular the ability to employ one's spouse and/or children, as we shall see, takes a rather peculiar form among the Cash for Care schemes. This discrepancy can be seen in the positions taken by umbrella organisations such as CURAVIVA Switzerland and INSOS, which, although they played a major role in the debate on the introduction of the system, subsequently stressed the limitations of the model adopted by the Federal Council.

> *It has to be said that, although the idea was well-intentioned, it was not thought through to the end. The singularly low level of use of the CA [Swiss personal assistance allowance] is undoubtedly due above all to the restrictions on access, as well as to the work involved in calculating assistance benefits.* (INSOS 2019)

> *The Swiss personal assistance allowance could therefore be an important instrument for ensuring the self-determination and personal responsibility of people with disabilities, for promoting their social integration and inclusion and for implementing the United Nations Convention on the Rights of Persons with Disabilities and national legislation. Unfortunately, [...] certain shortcomings*

> *of the instrument make it difficult to achieve its own objectives and social goals.* (CURAVIVA Switzerland 2018: 1)

The development of the Swiss personal assistance allowance in Switzerland is therefore largely influenced by the emancipation movements of the people concerned, but the assistance model finally implemented is not unanimous in all its aspects. In the sections that follow, we will show how the two main Swiss specificities (obligation to become a legal employer and prohibition from employing one's relatives) place the issues at stake in relation to this fundamental and transversal principle of autonomy.

A Cash for Care scheme Like No Other?

Based on a model that is now widely used in disability policies, the Swiss personal assistance allowance is part of what is known as cash-for-care schemes. Anchored in the de-institutionalisation movement - taking people with disabilities out of institutions - these are social policy benefits that consist of a monetary transfer - "cash" - to a person with a disability to finance the direct assistance - "care" - which they need to live at home, while allowing them to organise this assistance as they see fit. These schemes have been developing across Europe since the 1990s, in the wake of movements for the emancipation and empowerment of people with disabilities (Ungerson/Yeandle 2007; Le Bihan, Da Roit/Sopadzhiyan 2019). In contrast to the services or institutions provided directly by the state or private providers, these schemes were originally designed to secure recognition - including financial recognition - for informal care work, much of it performed by relatives (Le Bihan-Youinou 2011). This new approach contributes to a two-fold process of recognition: on the one hand, it tends to establish care as genuine work and, on the other, it raises the profile of the essential contribution made by family caregivers in the field of social policy (Le Bihan-Youinou 2011).

While the logic of cash-for-care schemes is becoming more widespread, there is a wide variety of forms (Ungerson/Yeandle 2007). The main area of differentiation relates to the tension between a family-centred and a non-family-centred approach - whether the system tends to increase or decrease responsibility for the family - depending on the criteria for granting, the objectives pursued, the amounts allocated and the types of control or regulation (Le Bihan-Youinou 2011).

If we refer to the typology proposed by Le Bihan, Da Roit/Sopadzhiyan (2019), the Swiss personal assistance allowance would fall into the 'defamilialisation by the market' category: in this model, the monetary transfer is used to buy services on the market, outside the family, combining an absence of policy supporting informal care by relatives with an incentive to develop a market for assistance services.

In this sense, the Swiss personal assistance allowance contrasts with most European countries, which give priority to supporting families by making it possible to pay relatives, tending rather towards a logic of familialisation. To cite just one example, we can mention the case of Germany, which differs greatly from the Swiss personal assistance allowance in that the monetary benefits are mainly intended to remunerate the assistance provided to relatives. In addition to services, the German long-term care insurance scheme provides for cash benefits where "dependent persons receive the money directly and can use it as they see fit... . When the law was passed, this cash assistance was conceived as a means of paying for assistance provided by family or neighbours". (Ledoux 2015: 95). Conversely, the Swiss personal assistance allowance was designed to relieve the burden on relatives: "At the same time, the Swiss personal assistance allowance will make it possible to relieve the burden on relatives who provide care" (Federal Council 2010: 1692).

Against the general trend, the Swiss personal assistance allowance is therefore a special social benefit with two notable features. It is based on a logic of outsourcing - since the tasks that are now recognised as being able to be taken on were not previously covered and were in fact carried out informally by family members, and are now placed on the market - and on a logic of defamilialisation, since the main family members concerned are removed from the scope of beneficiaries, even if it is legally possible for a brother or sister to become involved. These two movements - outsourcing and defamilialisation - also strengthen the autonomy of people with disabilities, since the benefit tends to reduce the dependency link with the family in particular.

Establishing Beneficiaries as Employers

The first specificity of the Swiss personal assistance allowance that we will discuss in this article concerns the obligation to conclude an employment contract between the disabled beneficiary and the assistant hired to help him or her. Most cash-for-care schemes do not include this requirement. The only other notable exception is the “Allocation Personnalisée d'Autonomie” in France, which also requires the conclusion of an employment contract (Le Bihan-Youinou 2011).

An Employment Contract as a Symbol of Autonomy

This obligation makes disabled beneficiaries the employers of the people helping them at home. This element fundamentally calls into question the relationship of assistance, since it introduces another pattern inside the relationship - a relationship of work - and thus enables beneficiaries to move out of their sole 'position of being helped', reconfiguring the relationship of assistance by reversing the asymmetry (Meigniez 2018). This legal provision therefore effectively establishes a double asymmetry in the relationship between the carers and the cared-for, and between the employer and the employee. This is a form of symmetrisation of the aid relationship that echoes and perfectly embodies the logic of beneficiaries as autonomous and responsible subjects (Pattaroni 2007; Ravon 2007). This model is intended to respond to the demands inspired by the UN CRPD, while reflecting the initial Swiss political will: "the employer model stems from the basic objective of encouraging the autonomy of people with disabilities and transferring skills to them (hiring assistants)" (Federal Council 2010: 1693). As an emblem of autonomy, this contractual formalisation enshrines the recognition of the person being assisted as the subject of the action in their own right and responds to the idea of self-determination. In this way, it strongly counterbalances the devalued status of disabled people, as established elsewhere by invalidity insurance (Probst et al. 2016).

However, this enshrinement of the subject - the autonomous and responsible individual - is highly ambivalent, since it goes hand in hand with the obligations and responsibilities arising from the employment contract: recruitment of staff, drawing up of employment contracts, salary statements, affiliation to social insurance schemes, declaration of salaries for tax purposes, etc. This set of responsibilities falls to the beneficiary since, from a legal point of view, he or she is the employer and therefore bears sole responsibility in the event of a dispute between him or her and his assistant[9], in employment law for example[10]. Neither the disability insurance authorities nor the support associations that help draw up the contracts are formally involved in these employment contracts. Moreover, throughout the process of setting up the Swiss personal assistance allowance for a beneficiary, no employment law specialist intervenes to guarantee or verify the accuracy of the contracts drawn up, for example. So, although they are partially supported, the beneficiaries bear full responsibility in so far as they themselves assume the role of employer. They have to deal with thorny legal and practical issues, such as withholding tax and calculating termination periods in the event of postponement due to illness.

Becoming an Employer: The Ambivalence of Autonomy

"Not everyone is born to be an employer". This quote from one of the beneficiaries we met sums up the difficulties involved in taking on the role of employer. The obligation to enter into an employment contract is a burden that is difficult to bear for most of the people concerned, who in most cases are already in a precarious or vulnerable situation. One mother of a disabled child told us of the fear this burden arouses: "I mustn't do anything wrong, or it will fall back on me", as the obligations arising from the role of employer act as an additional mental burden for the legal representatives of the minors concerned.

The results of our research thus show the ambivalence between, on the one hand, contractualisation, which affirms and recognises the autonomy of the beneficiary by establishing him or her as an employer, and, on the other hand, the obstacles this creates by having to take on the role of employer personally, with all the legal and administrative procedures and responsibilities that this entails.

In addition, we have also observed that some beneficiaries completely or partially waive their entitlement to the benefit because of the cumbersome and complex administrative tasks involved. This finding has already been highlighted in the evaluation report commissioned by the Federal Social Insurance Office (OFAS/BSV) (Guggisberg/Bischof 2020). The result is a transfer of tasks to professionals in support associations, on the one hand, and to family members, on the other. We will come back to this.

This tension - between the recognition of the subject through contractualisation and the complexity of the associated responsibilities - is expressed in different ways by professionals in support associations and by the beneficiaries themselves. From the point of view of the professionals, this translates into one of the well-known dilemmas at the heart of social work. On the one hand, there is the desire for autonomy, the injunction for social workers not to 'do things

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[9] Disputes may be brought before the Tribunal des Prud'hommes.

[10] From the very first years of the LAI Swiss personal assistance allowance, evaluations showed that these administrative procedures were "felt to be a burden" for the vast majority of beneficiaries (Lâamir-Bozzini 2014).

in place of' - emblematic of the transformation of social intervention from working 'on' to working 'with' (Astier 2009) - which has been characteristic of the aid relationship since the paradigmatic shift at the end of the 1980s (Ravon/Ion 2012). In line with this general trend, on the one hand, and the leitmotiv that underpins the Swiss personal assistance allowance, on the other, the professionals we meet in the field are keen to support beneficiaries while avoiding acting in their place as much as possible.

On the other hand, they are just as keen to avoid having to to forgo access to the personal assistance allowance because of these obstacles and legal and administrative difficulties, and their intervention enables them to support the beneficiaries, by carrying out a certain number of tasks for them or with them. The professionals at the association we met perfectly embody this delicate balance to be found in the intervention model. The professional team at the association we studied even changed their approach during the course of our survey. Whereas it used to do most of the start-up work and then transfer and teach the main tasks to the beneficiaries, it has now decided to involve the latter more closely from the outset. The idea is to move away from doing things "instead of/for" to doing things "with", in order to encourage the people concerned to become as independent as possible. At the same time, these professionals also report that, for some beneficiaries, they are well aware that this will never be possible, as they will not be able to do so without close support. So these complex situations present professionals with real dilemmas, in terms of the "promise of autonomy" at the heart of social work (Pattaroni 2007).

Our ethnographic survey of beneficiaries shows that different attitudes can be observed in relation to the complexity of the administrative tasks involved. While some people forego the benefit altogether, others rely on professionals or mobilise family resources or friends. In such cases, the spouse, uncle or brother-in-law is delegated to carry out the administrative tasks, because they have professional resources from different backgrounds supposedly linked to the function: trustee, lawyer, teacher, business employee or other. Finally, some of the people directly concerned acquire the knowledge and skills needed to carry out the various procedures themselves, thus embodying the model being promoted. Some parents in particular, whose children receive the Swiss personal assistance allowance, become true experts in their role as employers. They learn how to draw up employment contracts, salary statements, wage certificates, etc. This apprenticeship is particularly important for parents whose children are severely disabled from birth, and for whom this social benefit is a necessity in order to look after them at home until they come of age and beyond.

Underlying these results, our survey also raises the question of social inequalities when faced with such administrative tasks, depending in particular on the social and financial resources available and on prior skills: knowledge of social insurance or tax administration, or budget management. Professionals clearly identify profiles of beneficiaries, ranging from those with a high level of tertiary education and professional skills relevant to the job - accounting, human resources, for example - to those who live in a precarious situation and are discovering these administrative procedures for the first time.

In addition, the differences in terms of access and ease of use of IT equipment are significant, given that most procedures are carried out almost exclusively via the internet. Professionals also stressed that owning and using a smartphone, for example, is not enough to carry out all these administrative procedures. At present, it has been observed that some of the target group are not computer literate. So, in terms of the objective of empowerment, the implementation of the service raises issues in terms of social inequalities, which future research should make it possible to explore further[11].

Relieving the Burden on Relatives: The Challenges of Recognising Care Work

The Swiss personal assistance allowance makes it impossible to involve relatives in the direct line, i.e. those who are most often involved in this care work: the spouses, parents and children of the person recognised as disabled within the meaning of the invalidity insurance (art. 42quinquies LAI).

The impossibility of committing family and friends as a contribution to assistance raises questions about the very boundaries between formal and informal care, and between paid and unpaid care. While the literature on cash-for-care schemes has highlighted these different forms of care (Ungerson/Yeandle 2007; Le Bihan-Youinou 2011; Le Bihan, Da Roit/Sopadzhiyan 2019), it is above all the perspective of the ethics of care that endeavours to call them into question and "involves redrawing the boundaries between (private and public) spaces" (Molinier, Laugier/Paperman 2009: 27). While studies on disability are generally rather reticent about using the concept of 'care', some pioneering work, such as that by Eva Kittay (1999), has highlighted the contributions of the ethics of care to disability situations, given the radical dependency of people who need ongoing help on a daily basis. By questioning the central norm of autonomy, these works (Kittay/Feder 2002; Damamme, Filion/Winance 2016; Winance, Damamme/Filion 2015) tend to redefine disability and normality in order to rethink inclusion: "recognising the inevitable dependence engendered by certain forms of disability, as one form of dependence among others, makes it possible to acknowledge that these people are full members of the human community" (Winance 2016: 8).

Our survey highlighted the tension between the political plan to "relieve the burden on family members" (Federal Council 2010: 1692) by outsourcing care tasks and the situations observed, where family members still play a central and indispensable role in more ways than one. The evaluation report commissioned by the Federal Social Insurance Office (OFAS/BSV) already pointed to this paradox: while the discharge was widely recognised by the interviewees, the majority also stated that relatives were still (very) involved (Guggisberg 2020: XI).

A further explanation for the decision to restrict funding to assistants from outside the family circle relates to the political and economic issue of limiting the costs of invalidity insurance. The Federal Council justifies its position as follows: "this exclusion of relatives stems from the fact that compensation for the work they do - which is mostly done by women - is part of a wider social policy issue with considerable financial repercussions, which cannot be dealt with in isolation within the framework of the present project" (Federal Council 2010: 1693-1694). This position goes hand in hand with the idea that:

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[11] «Être para-employeur: développement d'une plateforme digitale interactive pour soutenir les bénéficiaires de la contribution d'assistance de l'assurance-invalidité dans leur rôle d'employeur/euse" project at the Haute école de travail social et de la santé Lausanne (HETSL | HES-SO), funded by the Fondation pour la recherche en faveur des personnes handicapées (FRH) as part of the "Technology&Special Needs" Innovation Booster.

> *more extensive compensation for relatives would considerably increase the costs for the AI/IV [disability insurance], as many more insured would assert their right to an Swiss personal assistance allowance. The main effect would be to increase household income, but this would not necessarily increase the disabled person's autonomy or personal responsibility (deadweight loss effect).* (Federal Council p. 1694)

So the Swiss personal assistance allowance and its delimitations highlight a fundamental issue in the social policy system - in Switzerland as elsewhere - and raise the question of the public and institutional recognition of *care* work.

Legal Recognition of Care Work

In this way, the Swiss personal assistance allowance indirectly raises the question of the recognition of care work, starting with that carried out by relatives. In the context of the public debate on the recognition and remuneration of informal caregivers, the Swiss personal assistance allowance proposes another route, that of outsourcing this work outside the family circle.

The legal literature highlights the distinction between benefits that finance family work and the Swiss personal assistance allowance that excludes it. A.-S. Dupont points out, specifically for disabled children, that "the existence of family ties or a de facto situation may also be an obstacle to the granting of social benefits. Such barriers derive from the legislator's desire to delimit the assistance that can be expected to be provided by family members or relatives because of their ties to the insured person, and that which is the responsibility of the State through social insurance" (2017: 174). Freimuller et al. (2018) also point to the legal exclusion of assistance from relatives. Conversely, the legal literature has focused mainly on legal provisions that allow for a "better status for family caregivers" (Baume/Guillod 2016), a trend that does not include the Swiss personal assistance allowance, which favours outsourcing to relieve family carers.

These factors reveal the ambiguous place of care in Swiss law, which recognises the role of informal caregivers within the family circle in certain specific cases. This is the case, for example, with the bonification for educational tasks (art. 29sexies LAVS), which takes into account the years devoted to educational tasks in the calculation of entitlement to retirement pension, or the bonification for assistance tasks (art. 29septies LAVS), which recognises the years devoted to assistance tasks for close relatives - the work of family caregivers - in the same calculation.

Non-Take-Up and Claims for Relatives

Although the care work performed by relatives cannot be recognised and financed by the Swiss personal assistance allowance, this does not mean that it disappears when the benefit is in place. In fact, according to the evaluation report on the Swiss personal assistance allowance commissioned by the Federal Social Insurance Office (OFAS/BSV), the main reason for the partial non-use of this benefit is the existence of unpaid help from relatives: "the main reason given by people who do not claim the full amount to which they would be entitled is the unpaid help from their partner or other members of their family" (Guggisberg/Bischof 2020: p. X). This was also the aim of the government when choosing the form of the Swiss personal assistance allowance, which anticipated a proportion of non-uptake in order to preserve financial equilibrium (Federal Council 2010: 1695).

However, the evaluation report commissioned by the public authorities states that a majority of beneficiaries would like to be able to hire their next of kin through the Swiss personal assistance allowance (Guggisberg/Bischof 2020). The impossibility of employing relatives is even one of the reasons why some people who are entitled to the benefit do not use it (Guggisberg/Bischof 2020: 40)[12].

This desire to include relatives in the Swiss personal assistance allowance is supported by umbrella organisations, which make it a stated demand. CURAVIVA Switzerland, for example, argues that "relatives who provide help and care should be recognised as carers. It should be possible to compensate their services, at least in part, through the Swiss personal assistance allowance" (CURAVIVA Switzerland 2018: 14). In this position paper, the national association of social institutions speaks on behalf of the groups concerned and defends this demand by invoking the principle of self-determination. Their justification is as follows: "people with disabilities can only live out their self-determination if they themselves and their needs are understood, which is often only possible if the person providing assistance and the person receiving assistance know each other well" (CURAVIVA Switzerland 2018: 3).

However, the observations and interviews carried out in our research show a more nuanced position among the professionals and beneficiaries we met. On the one hand, they see it as an opportunity to pay for work that is done for free anyway. On the other hand, they may also be wary of the idea of intimate persons - particularly spouses - becoming employees of people with disabilities. The main risk identified relates to a confusion of roles: a blurring of the boundaries between what is done as a spouse, for example, and what is done as an employee.

More broadly, this debate raises questions about the commodification of care tasks, particularly those performed in private. The introduction of a market logic into the private sphere raises anew the question of the "institutionalisation of care" (Pattaroni 2005), contractualisation being a very specific form of formalisation of care.

Involvement of Relatives and Task Shifting

Beyond this debate between outsourcing to relieve the burden on relatives and recognising the care work of relatives, our research confirms that, in the field, relatives are always very much involved in the implementation of the service. Indeed, the ambiguity of Cash for Care schemes is that, even when they are supposed to relieve families, they do so only in part, because they are always minimally involved in organizing the assistance, if not in the actual provision of care (Le Bihan-Youinou 2011). The Swiss government had even anticipated this and assumed that "the entire need for help will not be reimbursed in all cases, as family members will continue to provide part of the services and other people, neighbours or acquaintances, will also give their time on occasion" (Federal Council 2010: 1695).

Firstly, our results show that relatives continue to carry out a certain number of care tasks even when the benefit is in place. As we have pointed out, this explains, at least in part, the partial non-use of the benefit. This is particularly true at night, when the disabled person is

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[12] However, the difficulty of recruiting staff is also a frequent explanation for partial use or non-use.

living with them[13] . But it also applies to certain tasks that the person concerned will allocate according to their personal preference: "Loulou does the dressings best!"[14] explains this beneficiary when we ask him about the division of tasks between his spouse and his assistants. Sometimes, other factors come into play: difficulty in finding assistants, insufficient number of hours recognised by invalidity insurance, or (un)availability of relatives.

Secondly, relatives are still involved in the sense that there is a shift from care tasks to administrative tasks. The vast majority of people interviewed - both professionals and beneficiaries - noted that most of the time, it is the relatives - spouses, children or parents, depending on the family configuration - who do the administrative work arising from the role of employer. In fact, it is often these relatives who come to the meetings with the association's professionals, as one adviser told us about a beneficiary whose case he was following: "We don't do anything with him: everything goes through his wife!”.

This is all the more obvious in the case of people with disabilities who are minors, for whom the parents, the legal representatives, take on this role directly. On the one hand, they bear the responsibility, in the legal sense, with regard to employment law. On the other hand, in practical terms, they draw up the employment contracts, calculate salaries and holiday entitlement, and draw up the monthly or end-of-year statements, etc. In order to be relieved of a certain number of actual care tasks, they take on other administrative tasks. As one mother said in an interview: "It would be nice if the hours freed up [by the Swiss personal assistance allowance] weren’t spent on administrative tasks!”

The Swiss personal assistance allowance is thus particularly relevant to the debate on how to recognise and take into account informal caregivers, and shows a certain ambivalence in its implementation. While the political aim is indirectly to relieve the burden on informal caregivers, empirical evidence also shows that the burden on informal caregivers has shifted from actual caring tasks to administrative tasks arising from the role of employer.

There is therefore a paradox between the undeniable extent to which family members are relieved of their responsibilities through outsourcing and situations where family members remain very much present in two respects: in an unpaid capacity, family members continue to carry out a certain number of care tasks and they are also often forced to take on these administrative tasks.

Conclusion: The Commodification and Paradoxes of Autonomy

The aim of this article on the Swiss personal assistance allowance was to put into perspective the political project and social movements from which it stems, with the forms of the benefit itself and the issues surrounding its implementation, from the point of view of the people concerned and the professionals from the associations that support them throughout the process. These avenues of analysis highlight the ambivalence surrounding this benefit, which is taking on a particular form in Switzerland, perfectly embodying the logic of empowering people with

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[13] This also allows them to increase their daytime entitlement, as night-time hours owed can be converted into daytime hours.

[14] Nickname given to his wife.

disabilities, between recognition of the right to self-determination and the weight of great responsibility.

Beyond the issues specific to disability policy, the Swiss personal assistance allowance is also emblematic of the major issues at the heart of current debates in social policy: recognition of care work, the place of informal caregivers, outsourcing or familialization, or intervention or empowerment.

This unprecedented form of social provision, involving the conclusion of an employment contract between carer and cared-for, raises anew the question of the commodification of social policies. If Pattaroni (2005) asked the question: "Can care be institutionalised?”, we can just as easily ask whether care can be commodified, and what are the implications of such commodification through the contractualisation of aid. An approach based on the ethics of care invites us to reflect on the issues surrounding the definition and demarcation of the boundaries of care (Molinier, Laugier/Paperman 2009) and to rethink the very concept of autonomy (Damamme et al. 2016; Winance et al. 2015; Kittay/Feder 2002).

Finally, we can mention the current political situation regarding the Swiss personal assistance allowance. A parliamentary motion dating from 2012 has been postponed once again until 2025. This initiative is part of the debate on whether or not relatives should be liable for the Swiss personal assistance allowance, a debate that has been ongoing since the early days of the discussions that led to the introduction of the benefit. It is therefore a historic debate that is still ongoing, and its postponement in Parliament is symptomatic of the issues and tensions - which seem irreducible - surrounding the autonomy and empowerment of beneficiaries.

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