

THE VALUE OF DOMESTIC WORK

THE ECONOMIC AND SOCIAL ROLE OF EMPLOYER FAMILIES



Domestic work and disability



Firmataria del C.C.N.L. sulla disciplina del rapporto di lavoro domestico

THE VALUE OF DOMESTIC WORK

THE ECONOMIC AND SOCIAL ROLE OF EMPLOYER FAMILIES

Dossier 8

Domestic work and disability

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STUDI E BILIBUCHE SULL'ECONOMIA
DELL'IMMIGRAZIONE



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Introduction

By Lorenzo Gasparrini, General Secretary of DOMINA



Disability is a very common phenomenon in our country and it concerns all of the population, under different forms: we have motor disabilities and psycho-sensory disabilities etc. People affected by these disabilities find themselves in various situations and their situations change from person to person, even though they have the same disease.

The assistance of these people brings with it a higher obligation for the family and those who take on the task of supporting them in the continuation of their everyday life.

Within disability, as well as problems linked to the education of the person, the admission into work and social participation; we also need to consider the problem of the assistance of dependant people with regards to disability in two main aspects: quality and duration.

We speak of quality because the assistance of dependant people often requires the specialist expertise of nurses and private structures, especially in the presence of neurodegenerative diseases. Qualified personnel acquire expertise by following specially made training courses, but in domestic work these abilities are acquired in the field. Family assistants learn with the help of the family, whilst working.

The duration is another delicate aspect that the families often present to us. In fact, the domestic employment relationship involving a dependant person requires an elastic contractual composition which is able to allow for the turnover of workers. This is in order to avoid an excessive physical and psychological load linked to the carrying out of the strenuous care work.

We often forget that the condition of dependency doesn't only concern the elderly but that it concerns all bands of the population, including children. In the case of disability at a young age, the aspect of duration takes on different implications: continuative assistance concerns the present and poses an important question on the individual's future. We are dealing with the so-called "After us", to which Law 112/2016 is dedicated and which, for the first time, recognises specific safeguards for people with disabilities when their relatives pass away and it aims to give autonomy to disabled people.

In recent years the variability of technology has also been added to the debate on quality and duration of assistance. The technical development of equipment and tools that take

care of, at least in part, the deficiencies of those with disabilities or help everyday life processes in fact opens other questions on which it would be possible to write a research project in its own right: usage skills, purchase costs, accessibility etc.

It is clear that disability is a complex environment which has many aspects. In order to understand its implications within the domestic sector, we have decided to examine the theme in depth by trying to define, as far as possible, the outlines. A quantitative analysis alone is obviously not sufficient to fully understand the situation. For this reason the study has involved FISH (Italian Federation for the overcoming of disability) and AVI (Agency for independent life) which, as experts, can help us to define the current overview; clarifying the link between domestic work and disability. In order to fully understand the role of domestic work in the assistance of the dependant, it is necessary to call into question some experts who have a deep and direct vision of the phenomenon.

The objective of the dossier is not only to give a picture of disability in domestic work. Through the research we also want to understand what is missing, what steps need to be taken in order to ensure that the family, who for necessity turn to a domestic worker to assist a dependant person, can have the contractual tools and human resources necessary to best manage the situation.

The peaceful life of the families passes through the dignity of domestic work; if we give dignity to the worker we also give dignity to the assisted person. For this exact reason the research project always examines the two sides of the coin. The will to deepen the theme of disability comes from the necessity to understand the criticality presented by these particular employment relationships and the end goal is to design tools and propose long term resolution plans which take into consideration the needs of the families, whilst always respecting the role of domestic workers.

DOSSIER 8

Domestic work and disability

3,2 MILLION
PEOPLE WITH
DISABILITY IN ITALY

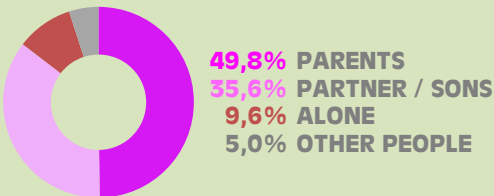


RECEIVING
ACCOMPANIMENT
ALLOWANCE

2.128.440 PEOPLE
70% OVER 65

1,8 MILLION
PEOPLE WITH
«SERIOUS DISABILITY»

LIVING WITH WHOM?



TOWNS' EXPENDITURE
FOR DISABILITY

EURO PRO-CAPITE

2.990 ITALY
5.302 NORTH-EAST
3.855 NORTH-WEST
3.445 CENTRE
3.282 ISLANDS
880 SOUTH



TAX RELIEFS FOR FAMILIES
WITH PEOPLE WITH DISABILITY

Deduction for domestic services. Deduction of income, up to 1549.37 euros.

Tax credit for personal assistance. Deduction of 19% up to 2100 euros of expenses.

Medical and specific assistance expenses. Deduction of 19% + Deduction from income of the costs incurred

Objectives and methodology

Speaking of domestic work, we have observed how the jobs entrusted to domestic collaborators enter into the intimate sphere of the family, such as care for the house and the person.

Even though we generally think of the “carer” as an assistant to elderly people, we shouldn’t forget the many people with disabilities who need help or assistance on a daily basis. We are dealing with categories that are often “invisible”, victims, as well as barriers (material and not) still present in our country and continuous cuts to public spending.

Fortunately in recent years the attention towards disability has increased, thanks also to the many associations present.

The objective of this Dossier is to analyse the specific basic needs of the families in which there are people with disabilities and to understand the implications in the setting of domestic work.

To begin with there is reference to the current terminology recognised in this environment, in order to reach towards a definition which is at the clear and at the same time not offensive.

After a reference to the national and international regulatory framework, we assess the phenomenon of disability in Italy; distinguishing between the elderly and not and between serious disability and not.

That which may seem a simple assessment is instead shown to be very complex, both for the big variety of cases included in the definition of “disability” and for the extent of administrative and statistical sources.

Entering then into the subject of the families’ basic needs, we will go on to analyse the public spending (town/region) destined to assistance and economic transfers that are currently available for the families who have people with disabilities.

A particularly delicate theme is that of people with disabilities who live alone, or of the risk related to the loss of relatives: Parliament has recently regulated this type of case with the so called “After us” Law (Law 2232/2017), establishing a specific fund. It deals with a very delicate issue which concerns the dignity of the people and the peace of mind of the families.

Lastly, with the help of the Italian Federation for the Overcoming of Disability (FISH), we will attempt to understand a special point of view on the disability and domestic work pair.

The use of terms

Reading the newspaper or simply talking, we realise that we very often use terms or locutions as synonymous while in reality they have different meanings. In certain settings, in particular, the use of one word instead of another determines the concept or image that we want to represent. The subject of disability fits perfectly in this sense: even if used in good faith, words like "handicapped" or "invalid" characterise the person only by their "deficit", forgetting that this deficiency comes from the interaction between person and environment. We could talk at length on these linguistic and semantic issues; for example analysing the origin and use of the terms but this isn't the object of our analysis. This reference is intended only to make the reader aware about the correct use of words and to make us reflect on those which are most common on the subject of disability. In order to study in detail we refer to two campaigns that have been conducted in recent years, "Civil talk"¹ and "Words that kill"².

As reported in the figure, some clearly inappropriate terms have gradually disappeared from common use: this is the case of "handicapped", "disadvantaged" and "invalid", which emphasise the detrimental conditions of the person with a disability too much. In the same way "normal" also appears inappropriate; in as much as it defines what is "normal" in absolute terms, excluding all the rest to a condition of diversity.

From "bollino giallo" instead, there are two very common terms: disabled and physically-challenged. In the first case, "disabled" used as an adjective appears quite neutral, indicating the disadvantage that a person can encounter. However, this term is ever more used as a noun, giving a connotation to the person. In this case it appears as only a "weaker" version of "handicapped".


Also "physically-challenged", even though having a clearly positive intent, seems a forced euphemism; almost displaying the negation of the disadvantage and transforming it (paradoxically) in an advantage.

¹ Civil talk, Social writer agency


² Words that kill, Avvenire

The most correct terminology is instead "person with a disability", introduced in 2001 within the new international classification of the operating principles of disability and health (Icf) of the world health organisation (WHO). The same expression has become an international standard with the approval in 2006 by the United Nations Convention on the rights on people with disabilities³, elaborated with the contribution of the most important international associations of people with disabilities and their families. This is the definition given by article 1: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".


Terms used to describe disability




- **HANDICAPPED.** It derives from the horse racing terminology (more weight was imposed to the fastest horse). It is therefore very similar to "disadvantaged": it indicates a person who has a physical, psychological or sensorial disadvantage.




- **ABLE-BODIED.** It makes no sense to talk about "able-bodied", a definition that contains a judgment between who can be considered normal and who does not. Normality does not exist because normality is not an absolute criterion.



- **DISABLED.** If adjective (disabled person), it indicates the condition of "disability", as a dynamic interaction between the person and the environment. Turning it into a noun (the disabled person), the person coincides with his own disability.



- **DIFFERENTLY ABLE.** Born more as a provocation, it appears artificial and too politically correct. Following the same logic, in fact, the deaf becomes "differently hearing"; the elderly "differently young", and so on ...



- **PERSON WITH DISABILITY.** Introduced by the WHO in 2001. In this case, the person is not disabled but has a disability: it is not the subjective condition of people that creates disadvantage, but the interaction with the environment.

Leone Moressa foundation elaborations – DOMINA

³UN Convention on the rights of people with disability, 2006

Institutional and regulatory framework

If in the past disability was a totalising condition that determined, almost relentlessly, a situation of social and working exclusion or a merely care orientated attention; in recent years it has moved towards a greater inclusion (at least in intentions) and socio-work integration.

A turning point in the management of disability is represented by the adoption of the already quoted WHO Convention on the rights of disabled people (2006).

The Convention represents a tool shared from the international community that marks values and objectives to widen the degree of social inclusion of disabled people and involves different stakeholders (regions and local bodies, companies, the world of no profit and civil society). This is in order to achieve, each with their own responsibility, “a society where disabled people can be more and more main characters and free”.

The concept of disability no longer indicates the extreme of the person, as in the past, but it concerns the relationship between the person and their reference environment. In this sense, over recent years and above all with the advance of new technology, numerous barriers have been demolished and the degree of disability whatever its kind has been reduced.

The Convention, approved in Italy in 2009⁴, explicitly quotes education and work as particular environments to which institutions and civil society should be committed.

In particular, the Convention refers to “the right of choice” and the “non-segregation”, principles that are unfortunately still far from fulfilment. The phenomenon, maybe little-known, dramatically emerges following new stories of violence and abuse, also in Italy.

The associations that deal with disability, like FISH⁵, in recent years have carried out numerous projects designed to overcome the conditions of “segregation” and guarantee the “freedom of choice” and the possibility of inclusion to people with disability.

⁴ Law 3 March 2009, n. 18

⁵ Italian Federation for Overcoming Disability (<http://www.fishonlus.it/>)

Disability in Italy

Now let's try to quantify people with disabilities in Italy. In order to do that, there are two main tools: administrative sources and the survey samples.

In the first case however, the only figure available concerns the recipients of accompaniment allowance, with details for gender, age and area. The surveys allow a precise description of the family context of the disabled and the type of help/assistance that they receive but, for the same definition of the state of disability, they use different definitions from those adopted in Law 104/92. In particular, the latter refers to a clinical type approach that envisages the verification of the presence of invalidating diseases. On the other hand, in the population survey carried out by Istat, people with disability are those who report having "difficulty in motor, sensory or essential everyday life functions", in line with the most recent development of international debates.

The same president of Istat has on many occasions underlined the necessity, that hasn't yet been satisfied, to mainly use the administrative sources potentially available; for example the disability inspection papers envisaged by Law 104/92.

More in general, however, we need to remember that the concept of disability for Law 104/92 is at this point considered to be overtaken by that which is promoted by the World Health Organisation and its International Classification of Functioning, Disability and Health (Icf). It is on this classification that the government has for years undertaken research work and experimentation also in collaboration with Istat.

Istat reveals the phenomenon of disability through the survey on "health conditions and the drawing upon health services", carried out on a multi-annual basis⁶.

The most recent edition of the survey goes back to 2012-2013. Precisely in this edition Istat produced an interesting modification in the definition and classification of disability, according to the classification proposed by WHO: disability is no longer considered a condition of the person, perceived as "reduction in the functional ability due to a disease or disability". Rather it is perceived as a negative result "of an interaction between the health conditions of the individual and the environmental factors in which they live" (cultural or physical barriers)".

⁶ Senate hearing of the president of Istat Giorgio Alleva, 05.04.2016

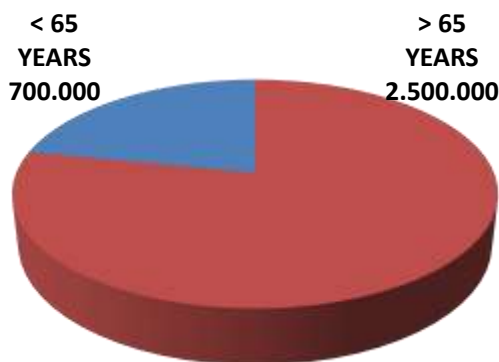
We are speaking, therefore, of people with functional limitations and no longer people with disability. Overall the survey reveals about 3.2 million people, over six years of age with at least one functional limitation, of which about 2 million 500 thousand are elderly.

Functional limitations can be of varying nature and naturally a person can have many limitations at the same time. These limitations can be related to the physical dimension (movement and locomotion functions, around 1.5 million people, equal to 2.6% of the population of 6 years and above); to the sphere of autonomy in everyday functions, almost 2 million people, equal to 3.4% (this refers to the activities of self-care, like dressing and undressing self, washing hands, face or body, cutting and eating food etc.); to the communication setting that concerns the functions of sight, hearing and words, around 900 thousand people, 1.5% of the population. Finally 1 million 400 thousand people (2.5% of the population of six years and above) report being forced to stay in bed, in a chair or to remain in their own home due to physical or psychological impediments.

As far as gender is concerned; the percentage is significantly higher amongst women, 7.1% versus 3.8% of men. From the point of view of area; in the South and the islands the percentage of people with functional limitations is significantly high compared to other areas. During the years 2000, the phenomenon has declined: from 6.1% in 2000 to 5.5% in 2013 and a similar tendency is observed for the elderly population (from 22% to 19.8%).

Distribution of people with disability in Italy by age (2014)

Total people with disability: 3.2 million



Leone Moressa Foundation elaborations on Istat data

In addition to disability in general; we can deepen the analysis of the level of "serious disability" further, in other words people who require specific interventions of assistance and support.

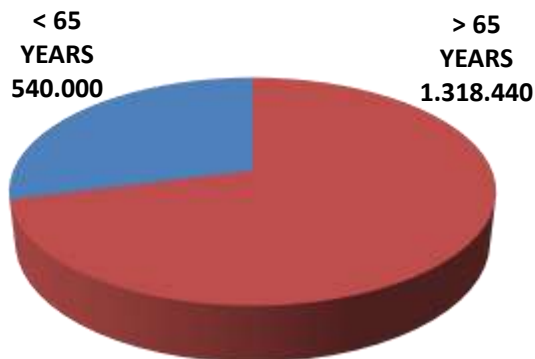
On this theme an important step forward was achieved in 2016 with the approval of the Law "After us" (Law 112/2016). This Law aims precisely to safeguard people affected by serious disability in the moment that they lose the support of their family (in particular with reference to people affected by "serious disability", which is not determined by natural ageing or by diseases connected to senility, who are without the support of family in the fact that both parents have passed away or because their parents aren't able to bear the responsibility of their assistance").

In various parliament hearings⁷, the President of Isat sketched a panorama of the problem. Even in the case of serious disability; figures from administrative sources don't allow a precise estimate (the same person can suffer from more than one functional limitation). From the archive of those who benefit from Inps pensions; it is possible to identify those who receive accompaniment allowance. With this it is considered possible to estimate the state of serious disability (according to the legislation in force; the receipt of accompaniment allowance is assigned to people who are recognised by a commission of legal doctors working for Asl as being in serious conditions). In 2014; in addition to the total amount of people hosted in socio-assistance departments, there are 1.858.440 who receive accompaniment allowance. Of these about 70% are elderly (over 65), while there are about 540 thousand people under 65 with a serious disability.

⁷ 22 October 2014 and 5 April 2016

Distribution of people with serious disability in Italy by age (2014)

Total people with serious disability: 1.8 million

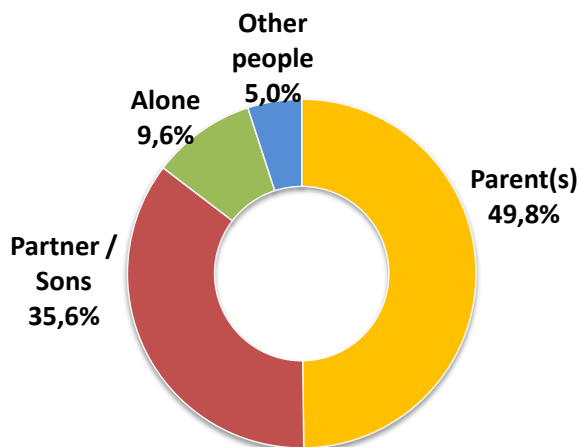


Leone Moressa Foundation Elaboration on Istat data

Among these, in order to take into consideration the needs indicated by the law's proposals of considering disability as that which is not associated to natural ageing or diseases connected to senility, we consider about 269 thousand people who live with one or both parents (49.9%). For these people the risk of exclusion and marginalisation is particularly high, considering the strong dependence on the family network. In particular, amongst these, around 89 thousand people live with elderly parents.

Around a third of people under 65 with serious disabilities (192 thousand, 35.6%) live with their partner and or children, while 52 thousand (9.6%) live alone (of these, 73% no longer have their parents).

**Distribution % people with a serious disability < 65 years by family composition
(2014)**



Leone Moressa Foundation elaborations on Istat data

Towns' expenditure for assistance

Firstly let's analyse at what level the competence of the subject falls. Framework legislation n. 328 of 2000 allocates to towns the competence on the subject of social assistance, in particular as far as economic and logistic support is concerned to families in which there are social needs of varying nature. Amongst these are those connected to the care and integration of disabled people.

Therefore analysing public expenditure for the assistance of people with disabilities requires a comparison of different town sources which are not always uniform. An interesting study by Istat⁸ allows us to compare the town expenditure by geographic area.

Starting in 2009, transfers to towns which are aimed at financing the social expense have suffered drastic reductions. This is mainly due to cuts in the national fund for social policies, but also other funds destined to generate resources for this sector. Amongst these is the fund for dependant people.

In 2013 it is estimated that the resources destined by towns to welfare policies add up to around 6.8 billion euros, of which 24% (1.7 billion) is dedicated to disability, and 19% to the elderly. In the most part this is to support those who aren't self-sufficient. A total reduction of 2.7% is registered compared to the previous year and 4% compared to 2010; when the maximum expense of around 7 billion, 127 thousand euros was reached.

People who receive accompaniment allowance (2014)

Age	Value	Distrib. %	Effect on the population by age
< 65 anni	607.752	28.6%	1.2%
> 65 anni	1.520.688	71.4%	11.6%
Total	2.128.440	100%	3.5%

Leone Moressa Foundation elaborations on Istat data

⁸ Hearing of the President of the National Statistical Institute 11th "Labour, Social Security" Commission of the Senate of the Republic. Rome, 5 April 2016

On the whole, more than half of the around 1.7 billion town expense for disability is spent in the North (Northwest 29.3% and Northeast 25.6%). The average value per person⁹ is 2990 euros on a national level, while this grows a lot in the North. The peak is registered in the Northeast with more than 5300 euros for every disabled person. The highest expense per person is registered in Trentino-Alto Adige (16,912 euros per person) and in second place, in Sardinia (8517 euros per person). At the bottom of the classification the Southern regions are found, in particular Calabria with 469 euros and Campania with 706 euros.

Unlike other user areas, the trend of expenditure for disabled people is still growing, even if with a more controlled rhythm than in the past: from 2003 to 2010 the average annual increase was 8%, in 2012 the cost of services aimed at the disabled decreased in some regions and increased in others, producing an overall increase of 4%.

Towns' expenditure for social interventions and services by disability area (2012)

Area	Total expenditure (Million euros)	Distrib. %	Expenditure per person (euros)
Northwest	496.6	29.3%	3,855
Northeast	433.1	25.6%	5,302
Central	362.9	21.4%	3,445
South	154.3	9.1%	880
Islands	248.1	14.6%	3,282
Italy	1,695.0	100%	2,990

Leone Moressa Foundation elaborations on Istat data

⁹ The values per person are the relationship between the expense and the disabled population. They are estimated on the basis of the number of disabled people that live in the family, resulting from the Multiscopo survey on "Health conditions and the appeal to health services" and from the number of disabled people who are hosted in residential structures, resulting from the "Revelation of the socio-assistance centres".

Almost 211.000 people in a year are employed by professional social services by towns. The main interventions and services by disability area are socio-educative scholastic support which absorbs 21% of resources; day-care centres and other day support structures like protected laboratories which on the whole account for 19% of the expenditure (considering also the network of private centres); residential structures (and the integration in the networks) with 17% of the expense; domestic assistance which accounts for 14% of total expenditure in favour of people with disability.

The domestic assistance offered by towns to disabled people includes various types: that of a socio-assistance type (care and hygiene of the person, help in managing the house and psychological help in the home) has around 38,800 beneficiaries, equal to 6.9% of the population with disability up to the age of 64. The average cost of the service for towns is almost 3700 euros annually per user. There is then also domestic help integrated with health services, of which towns sustain the socio-assistance component (2300 euros on average for almost 10,700 users) whilst the charge of a health nature is at the expense of the National Health Service.

Vouchers, care allowances or socio-assistance vouchers are distributed to almost 22,500 disabled people with an average value of 1992 euros a year. There are also less common forms of domestic assistance which include telephone aid and telephone support (around 2300 users a year) or the distribution of meals and/or laundry at home (1900 users a year). Other significant interventions in the area of disability are: social transport, the support with work integration and various types of economic contributions. Amongst these latter, those which are particularly significant are those for service to people, with around 13,700 users a year and an average amount of almost 3600 euros, contributions for care or health services, with almost 10,300 users a year and an average amount of around 1740 euros a year and economic contributions to integrate family income with almost 13,000 users a year for around 1900 euros per user.

A significant component is made up of socio-health residential structures: we are dealing with an offer mainly financed by the central government, in particular the cost of assistance of a more strictly health nature and of local welfare of a social nature. The distributing agencies are of both public and private nature (profit and non-profit) in particular, in 2013, 29% of beds were offered by public resources, 45% by non-profit and 25% by the private sector for profit (2013 data).

There are 307 thousand beds available for people with disabilities in residential structures, of which 240 thousand are aimed at the elderly, 48 thousand at adults and 19 thousand at minors. These structures assist more than 263 thousand people with disabilities each year, of which more than 80% are elderly, around 19% adults and less than 1% are minors.

The area analysis highlights a strong unbalance; in particular we go from 825 beds per 100 thousand inhabitants in the Northwest to 194 in Southern regions.

Tax reliefs for the families

The current legislation, until now illustrated in its main aspects, offers families with people who have disabilities the possibility to obtain some reliefs of specific assistance costs, domestic services and personal assistance costs with their annual income declarations. There are three possibilities of subtraction and deduction which are applicable in different ways according to the occasion or type of service that the person or nuclear family needs. Three cases in particular are expected.

1. Deduction for domestic services

Also for families of disabled people there is, naturally, the possibility to deduct part of the cost for domestic services of those who are employed legally (home help, carer etc.) up to 1549.37 euros.

In substance though, you cannot deduct any part of the final salary paid to the collaborator, but only those payments that every employer is obliged to pay for social security payment at the moment of salary payment (social security and assistance payments).

2. Tax credit for personal assistance

As well as deductions for domestic services to dependant people and their families, there is also an added opportunity to recover, at the time of the income declaration, a part of the expense incurred in giving the salary to assistance personnel. Until 2006 (Law 311/2004) a fixed deduction of 1820 euros was envisaged, this lowered according to income and other factors. From 2007 (Law 296/2006) this opportunity has been reduced: the expense is no longer deductible on income but there are **tax credits** (from the tax of income) **to the percentage of 19%**, calculable on a total amount no higher than **2100 euros**. An income limit of the taxpayer has also been introduced: if over 40,000 euros tax credits aren't allowed. We need to specify that, different to health costs or costs for buying a vehicle to be used for disabled people, these tax credits can be used by civilly obliged relatives as well as the disabled person themselves and the family who are physically responsible for them .

This concerns a relevant opportunity in that it allows, for example, also relatives that aren't directly responsible for the disabled person to access the tax relief and it also allows "someone" to deduct the expense sustained, in the case that the interested person is without income or has an income that is so low that it doesn't allow for deductions.

It is important to underline that the two measures (tax relief for assistance personnel and deduction for domestic services) can be combined.

3. Medical and specific assistance expenses

The third type of benefit, at the annual declaration of income, concerns the cost of **specific assistance**¹⁰.

This type of expense benefits from a different treatment, depending on whether it is for a person with a disability or not. In the second case, the expense can only be deducted for 19% of the costs incurred.

In the cases that concern people with disability, income can be deducted not only by the direct person involved or their partner who is responsible, but also by relatives who are civilly obliged.

Furthermore, in the case of admittance to an assistance institute, it is not possible to deduct the full costs incurred but only the part that concerns medical expenses and the paramedic expenses of specific assistance. It is necessary though that the expenses are clearly shown in the documentation issued by the assistance institute.

Individuals recognised as people with disability in accordance with article. 3 of Law 104/1992 can self-certificate the existence of personal conditions. This concerns the substitute declaration of affidavit, whose signature cannot be authenticated if accompanied with a photocopy of an identity document.

Summary of tax benefits for families

Type	Beneficiaries	Body	Allowable expenses
Deduction for domestic services	All taxpayers (directly interested or family members who are responsible in a tax way)	Deduction of income, up to 1549.37 euros	Only social security and assistance taxes
Subtraction for personal assistance	Only for dependant people (directly interested or family members who are responsible in a tax or civil way)	Deduction of 19% up to 2100 euros of expenses. Income limit of 40,000 euros	Expenses for the salary of assistance workers (also home helps and carers)
Medical expenses and specific assistance	All taxpayers (directly interested or family members who are responsibly in a tax way)	Deduction of 19% of the costs incurred	Expenses for health workers and for assistance by professionally qualified
Medical expenses and specific assistance	People with a certificated invalidity or disability (directly interested or family members who are responsible in a tax or civil)	Deduction from income of the costs incurred	Expenses for health workers and for assistance by professionally qualified

The role of associations. An interview with the *Italian Federation of overcoming a disability* and *the Agency for an independent life*

When dealing with the theme of assistance for dependant people, one of the aspects to consider is that of assistance for people with a disability. In this paragraph we will deal with the main themes linked to this environment; through an interview with Vincenzo Falabella, FISH (Italian Federation for overcoming Disability) and with Dino Barlaam, director of AVI (Agency for an independent life).

The UN Convention of the rights of people with disability (2006) approved by the Italian Parliament in 2009 and by the EU in 2010, represents a turning point in recognising the dignity of people with disability and the activation of specific policies. What has change thanks to the Convention ?

The UN Convention on the rights of people with disabilities wants to represent a specification in the most precise application of the Charter of Human Rights.

Hinged on the principles of equal treatment and non-discrimination of the individual, it was proposed to change the disability paradigm; urging countries to implement actions that can enable people with disabilities to live their lives fully without any particular restrictions that could damage their dignity.

The Convention obviously deals with all aspects of daily life, but we can find different reflection points in order to reflect on what concerns daily life and specifically the personal assistance to which Article 19 is dedicated. However, it is necessary to organise the text with other articles in order to better understand the range of changes that it intends to achieve¹¹.

Article 19 - Living independently and being included in the community

States Parties to the present Convention recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

¹¹ Starting from the general articles, it is necessary to pay attention to article 1, clause 1 or to article 2, clause 3, unto coordinating the assistance subject with articles 3, 4, 5, 17, 22.

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

What are the steps that still need to be achieved ?

The UN Convention, like all international agreements, has only traced the inside of the crack out of which legislations should be released: now it will be necessary to adjust the existing ones in order to make the rights achievable. The same thing has to concern private and contract agreements, and not least that which is relative to the discipline of family assistance that concerns thousands of families.

The International Commission for the Supervision of the Convention's Implementation (CRPD¹²) has already reported several shortcomings in our country.

One of the objectives of the associations that fight for the rights of people with disabilities (like FISH) is to pass from "segregation" to full "inclusion".

As we said previously, CRPD has imposed a change of paradigm with respect to the consideration of people with disability that live in the world. In other words; that they are not people who should adapt to the situations that are often incompatible to them, but that choices should account for the rights of disabled people that are then the rights of everyone. This should be done with the construction of physical, virtual and relational environments in accessible ways and therefore usable by everyone, including those with physical, sensorial, intellectual and mental disabilities. When necessary, there are specific supports planned for with the aim of producing equality in opportunities to create your own life.

In the perspective of human rights there are no limits; in other words where biological conditions meet an environment which is difficult to access, the concept of "reasonable accommodation" is introduced. On the plan of essential rights, particular attention is given to the contrast of segregation. For this reason there is an article dedicated; 19 for the right to live like everyone else within society, practising every choice and control of your own lifestyles, favouring the use of personal assistance for people with disabilities of whatever age.

¹² Committee on the Rights of Persons with Disabilities

The use of specific residential structures represents in itself the negation of fundamental rights and their structure will therefore need to be radically reviewed in order to make them compatible with the need of the right to live your adult life, assistance needs and adequate support needs according to the indications of the Convention itself.

What do you mean by "inclusion" of people with a disability ?

Up until today the policies in favour of people with disabilities were orientated to integration; in other words to make the disabled person's needs adapt to existing organisations without thinking about their rights. In summary; there needs to be a great change in standards: open up without hesitations to the acceptance of people with disabilities and to the intrinsic dignity of their lives. This also involves taking into consideration the only possible main route, in other words their full participation in the determination of laws, rules and standards that concern citizens, also those with disabilities. The motto of our world is "nothing about us without us".

What are the concrete implications of this principle ?

To plan the territory on the basis of the concept of "universal design", in other words plan for everyone. This means to think that public and private spaces can also be enjoyed by people with disabilities: the concept of inclusion also passes to the possibility to enjoy spaces and every environment of relational life that contributes to the individual's growth, from a child's game to the pension. This passes through school, university, work, home, free time etc. The lack of being able to enjoy these spaces also has psychological effects, in the sense that it discourages the person to fully live their own life. The smaller the enjoyable spaces are, the lower the level of inclusion will be. With respect to services; it is necessary to promote the presence of people with disabilities within the community, recognising their full right to use their own choices and live within society like everyone else. This implies, in the matter of personal assistance, the priority development of services and support for assistance in the person's own home and the adaptation of the regulations which govern welfare services, making them compatible with the rights of workers and other subjects involved in these processes and giving equal dignity to both.

One of the principles of the Convention is that of guaranteeing to people with disabilities the possibility to continue living in their own home. At present, how frequent is the use of residential structures ?

The current situation of our country presents itself as leopard's spots and for this reason we have areas in which there is a discrete presence of assistance services to support staying in their own home and with their own family, and areas in which personal assistance services to the person are basically non-existent. Such a situation doesn't allow us to have a precise vision of the area, but the overall value supplied by ISTAT is the following.

**People aged 6 and over with disabilities (total value in thousands) - Italy
Geographical distribution detail. Year 2013.**

Geographical distribution	People with disability (total value, rounded to the thousand)	Distribution %
North-West	695,000	21.90%
North-East	556,000	17.60%
Centre	625,000	19.70%
South	860,000	27.20%
Islands	430,000	13.60%
Italy	3,167,000	100%

Istat source

**Patients with disabilities or dependant of socio-welfare and socio-health
residential centres**

Year	Total values
2009	284.775
2010	277.541
2011	264.378
2012	257.009
2013	263.048

Istat source

These figures show us how around 8.3% of disabled people are admitted into structures, but this figure is much higher if we analyse only the age range of elderly people. On this theme the numbers take on a relative value if we analyse the phenomenon from a human rights point of view, while we ask the question of identity of values that arises from non-discrimination and equal treatment principles.

How much is this phenomenon attributable to the lack of support on the part of institutions ?

The theme of quality of life of people with disabilities is a recent topic and until now it struggles to be central in the culture of social policies. It is squashed between the absence of a perfect payable right that has brought institutions to overlook the theme and the concept which calls for interventions of support to the families. In this way it has moved attention to another plan that, even if significant, generally still shows the person as a burden instead of an individual with rights. This type of political and cultural planning has produced and produces consequences in terms of support and quality of life of people with disabilities, favouring in fact the use of residential or semi-residential interventions, instead of favouring inclusion and personal assistance policies.

“Deinstitutionalisation” and home assistance until the aged of 70 years are talked about. From that debate, the following were born: Law 180/78, the numerous town and region initiatives to build home care services, and Law 104/92 which describes it in detail, as well as its subsequent modifications in 1998 (Law 162) which introduces indirect assistance. All of this doesn't qualify as a perfect subjective right in every part of Italy, despite the introduction of Law 328/00 that, through the structuring of a real system of social policies in the country, foresaw the incorporation of those services at essential levels (Liveas referred to in art. 22) basing it on the individual project of life (art 14 e 15).

A regulatory body which makes all the instruments necessary available to us: the individualised project, the health budget (with the socio-health integration), and the self-management of health care. Services to people with disabilities in which workers, and potentially their organisations, are mere facilitators.

The peculiarity of support in favour of people with disabilities is fully evident, in that it is characterised by long-term interventions that should be considered for the full period of life, on the contrary to what happens for the elderly and children/adolescents. This is one characteristic that strongly affects the quality of present and future life and it is therefore

necessary to base welfare planning on ways that can favour people to participate in a social life in the fullest way possible. Any welfare path that tends to exclude people with disabilities from social life, be they residential or semi-residential, are potentially isolating.

In this sense, what is the role of domestic and assistance work ?

Law 162/98 opens a significant space to employing family assistants through funding dedicated to the direct hiring of an assistant chosen by the person with the disability. This regulation has in fact tried to recognise a very common practise which is in expansion, as it results also in INPS 2017 annual report of domestic work, hiring of family assistants that often guarantee and favour the person with disabilities staying in their own social environment.

As already said; public funding is fundamental for this type of auto-managed service, in that people with disabilities are rarely able to independently sustain assistance costs because they don't have the economic ability and very often don't have stable work. Conditions that, if they occur, at best, allow the participation in assistance costs. In fact we also need to take into account the burdens that each one sustains in order to live in dignity like others.

The role of domestic work and family assistance is currently able to mainly respond to the aspects that concern the functions relative to the dependant and, therefore, to the care of the person, of things, accompaniment etc. In other words, to those classic functions that have evolved over time, but also those of informal sociality.

What are the specific needs of families and workers in this case ? What are the main difficulties that we meet in this environment ?

The peculiarity of assistance in favour of people with disability is characterised by the long period that accompanies the person. In fact, it accompanies them in the various phases of their lives and takes on an important function in promoting the person and not only that of including the disturbance.

This aspect poses new challenges to domestic work and assistance and a different way to consider work. It no longer concerns taking care of the house and the person in the house, but of thinking of the assistant as a facilitator in life projects. Considering the different disabilities, the needs that can be expressed are also different. For people with a cognitive type disability for example, the service of "carer" designed to control is no longer required. More and more often they are required to contribute to ways towards the disabled person's

autonomy in doing things, when possible, for themselves and/or bettering the level of autonomy, stimulating participation in external activities etc. This is different to the disability of a motor functional type where car accompaniment is often required, in addition to the classic tasks in order to promote inclusion in society rather than staying in the home.

It is precisely with respect to these articulated and diversified needs that needs on the part of workers, with respect to the work load, also emerge. This is a work load that in the most complex cases is trusted to only one person, above all in the cases in which a cohabiting work relationship is established. Such excessive work load often doesn't allow even the workers themselves to have an adequate social life and the result is a modest duration of employment relationships that leads to instability in the assistance and the work.

Having taken account of the needs of people with disabilities and of workers it is fundamental to review the contractual legislation in the light of what has been shown. Mainly regarding some unavoidable elements:

- The prevision of the possibility of Sunday work, even if guaranteeing a weekly rest day on another day, for all types of employment relationship that concern dependant disabled people, in as much as such limit clearly contrasts the CRPD.
- The prevision of part-time 30 hours a week of cohabiting work also for levels C-super and D-super, limiting it in the presence of other employment relationships. In this way a better quality of service and more space for the workers' social life would be guaranteed. With regards to this point, a good availability to work part-time has been shown by people with a discrete socio-cultural level, who see an arch of time weekly reserved for their own lives. This would increase the quality of service offered.

Do specific competencies required of the worker exist in this sector? If yes, how does the certification of the competencies happen?

No, even though they would be necessary. The so-called training on the job is very common; in other words you learn while working. Obviously every certificate of competencies is actually illusory. It would be advantageous; but a different work qualification would lead to a different charging on the part of public and private that doesn't seem to be on the agenda. That which is indispensable is that there are organized individuals that are non-profit and are managed by people with disabilities in the view of peer counselling (art 19 and 26 CRPD). These people have the structural function, in other words already recognised by numerous

second level legislations, to support people with disabilities in the choice, training, management and substitution of the worker.

EBINCOLF - National Bilateral Body of the branch of Employers and Family Collaborators Sector

It is a joint body which was made on 23 December 2002 from the employers' national union organisations and of the most representative workers in the sector of domestic work in Italy: on the part of employers; DOMINA and Fidaldo, on the part of workers; the union organisations Federcolf, Filcams CGIL, Filcams CISL and UilTucs. Ebincolf gave way, in 2017, to an activity of certificating the competences aimed, only initially, at those who had attended with benefit one of the many training courses organised by Ebincolf on a national level. For these reasons; a Commission of Certification was taught which was able to activate all the necessary measures for the management of the activity of certifying domestic workers based on Law n. 4 of 2013.

For more information www.ebincolf.it

Tax reliefs or economic contributions to support families with disabled people exist. Do you consider that these measures are enough to accompany families with disabled people ?

There are different competencies: tax reliefs are national competencies while taxes in general are of the town. This entails the enforceability of the law in the first case and none in the second. In the first case it is a completely non-existent recognition, while in the second it reaches even 2000 euros a month, when you are able to enter in the rankings and above all when there is one (for example until now nothing exists in Sicily).

What are the most urgent measures you would ask the political class in order to improve the living conditions of people with disabilities?

The review of the whole social and socio-health expenditure, intending the 38 billion euros that today are spent in accompaniment allowance, nursing home, work permits etc. This is a substantially unjust expense. Don Milani said that there is nothing more unjust than making equal parts amongst unequal ones. Therefore we need to have very clear that we need to tackle inequality, but the reorganisation of the 38 billion euros, given the ageing of the population, isn't enough. We need a serious investment of 7 billion euros on the so-called

plan of dependency; these are our sums and are to be allocated gradually but in a defined space of time (four years). Without these, nobody is willing to leave the certain for the uncertain.

Conclusions

by Massimo De Luca, lawyer of DOMINA association

As we have been able to experiment with the work carried out until now by DOMINA and FLM, the ultimate objective of the whole research activity is to supply reflections which are useful to know, evaluate and elaborate improvement strategies in Italy in the domestic work sector. In this Dossier we have examined domestic work and disability, analysing from time to time situations and numbers that emerged during the analysis work. We have read and commented in the light of current situations, also with the help of the non-profit organisation FISH – Italian Federation for the Overcoming of Disability and the agency for Independent Lives and whom we sincerely thank.

Addressing the survey carried out and commented on in this dossier, enriched by the interviews with Vincenzo Falabella and Dino Barlaam, we can relaunch the pairing of domestic work and disability in 3 main directions: national collective bargaining agreements, public intervention and training. We are dealing with strongly correlated paths that require a real long-term integrated design, since in this case the assistance to the dependant person becomes one of the many tools to improve the quality of life of the assisted person.

As already faced in Dossier n.2, there are different areas of improvement of the national collective bargaining agreement on the discipline of domestic work, above all if we read it in the light of the needs of the disabled world. While facing certain issues on the theme with Dino Barlaam during our meetings, more than once I was invited to look with different eyes at the assistance of a disabled person compared to that of a dependant elderly person and the assistance of a disabled person. Disability, not being ascribable to a specific age, requires a continuous and consistent assistance which is active and attentive to the needs of the person that is in the plan of their life.

For the assistance of a disabled person, even more so than for other forms of dependency, it is necessary to provide continuous assistance for the person, the home, transport, the kitchen and for everything that rotates around their everyday routine. On the other hand; the worker who assists a disabled person undergoes a strong professional, psychological and physical commitment. Care work, within this frame, risks becoming an excessive load for the worker with the effect of generating negative consequences on a personal level and

their performance capabilities, as well as negatively affecting the relationship with the assisted; since it could become little inclined to a healthy interpersonal relationship.

The national collective bargaining agreement of the sector doesn't foresee the possibility of hiring part-time family assistants for dependant people (levels CS and DS), while art.55 of D.Lgs n.8, 15 June 2015 revoked with effect from 25 June 2015 articles from 41 to 45 of D.Lgs n.276, 10 September 2003, concerning the shared job better known as "*job sharing*". This limitation of the contract represents an organisational and economic obstacle for employer families, since it doesn't give them the opportunity to hire two workers to fulfil a single obligation. Not being able to guarantee a turn over to the sector with shared work or with a part-time contract for the family assistant of a dependant person, level CS e DS, is not acceptable if we reason with a view to improving the quality of life of the patient and the work of the employee.

The other vital element in order to start an improvement path in the sector of caring for people is that of public intervention in the environment of economic benefits. The overview of public help, as we have seen from the analysis, is fragmentary and with the crisis investments in favour of assistance for dependant people, instead of increasing to support families in their moment of difficulty, have worn thin. As highlighted by the representatives of F.I.S.H. and A.V.I., public financing is vital for care work since often the people with disabilities don't have the work opportunities and resources necessary to maintain the cost of private assistance.

Always in the field of public intervention; a greater reactivity in the adaptation of national regulations to ensure that the environment, services and tools are accessible is necessary. The slowness of our country towards the adaptation of European and international legislation is well-known but cannot be used as a justification in front of the people that have to live their daily lives. The project is a path of independent life that disabled people pass, not only for the right payment of funds for the dependant, but also for proactive and supportive policies for the choice of intelligent spending and valid *erga omnes*, as well as for the permanent knocking down of all the physical and cultural barriers of our society.

Formation is the third element that makes up the "trio" that has to sustain the project of change. The complete planning in fact cannot exclude the value of professionalism and of the human resources in our sector, in other words the domestic workers.

In the domestic work sector, as we know, a register on a national level doesn't exist, nor does a recognised formal study path. Yet still the work of domestic collaborator and family

assistant require specific competencies. Until today such abilities are acquired directly in the work place that, in this sector, is the families' home as well as the family themselves. In the big companies; the new human resources are chosen, or formed directly in the company, to fill a space of competence needed to continue a productive activity. In the "family company", the family assistant is a functional resource for the normal continuation of the life of the assisted person, in as much as they need to be ready to follow them and foresee any needs.

In the case of workers who assist dependant people in general; there needs to be complete training which is even more specific in the case in which the dependency is due to disability, since necessity and need are different. Generally speaking; we can pay attention to some aspects which are considered fundamental: communication, first aid, nutrition, hygiene, administering medicines and illnesses.

The first macro-area is that relative to communication; an essential tool to enter into relationship with another person. The ability to interact with others is maybe the main competence required of a family assistant and at the base of a good assistant there is in fact a deep two-way interaction which has to account for the needs of the assisted and also the family. The possibility to establish a relationship assumes in fact the ability to perceive and interpret the characteristics of the person with whom you have contact in the domestic work relationship. Also having an idea about first aid is more than ever a necessity in this sector, given the many situations in which you could find yourself daily. The speed of action, knowledge of basic rules and a first aid box make the difference in situations of emergency. In assistance work for example it is vital to know the emergency numbers, anti-choking manoeuvre and burns treatment etc.

Going in order with the above points; we can say that a correct nutrition is an essential ingredient in order to conserve a good state of health in all ages and especially for older people or those with invalidating diseases. It is important that the worker knows the precautions which allow them to better cope with the physiological changes that can influence nutrition when the years increase.

Personal hygiene is also a fundamental element for the physical and psychological wellbeing of the assisted person. In the case of dependant people; the worker then takes on the role of controller. The assistant, having daily care of the person, can verify symptoms of dehydration, possible allergic reactions to aggressive products etc. In order to carry out the

function of wellbeing guardian; the worker must be trained in how to help the assisted person to carry out physiological functions and daily hygiene.

Another macro-area to not undervalue is that relative to the distribution of medicine and this implies the ability to follow the indications of the assisted person's family members, know how to understand the warnings on the package leaflet and to know the techniques of administering a medicine in the case in which the person can't take it autonomously. In the environment of dependency, there are many diseases that the domestic worker can find themselves facing in carrying out their work of assistance to the person. For this reason it is vital that they have a general knowledge of motor difficulties and of the disturbances linked to neurological diseases etc.

The training of domestic workers has to provide methods and techniques to approach people with disabilities in the correct way, in order to integrate themselves into the daily routine in the best way and better it. The possibility to have personnel with certified competences represents a precious resource for the family. In this sense Ebincolf is moving forward (Bilateral body - art.47 of the national collective bargaining agreement on the discipline of domestic work) which promotes training initiatives and professional qualifications, to give the domestic sector a trained work force. The certification of competences, in fact, has the objective of providing a reference background that frames the duties and requirements of family assistants, so as to increase the qualitative level in terms of services.

THE VALUE OF DOMESTIC WORK

THE ECONOMIC AND SOCIAL ROLE OF EMPLOYER FAMILIES

DOMINA research

National Association of Domestic Work Employer Families

Carried out by the Leone Moressa Foundation

DOSSIER 1. Profile of domestic work employers in Italy. Dimensions of the phenomenon, population trends, economic and social impact

DOSSIER 2. The National Collective Bargaining Agreement on Domestic work and its future prospects

DOSSIER 3. The socio-economic impact of domestic work on the family

DOSSIER 4. Domestic work policies concerning the ILO Convention n. 189/2011. The Italian situation and international comparison

DOSSIER 5. Welfare policies in support of employers' households: European comparison

DOSSIER 6. Care economy: domestic employers as economic actors

DOSSIER 7. Criminal offenses in domestic work

DOSSIER 8. Domestic work and disability

DOSSIER 9. Domestic work in Italy: regional deepening

DOSSIER 10. Disputes in domestic work: balance between legality and necessity

THE VALUE OF DOMESTIC WORK

THE ECONOMIC AND SOCIAL ROLE OF EMPLOYER FAMILIES

Dossier 8

Domestic work and disability



Firmataria del C.C.N.L. sulla disciplina del rapporto di lavoro domestico

DOMINA - National association of domestic work employer families, signatory of the National Collective Bargaining Agreement on the discipline of the domestic employment relationship. Safeguarding and assisting Italian families who, by taking on a domestic collaborator or a family assistant, become employers.

The Association is active throughout the country with its Operational Points in support of domestic work employers.

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