



Program « AGORA »

(...)

Summary HANDILAB

The project HANDILAB has two main goals:

1. An analysis of the socio-economic profile of people with disabilities based on the current administrative data;
2. An evaluation of the effectiveness of the allowances for disabled persons.

The researchers of CESO answer the first question. The second part of the research is carried out by the LUCAS research team

1 Socio-economic profile of people with disabilities

1.1 Overview

In this research report, the possibilities as well as the difficulties of research on people with a disability are examined based on Belgian administrative data. When policy is made for people with a disability, frequently administrative databases are created in which the bare minimum of required data is registered for the policy's implementation. However, when this data is compiled and centralized, it constitutes an invaluable source of information on people with a disability. Moreover, it is a source of information that could strongly complement already existing databases from which current knowledge on people with a disability stems.

Despite the fact that existing databases have provided interesting insights on the living and working situation of people with a disability, an administrative database offers several key advantages. Firstly, administrative data offers an alternative definition of what constitutes 'disability' that would enrich the definitions that are currently used in surveys. The administrative definition of disability is not based on self-reporting, but on policy stipulated criteria. This limits the influence of individual interpretation that is present in self-reporting. Moreover, much survey research is limited by insufficient sample sizes, since people with a disability usually only constitute a small sub-population of the already limited general survey population. Administrative data, on the other hand, allow researchers to draw a sample directly from the entire population of people with a disability. And in this case, the larger the sample size, the smaller the relative cost- unlike in survey research where sample size and cost are directly linked. What's more, all people that could potentially be included in the sample can effectively be incorporated, including the considerable number of people that live

in collective institutions as well as those who are only minimally able or entirely unable to (autonomously) participate in a survey. Finally, administrative data regarding income are more reliable since they are acquired more directly from their administrative source.

However, an important challenge when drawing on administrative data for research on people with a disability lies in the strongly fragmented nature of Belgian policy regarding this target group. This fragmentation is not only caused by the division of jurisdictions between districts, provinces and the federal government- nor by the traditional division of labor categories into (former) employees, the self-employed and civil servants- but is also due to the divergent goals of all relevant actors. For instance, some actors prioritize financial compensation for people with a disability while others place greater stock in labor negotiation. The result being an arena in which very diverse administrative data are collected.

This fragmentation has two notable effects on available administrative data. Firstly, it is currently a challenge to merge the different datasets in order to generate a holistic picture of all people with a disability. Secondly, each institution defines its target group differently. For instance, while some institutions determine disability status based on diminished earning power, others define being disabled on the basis of reduced self-sufficiency. These criteria often oversimplify disability as a chronic physical, mental, intellectual or sensory affliction coupled with behavioral and/or environmental limitations that impede full everyday participation in society on equal footing with the general population. As such, these criteria are proxies, just as self-reported disabilities in survey research are also only proxies for people with a disability. Therefore, all research based on existing administrative data is colored by the distinct criteria established by each defining institution for what constitutes a disability. This fact has disadvantages that become apparent when the determination of disabled status depends on a threshold value (i.e. 66% incapable of working), when determining criteria differ between institutions or when criteria change over time. Nevertheless, these data still provide a broadly accurate overview of the disabled population for policy makers and, as such, are complementary to those based on self-reporting.

The Datawarehouse Labor Market and Social Protection (DWH LM&SP) offers a unique opportunity for research on people with a disability since this database incorporates data from a broad spectrum of administrative institutions and applies them at the individual level. More concretely, for each person an extensive number of background variables related to his/her socio-demographic profile, employment status and unemployment benefits can accurately be mapped. An additional advantage is that this database provides a consolidated and longitudinal collection of information in which cross-sectional characteristics can be examined and trajectory analysis can be used.

Despite the fact that the DWH LM&SP has become indispensable for in-depth administrative research, certain gaps remain. For instance, it is not possible to access the entire research population of people with a disability from this database.

Certain data on medical recognition of disability are not available:

- There are no data available on the target groups of disabled individuals in regional institutions.
- Information on social compensation regulations (for victims of war) is not accessible.
- The DWH LM&SP will only have information on permanent work disability due to an occupational accident at a later date. Therefore, accessing the entire research population based solely on this database is not yet possible.
- The available National Employment Office (RVA) data do not have explicit indicators on disability due to occupational accidents, as is registered by labor mediation services.

Other data on medical recognition of disability are only partially available.

- Limitations were noted in the public sector in the registration of sick leave, occupational disease, occupational accidents and the allotment of retirement pensions due to physical disability.

Furthermore, another set of limitations were apparent regarding the structure of the available data:

- Statistical gaps in databases were evident in the Fund for Workplace Accidents (FAO) (work accidents), the Provincial and Local Governmental Social Security Services Office (RSZPPO)- (state institutions – employers) and the Pension Services Office for the Governmental Sector (PDOS) databases, among others, in which such institutions use different data structures or variables from different periods of time.
- Such discrepancies can obstruct the standardization of the above-mentioned periods and, therefore, can confound data on the period spanning primary disability to invalidity.
- Another structural gap is evident in the fact that institutions employ different units of measurement for these periods. While some data are updated monthly (i.e. POD MI-data), other data are only updated at four-month intervals (i.e. RSZPPO) and still others on a yearly basis (i.e. PDOS professional career information).

1.2 Population size, socio-demographic profile and labor market participation

Based on the available administrative files from the DWH LM&SP, approximately 793.700 people, or 7,4% of the Belgian population, have a medically recognized disability. This percentage is lower than that found in the existing statistics based on self-reporting, according to which approximately 10% of the general population reports having a moderate to serious disability. Based on administrative data, the number of people with a disability that fall into the active workforce age group is estimated at approximately 464.470, or 6,7% of the above-mentioned disabled population. This discrepancy between administrative and self-reporting numbers might, in part, be attributable to information gaps in the DWH LM&SP - which still falls short of providing an exhaustive overview of the Belgian disabled

population- and in part be due to the fact that the administrative criteria used to define disability are stricter than the self-reporting criteria. Regional differences in reporting draw even more attention to discrepancies in data on the Belgian disabled population. One such example being the large-scale under-reporting of disability in the Brussels Capitol Region, making it clear that supplementary analysis is required.

It also became apparent that a relatively large percentage, namely 20% of all the people with a medically recognized disability, were counted twice or more by various institutions. More than 80% of these cases were counted twice or even multiple times in the social security system's invalidity services section and in the income replacement and integration benefits service.

In this way, the centralization of the various administrative databases at the individual level- undertaken for the first time in this study- is vital to prevent future inconsistencies in data on the Belgian disabled population (such as double counting) from occurring. Without such data centralization at the individual level, people with a disability would appear twice or more in the census count. Therefore, it is clear that data on the medical recognition of a disability should be linked with the DWH LM&SP.

Socio-demographic data have indicated a number of trends and have led us to draw certain conclusions. The population of people with a disability is on average older than the general population. Furthermore, the relative weight of the oldest age group within the disabled population increased between 2003 and 2007: therefore the aging of the general population is also reflected within the disabled population. Another specific trend is apparent among the disabled population. The percentage of people with a disability has increased proportionately more among the oldest elderly (75+) than among younger elderly and those of a professionally active age. Accordingly, policy for people with a disability has become integrated with policy for the elderly. This point is extremely important since elderly with a disability run a higher risk of becoming socially excluded (Council of Europe, 1997: 18).

In the registers of (medically) recognized disabilities, women have gradually come to account for half or more of the disabled population. The fact that this increase is apparent in the social security system points to an increase in women's participation in the labor market. Their numbers have also increased in groups that "traditionally" included a more limited percentage of women, such as those with permanent disability due to work related illness.

On another note, the number of people with a disability who can effectively be supported by their respective households is also changing. Four out of ten people in the 16-64 age group have a vulnerable household situation, not only in terms of being single themselves, but also often coming from a one-parent household. In this light, the fact that the number of single individuals among the disabled population has increased by three percentage points within the last few years- and up to six in the social assistance system- is noteworthy.

Additionally, people with a disability are only minimally active in the labor market. The data analyzed did not show any general increase in the number of effectively working disabled people between 2003 and 2007. Despite the fact that 30% of this group is supposedly

officially employed, this percentage decreases by almost half after adjusting for those that effectively work. Therefore, less than one fifth of those with a disability of a professionally active age can rely on employment as a source of social integration. Additionally, disabled people of a professionally active age tend to more frequently fall back on free-lance work than do their counterparts in the general population, which may be attributable to both to the disability itself as well as to official labor restrictions. These restrictions may also have an impact on the labor regime of previously performed salaried employment. Accordingly, a high percentage of part-time work was noted (41%). These factors highlight the limitations of the labor system in terms of partial or progressive return to work for most employees regarding health insurance. In the social assistance system, the percentage of full time employees is 76%. This does not necessarily refer to the accumulation of work and unemployment benefits; however, this does concern full-time employment coupled with medical recognition of disability, in which a person with a disability can fall back on this safety net in case of loss of income from work and from income replacement allowances.

Labor market participation was supposed to be the driving force behind the expected increase in average income. However, our previous findings indicated that there was no positive evolution in real labor market participation during the period being researched. And at the same time, the average individual income for people of a work active age decreased considerably between 2003 and 2007, thereby decreasing the average proportion of work for individual income. Conversely, the importance of social assistance benefits as a means of compensation for disability increased. Currently, such allotments account for approximately four fifths of the income for people with a disability; moreover, nine out of ten individuals with a recognized disability have, at the bare minimum, access to such disability compensation benefits.

Moreover, in 60% of cases, this source of income accounts for the only (known) source of income. Nevertheless, during the same year of research, approximately 30% of disabled people of a work active age supplemented their disability allowance with at least one income from formal employment (22,5%) or with (an)other social assistance benefit(s) (14%). On the other hand, 7% of the study population that did not receive disability benefits did have another source of income. This percentage refers to people that were likely recognized as having a certain disability but who relied on other sources of income due to the application of the conditions for accumulation, for instance.

Since disability benefits are often linked to earnings from previous employment, it was expected that certain groups with a (potentially) more extensive professional career, would have higher incomes. For this reason, emphasis was placed on the relatively stronger position of men, on older age categories and on individuals covered by the various social security systems. The data indeed confirmed that, during work active ages, the average individual income is higher among men, increases with age and is higher among people that are covered by social security. Although the right to disability benefits has increased, this has not necessarily translated into a higher average income for all individuals with a disability. Rather, the average income has only increased among younger age categories,

among women and among people that solely rely on social assistance benefits. For the elderly, men and individuals covered by the social security system, disability aid does not sufficiently compensate for a decrease in income from employment and/or other benefits.

It is, furthermore, striking that people with a medically recognized disability, as determined by the social security system, are largely limited to disability compensation aid. Less than half of all those covered by the social security system solely receive this kind of benefit. In this system, fewer people rely on 'supplementary' income than they do on "additional' income from disability benefits. Moreover, there is a higher incidence of people without a (known) source of income relying on the social assistance system (12%), whereas their counterparts in the general population with similar barriers to labor market participation (depending on the system to which they belong) become more reliant on intra-family solidarity.

1.3 Itineraries

Longitudinal research into the itineraries that people with a disability follow is rare, particularly in Belgium. However, the presented research provides new insights into this area. First, having a medically recognized disability is not always a static state of being, but often a dynamic reality. More concretely, in 2007, 15% of all disabled people had an intermittent integration itinerary, during which periods of recognized disability alternated with periods of non-recognition. This flexibility confirms the existence of 'intermittent disability'- also in the Belgian context- and calls into question the perception that disability is a linear one-way evolution. Intermittent integration itineraries are more common among 25-34 year olds, and more so among men than among women. A possible explanation for the higher proportion of such itineraries among these groups may be that they run a higher risk of having non-permanent conditions, such as temporary mental problems. Conversely, a large majority (64%) must still undergo an extended disability recognition process (a minimum of five years). The importance of these extended processes increases with age and rises to 74% in the oldest age group.

Second, analysis of people's last socioeconomic situation before the start of the recognition process only provides limited evidence to support the premise that disability benefits function primarily as a last resort for people who have exhausted all other kinds of social security and social assistance options. More than half of all people with a disability draw on such benefits while having a job. This percentage is slightly less than one might expect based on general population statistics. Approximately 27% enter this system from an unemployment benefits entitled position. This percentage is just slightly higher than one might expect based on general population statistics. However, further refinement shows that of those who partake in this system, the number of people looking for work who receive RVA unemployment benefits is significantly higher than among the general population. This disparity is, nevertheless, compensated for by the fact that individuals entitled to an Early Leavers' Pension seldom partake in the disability benefits system at a working age.

However, more important than the influx of non-working disabled individuals- who are

beneficiaries of unemployment benefits- into the disability benefits system, is the influx of those who are not entitled to unemployment benefits: the latter accounting for 21% and is almost double of what one might expect based on general population statistics. This shows that it is not so much the influx of disabled people from other social benefit systems, but rather, the influx of a non-active, non-beneficiary population that is over-represented in the population of people with a recognized disability.

Third, the percentage of people with a disability that enters the social assistance system after having exhausted all rights within the social security system seems to be relatively small. Rather, most cases (57%), draw directly and exclusively on the social assistance system. In only 6% of cases did people initially have medical recognition from a social insurance provider- that they later lost- and who, consequently, came to rely on social assistance benefits. Another 27% supplemented initial medical recognition of disability (and the accompanying benefits) from the social security system with recognition (and benefits) from the social assistance system.

Finally, longitudinal data showed that even among the group of people with a long-standing medical recognition of disability (a minimum of 5 years), there is still some labor market participation: 11% of this group was working for the full 5 years and 22% was employed at some point during this period.

1.4 Administrative recommendations

In the previous sections, the advantages of administrative databases, the Datawarehouse Labor Market and Social Protection in particular, were discussed. However, so too were the shortcomings of the available variable sets. Based on our experience with the variables in the DWH LM&SP, we offer a series of recommendations in the hope of improving possibilities for research on people with a disability when drawing from this administrative source. As such, we make a number of suggestions concerning the use of derived variables that could ultimately complement the DWH LM&SP. Such derived variables could save time and money in future research, as certain relationships between and within databases would not have to be continuously re-entered and retrieved from the data - as is the current practice. The annexed documentation and the SAS database would be of use for this undertaking.

We stress the value of including variables that would facilitate the follow-up of people with a disability over time as well as incorporating a variable that would provide a more accurate starting point in relation to labor market participation.

Imagine, for instance, the inclusion of secondary frame variables in the nomenclature of socio-economic position that would indicate, per quarter, whether or not someone –under more stringent delimitation rules (such as are used in this study)- is formally recognized, by one or more institutions, as having a disability, and –by extension- whether he/she is entitled to an income based on this recognition. This would offer researchers the possibility of immediately distinguishing a global and unique population of people with a disability; and, of

being able to do so at different points in time as well as both by level of recognition and level of benefit entitlement.

Measurement error of employment rates, when based on *formal* employment rates, increases when focusing on specific target populations, such as people with a disability who are often in the midst of a period of assimilation. The inclusion of a secondary variable in the nomenclature of socio-economic position that, on a quarterly basis, would link formal employment to volume of work performed for the most important jobs would prove, in this respect, invaluable. Accordingly, not only should salaried work be corrected for based on the National Social Security Office (RSZ) and Provincial and Local Governmental Social Security Services Office (RSZPPO) supplied Full Time Equivalent (FTE) variables, but so should self-employment, for which no work volume is registered.

A number of variables could provide insight into the medical recognition process followed, among which include the influx background of the most recently known disabled population. However, since the construction of these variables requires extensive integration of employment data, institutions acknowledging disability and other social security institutions throughout the years, this integration should automatically be made available in the Datawarehouse Labor Market and Social Protection.

- Firstly, this refers to the type of medical recognition process that the disabled person in question underwent: i.e. an extended process, with or without moment of influx, or an interrupted recognition process.
- Moreover, the length of the most recent recognition process, as well as the socio-economic position of the person prior to this process, could be shown.
- In order to analyze transitions between compensation schemes, it would be possible to verify in the first quarter the position of the most recent recognized period in the disability systems.

In relation to the income position of people with a disability, and building on the Datawarehouse Labor Market and Social Protection: Expansion Concerning Content and Methodology (DOCDWH) concept of income, additional variables could be incorporated that divide income into three major components, with emphasis on a separate component for 'disability benefits.' This would facilitate comparison of the financial support this population receives from governmental agencies specifically targeted at this group proportionate to the contributions this population likewise makes in support of employment and other welfare benefit systems.

There is room for further expansion on existing reflections: especially with regard to a number of aspects related to labor market participation, including the relationship between formal and other forms of employment.

2 Effectiveness of the income replacement allowance and the integration allowance

Income replacement allowances (IVT) are part of the system of social assistance. Persons who are not able to acquire a full income from labour because of their disability are eligible for an IVT. Moreover, these disabled people are not entitled to other social security benefits because they didn't build up sufficient social security rights. So, IVT is a form of needs-tested social assistance aimed at a specific target group. The integration allowance (IT) is awarded to persons who have additional costs due to their reduced autonomy. In order to receive an integration allowance, the impact of the disability on performing various daily tasks is examined.

This research focuses on this group of beneficiaries IVT/IT between 21 and 65 years. In 2011, there were 133.501 beneficiaries, compared to 94.044 in 2002, representing an increase of 42%. Little is known about the life situation of this specific and growing group of people who are entitled to IVT/IT allowances.

2.1 Three viewpoints of effectiveness

We can distinguish between three main objectives of social security: (1) ensuring a minimum level of protection for every citizen, (2) providing an adequate standard of living, and (3) enabling social participation (Cantillon et al, 2003). The first objective is linked to the system of social allowances which should guarantee a dignified existence for everyone. Social insurance realizes the second objective by guaranteeing a certain level of standard of living when social risks occur (unemployment, illness, old age). The third function of social security implies that benefits are just a means to an end, namely to enable participation in society.

Based on these three objectives, we distinguish three distinct viewpoints concerning the effectiveness of IVT/IT allowances. The first question is to what extent the allowances ensure a minimum level of protection by preventing poverty and severe material deprivation. To encompass the different faces of poverty, this study uses a multidimensional measurement of poverty. Poverty is viewed from a broader perspective which is less unilaterally linked to income and the degree of deprivation.

Secondly, this study analyses to what extent the allowances provide an adequate standard of living for disabled persons in comparison to non-disabled persons. Therefore, we first analyse the extra costs beneficiaries have as a result of their disability. Then we examine to what extent the allowances offset these additional costs.

Third, this study examines to what extent beneficiaries participate in society. We thereby distinguish three aspects of participation: (1) work, (2) participation in socio-cultural activities and (3) social contacts.

One can also speak of different degrees of effectiveness. When only a minimum protection is realized, the effectiveness of the IVT/IT allowances is limited. The effectiveness is optimal if beneficiaries are able to fulfil all three objectives.

2.2 Measuring the extra costs of disability

In the literature, roughly four methodological approaches are distinguishable to measure the extra costs of disability.

By using a subjective approach, people with disabilities are asked to indicate their additional costs. The total of these expenses is an estimate of the extra cost of disability. The disadvantage of this approach concerns the difficulty to estimate the additional cost. Therefore, only rough estimates are obtained from persons with disabilities. In addition, it should be taken into account that expenditures depend on the income. Spending more on disability-related goods and services automatically implies spending less on 'ordinary' goods and services. As a result of this compensation mechanism, the estimations of the actual additional costs often tend to underestimate the total cost of disability. Following the subjective approach, it is difficult for most people to remember how much they spend or have spent on an item or service. Some people have no clear overview of their spending, others can only give a rough estimate. Some costs are (partially) reimbursed which causes difficulties for respondents in finding out the net costs.

The comparative approach compares the spending pattern of similar disabled and non-disabled people. The expenditures on various goods and services are mapped. Often, respondents are asked to keep track of all household expenses in a written journal, e.g. for an entire month. The difference in expenditures between disabled and non-disabled people indicates the additional costs of disability. This comparative approach can only be used to measure the actual costs, not the potential costs. The disadvantage of this approach is that keeping a household expense journal is a tedious task for many respondents. Moreover, sometimes the results of this approach are difficult to interpret. Given the study population, the feasibility of this method is questionable. For example, Pacolet et al (2008) experienced difficulties when surveying chronically ill.

In the budget approach, the needs of disabled people are clarified by organizing focus groups, resulting in a comprehensive list of goods and services necessary for an adequate standard of living. Based on this list, the required income is calculated. A disadvantage of this approach is the lack of an unambiguous definition of standard of living. Determining the list also takes up much time. In addition, a specific standard budget for disabled people is required to make the comparison with the standard of living of non-disabled people. In general budget standards are scarcely available. Recently, however, Storms and Van den Bosch (2009) established a budget standard for Flanders and Belgium.

The Standard of Living approach emphasizes the relationship between income and standard of living (Zaidi and Burchardt, 2003). The main premise is that people with disabilities have a lower standard of living than non-disabled people with the same income, precisely because they have additional expenses due to their disability. Therefore, to achieve the same level of standard of living as a comparable non-disabled person, a disabled person needs more income. Those extra costs resulting from the disability are thus expressed by measuring the difference in living standard between comparable disabled and non-disabled people with the same income.

This study uses the Standard of Living method, supplemented with the subjective method, to

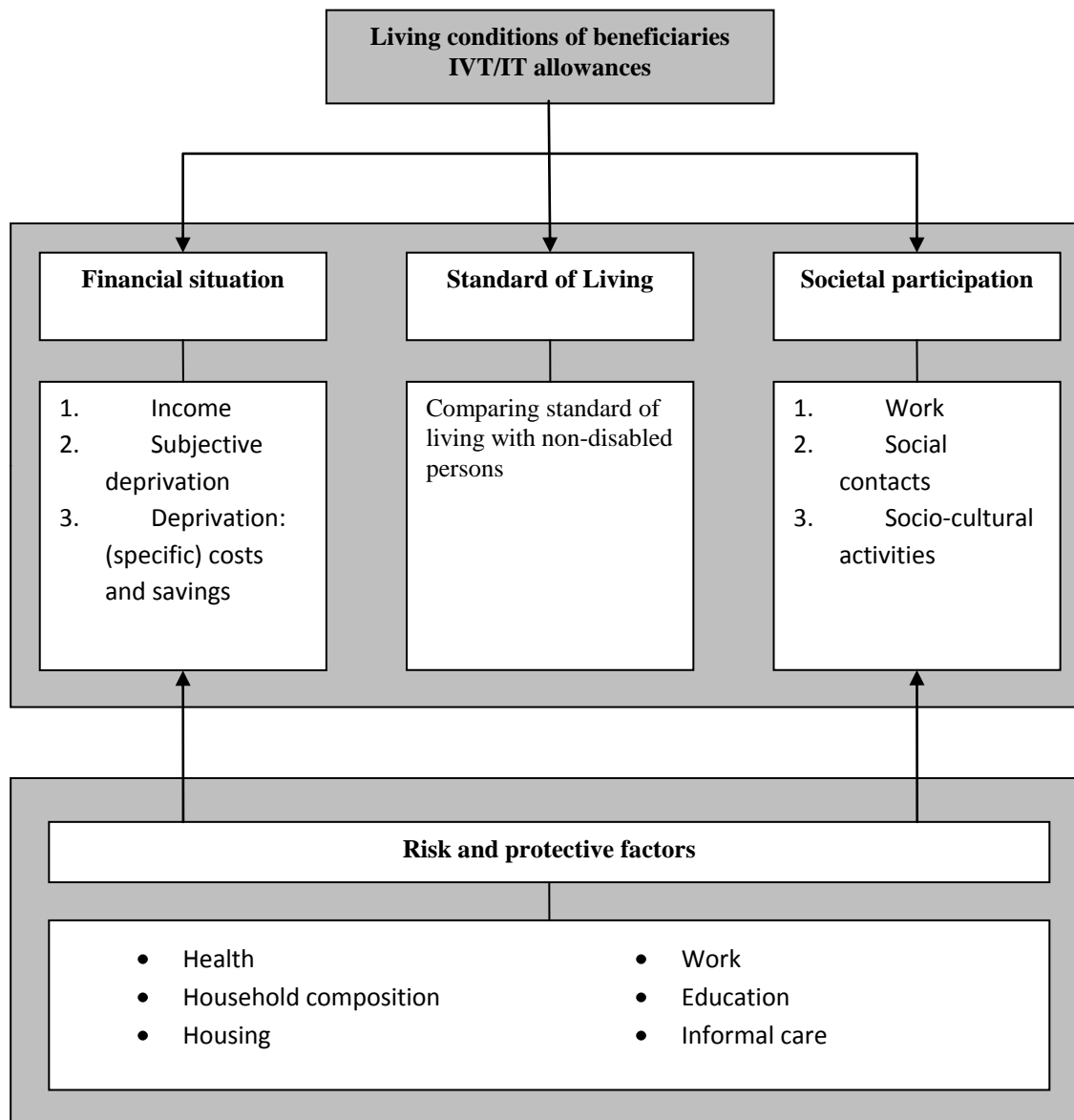
measure the extra cost of disability. The Standard of Living approach is practically feasible, because relatively little detailed information about the expenditures is required from the respondents. Using the representative EU-SILC data on income and living conditions of Belgian households, we delineate households without persons with disabilities in order to compare their standard of living with the group of households which include IVT/IT beneficiaries.

A disadvantage of the Standard of Living method is the abstractness of the results. In the end, neither the type nor the heights of the cost of disabled people are clarified. The Standard of Living method is 'top-down' and only results in an estimate of the extra cost of disability at household level. The Standard of Living approach is not able to specify which types of expenditures contribute to the extra costs (Berthoud et al., 2003).

In order to make the extra costs of disability more tangible, we also make use of the subjective method. We pose questions directly both about medical and non-medical costs. This provides more clarity in the use of care, goods and services by persons with disabilities and the associated costs. To take the compensation mechanism into account, which leads to an underestimation of the total cost of disability, we also highlight the saving patterns of beneficiaries.

2.3 Research questions

The figure below visualizes the conceptual model of this study. The three aspects of effectiveness are the dependent variables. To encompass the diversity within the population of persons with IVT/IT allowances, we include several independent protective and risk factors, namely health, household composition, housing, work, education and care. Thus, it is possible to define specific target groups within the general population of beneficiaries for which the effectiveness of the allowances is more clearly limited.



To assess the effectiveness of the IVT/IT allowances, we pose three questions:

(1) To what extent do the allowances guarantee a minimum protection by preventing poverty and severe material deprivation?

(2) To what extent do the allowances compensate the additional costs of disabled people, by guaranteeing an adequate standard of living, comparable to a person without disabilities?

(3) To what extent do the beneficiaries participate in society?

2.4 Method

In existing surveys, respondents entitled to IVT/IT allowances are underrepresented and/or difficult to delineate. In order to obtain a representative sample, this study draws upon administrative data containing payment information from the Federal Social Security Administration. The sample is based on the data of the month December 2010 which contains all beneficiaries between 21 and 65 who are entitled to IVT and/or IT allowances.

Persons who reside in an institution or speak German are not included in the population. The sample is stratified based upon type of benefit, region and age, resulting in a sample of 2,000 persons. These individuals received an announcement letter containing information about the survey on behalf of the DG Persons with Disabilities of the FPS Social Security. TNS Dimarso realized 1.118 face-to-face interviews based upon a written questionnaire between March-May 2011, representing a response rate of 56%.

We also make use of the Belgian EU-SILC data from 2009 (European Union - Statistics on Income and Living Conditions). This sample aims to make representative conclusions concerning the income and living conditions of all private Belgian households. To estimate the extra cost of disability, we compare households including a beneficiary IVT/IT (from the sample HANDILAB) with households without persons with disabilities (from the sample EU-SILC).

2.5 Results

2.5.1 Profile of beneficiaries IVT/IT allowances

28% lives alone. 32% lives together with another person. 20% lives in a household with 3 persons and 19% is part of a household with four or more persons. Nearly a quarter of the respondents lives together with his parents. 18% lives together with a partner but without children. 15% lives with partner and child(ren) under 14 years of age. 8% of the respondents are a single parent with a child younger than 14 years. In 43.4% of the households, one or more other members of the household have a disability, a chronic illness or disability, in addition to the respondent. This results in an additional financial and social vulnerability.

28% of respondents own their home. In total, 42% of respondents rent: 20% are tenants of social housing and 22% are tenants of a private home. 11% lives with a family member/friend/acquaintance while paying fee. 11% doesn't have to pay for housing.

11% of respondents currently has a paid job. A large majority of has a permanent contract (82.1%). Of those respondents who are unemployed, only 5.8% is currently looking for work. However, 59.8% of the respondents who don't have a job once had paid work. 40.2% has never had a paid job. Of those respondents with a partner, this partner has a job in a quarter of the cases. When a combination is made on whether or not the respondent works or the partner works, it appears that in 71% both the beneficiary IVT/IT as well as the partner don't have paid work.

There is a great diversity in the types and combinations of disabilities. Thirty per cent indicate having a visual impairment. 14% of respondents have a hearing impairment. 37% has an intellectual disability and 32% has a chronic illness. 22% has a psychic or psychiatric illness or disability and 3.3% has an autism spectrum disorder. 71% of respondents indicate having a physical disability. A third of the respondents indicate having one type of disability. Thirty per cent has two types of disabilities and twenty per cent has three types of disabilities. Despite the limitations, 1 in 5 respondents indicates to have a good health. Besides the physical limitations, beneficiaries proportionally experience more mental health problems. For example, 31% has a life satisfaction score of less than 5 out of 10 and 34%

often or always feels lonely.

26% of respondents are severely limited in activities of daily living and 63% experiences severe limitations in the instrumental activities of daily living. The care dependency for instrumental activities especially is very large. It is striking that 40% can't manage independently the daily administration and 38% can't carry out their finances. Almost two thirds of respondents receive informal care. Informal carers are usually parents (32.6%), the partner (26.4%), children (14.0%), siblings (10.2%) or an acquaintance or friend (6.8%).

2.5.2 Effectiveness in terms of minimum protection

The results of the survey highlight the precarious living conditions of households including a person with an allowance IVT/IT. Their median standardized household income is € 1047. 39.3% has an equivalised income below the European poverty threshold, compared to 14.6% in the total Belgian population.

On average, the beneficiaries IVT/IT spend € 251 a month on health expenditures, representing 17% of their disposable income. In the past year, 25% was unable to pay the bills of health expenditures timely at least once. 34% of households with an IVT/IT beneficiary postpone medical consumption due to financial reasons. Herein, the health gap and the social gradient are clearly reflected, since only 14% delays medical consumption in the total Belgian population.

Expenses for non-medical professional care (i.e. home aid, cleaning aid, grocery aid, chores aid) amount up to € 104 a month on average, or 6.5% of disposable income. 28% saves on these types of formal care due to financial reasons. Within the non-medical disability related expenses, the transportation costs as a result of the disability are particularly high. On average, beneficiaries spend € 133 per month on these specific transportations. 22% indicated that they had to save on their travel costs in the past year.

The average house rent amounts to € 371 per month. 1 in 2 private tenants and 1 in 3 social housing tenants indicate that their housing is a heavy financial burden. 14% indicates that major changes are needed in the home, and 19% would like minor adjustments. Yet, 1 in 5 saves on these modifications. Beneficiaries are also more likely to live in a house where basic facilities, such as a shower or toilet, are missing. 1 in 2 saves on energy costs, but still, 24% was unable to make (timely) payments for the utility bills in the past 12 months.

46.8% has difficulties making ends meet, keeping in mind that beneficiaries IVT/IT adapt their definition of making ends meet to their lifestyle. For example, 73% saves on general non-medical expenditures. 56% never has any money left at the end of the month and can therefore never save. 68% can't pay unexpected expenses up to € 750. In the past 12 months 38% was unable to pay the bills (on time) at least once. 26% has to pay off debts, for an average amount of € 250 per month. These debts don't include mortgages, but are incurred for personal loans or hire purchases.

In comparison to the average Belgian population, beneficiaries IVT/IT are less able to afford durable consumer goods. The multiple deprivations are also reflected in the inability to fulfil a number of basic needs. 1 in 5 can't afford to eat meat, chicken, fish meal (or vegetarian

equivalent) every two days. 23% can't afford to heat the house sufficiently. 71% can't afford to pay for a vacation annually.

Based on the European indicator, 29.6% of the beneficiaries IVT/IT experiences severe material deprivation in comparison to 5.9% in the total Belgian population. The objective poverty risk is a less suitable indicator for beneficiaries IVT/IT than for the total Belgian population. In the sample of HANDILAB, 13.2% faces severe material deprivation although they have an income above the poverty threshold. In total, 52.5% faces poverty and/or severe material deprivation. This can be explained by the additional costs beneficiaries have, which imply that they have to save on their basic needs to compensate for the extra cost of disability.

Those traditional factors that poverty research highlights as risk factors also increase the risk of insufficient minimum protection in this specific population. The objective poverty risk and the risk of severe material deprivation increase in households with children, households without work and for those who do not own their own home. Among single parent households, 58% lives below the poverty threshold, 64% is severely materially deprived and 63% postpones medical consumption due to financial reasons. Therefore, families with children, and especially single-parent families, whose parents receive an IVT/IT allowance, are particularly vulnerable.

2.5.3 Effectiveness in terms of guaranteeing standard of living

The results concerning providing a minimum level of protection are biased because they don't take into account the additional costs incurred by the respondents as a result of their disability. Therefore, in this study we use the Standard of Living approach to measure these extra costs. The results show that the IVT/IT benefits insufficiently cover the additional costs resulting from the disability. Households including beneficiaries IVT/IT need a higher income than households without persons with disabilities in order to achieve the same living standard. The amount of these additional costs depends on the way the concept of living standard is operationalized.

The dissimilarity in living standard between households with and without persons with disabilities is limited when focusing on the extent to which both groups can make ends meet. If an objective indicator is used instead of subjective deprivation, the difference increases largely. To make ends meet equivalently, households including an IVT/IT beneficiary monthly need € 189 extra (95% CI 71-329), while the extra cost to equivalently fulfil basic needs go up to € 661 per month (95% CI 495-863). The indicator of the standard of living that reflects the degree to which one can afford durable consumer goods, shows results that are in-between. On average, these extra costs amount up to € 412 monthly (95% CI 231-645). The subjective evaluation on making ends meet shows a different picture than the objective indicator of fulfilling basic needs. This confirms that beneficiaries IVT/IT learn to get by with the disposable income by saving on various expenditures and by not fulfilling certain needs.

People who are moderately restricted in daily life face the highest extra costs. The extra costs as a result of the disability are lower for persons who are not limited or severely

limited. Proportionately, the current system of allowances covers the additional costs for the intermediate group the least.

The high amount of extra costs, resulting from the presence of persons with disabilities in the household, indicates that poverty research should be conscious of these extra costs. Poverty figures that don't take into account these extra costs, and, as a consequence, underestimate the actual risk of poverty. Poverty research must work with equivalency factors which take into account the extra cost of persons with disabilities.

For a household with one IVT/IT beneficiary, the equivalence factor equals 1,18 to equivalently make ends meet, 1,39 to equivalently afford consumer goods and 1,63 to equivalently fulfil basis needs. The objective poverty risk of 39.3% increase significantly when taking the extra costs resulting from the disability into account. When we use the disability equivalence factor which takes into account the extent to which households IVT/IT beneficiaries can make ends meet, the poverty risk increases from 39.3% to 63.2%. When we take into account the additional costs for households with disabilities to achieve the same level of owning durable consumer goods, the poverty risk rises to 76.0%. The indicator of standard of living that indicates the extent to which households with disabilities are able to afford basis needs results in the highest poverty within HANDILAB, namely 89.0%.

2.5.4 Effectiveness in terms of enabling societal participation

The results of the survey illustrate that the allowances don't succeed to realise social participation. One third of the respondents never take part in both informal and formal activities. For example, 86% never participates in the activities of associations and 57% has never been to a restaurant in the past year. The cost of socio-cultural activities is the main reason for 46% of people entitled to IVT/IT for participating less than desired. Participating in social life is not just a financial problem, but is also limited by a lack of accessibility, lack of appropriate activities and a lack of friends.

27% of respondents never see their friends and 2.7% don't have any friends. In total, 56% had no weekly contact with friends. 8% of beneficiaries IVT/IT never have face-to-face contact with other family members who are not in the same household. The risk of social isolation increases largely for elderly beneficiaries. Throughout the week, 24% of those beneficiaries over 50 has no contact at all outside their own household.

1 in 3 IVT/IT beneficiaries often feels lonely. This underlines the limited social participation and integration in social networks, which have a strong positive impact on the health and quality of life. Therefore a holistic approach is required to break social isolation and feelings of loneliness.

The integration into the labour market of beneficiaries IVT/IT is limited, even though this is a key driver of social inclusion. At the time of the survey, 11% of respondents had a paid job. Traditional risk factors, such as older age, lower educational level and being more severely limited, reduce the chance to be the work. Of those beneficiaries IVT/IT without work, 6 out of 10 once had a paid job, but there are not enough disability adapted jobs to reintegrate them into the labour market.

3 Policy recommendations

3.1 Labour market policy for disabled people

For the development and application of adequate policy for people with a disability, high quality and comprehensive administrative data are necessary. However, our research revealed a number of limitations concerning the availability of data from certain government agencies. In addition, a standardized set of indicators, whether or not ‘complementary’, was lacking for the domains in which the different target groups face barriers to long-term participation in daily life. Based on these observations, a number of recommendations can be made.

Firstly, we call for the submission of additional data related to the target groups that were included in our administrative population but that were inaccessible in the Datawarehouse Labor Market and Social Protection. Secondly, we hope to foster a discussion on the incorporation and/or streamlining of indicators of disability that, according to more recent (disability) definitions, can measure the impact of disability on various societal domains.

As such, we draw our attention to a comparison of the acquired administrative population and the survey population. Regardless of the limitations of the administrative data (unavailable data) and survey data (survey setting, time of measurement, etc), it is also possible that a number of people confronted with certain chronic disabilities remain outside the margins of the administrative data framework. This may be related to the fact that certain institutions employ stricter ‘tipping points’ such as with the reduction of earning power by two thirds for primary disability or invalidity or income replacement benefits.

The focus on remaining labor capacity, or the Organization for Economic Cooperation and Development (OECD) notion of ‘partial work capacity’ (OECD, 2009: 19-22) also implies more gradual access to the different compensation schemes. A timely service targeting people with certain limitations could, to a certain extent, prevent and/or remediate further escalation of the participation problems that these individuals face.

Supplementary (survey) research into the various influx thresholds could reveal the importance of such thresholds. Moreover, questions arise concerning previous influx motives as well as the motives behind possible ‘non take-up’ by individuals who have indicated that they face certain limitations.

Furthermore, we hope that the above overview of the detected overlap between the various target groups (targeted by public administrative services), has confirmed that the target group of people with a disability is characterized by administrative complexity.

Further strengthening of the coordination mechanisms between the different public administrative services is, therefore, wise. A prominent overlap concerns the recognition of reduced earning power (albeit under separate legislation) within the health insurance system and within the disability benefits system for people with a disability. Institutional coordination

could prove useful in situations in which an institution can confirm to another that an individual has an existing, administratively recognized participation problem, thereby circumventing the need for the individual to undergo a completely new recognition procedure.

People with a disability often find themselves in a precarious domestic situation. Moreover, this group is often made up of the elderly who are increasingly accounting for a larger proportion of the total elderly population.

This dynamic raises questions regarding the relationship between policy for the elderly and policy for the disabled (Raad van Europa, 1997). Currently, legislation on the various disability provisions does not grant complete access to these provisions to people that only become disabled later on in life. Consider, for instance, the age requirements set by the Flemish Agency for Disabled Persons (VAPH) and the Walloon Agency for the Integration of Persons with a Disability (AWIPH). Given the demographic evolution, the dichotomy between both policy types will become increasingly untenable.

The income that people with a disability have at their direct disposal is more limited in the social assistance system than in the social security system. Furthermore, the former have to rely more often on additional sources of income, including personal as well as household income.

The 'prize of love' benefit accounts for an important goal in this issue. According to Bogaerts et al. (2009), the 'partner's' income exemption from the social assistance system, with emphasis on the Income Replacing Compensation (IVT), may be subject to extension.

More generally speaking, a further reform of the social security system's exemption limits for people with a disability could provide additional opportunities to supplement individual incomes with self-obtained sources of income.

In this study, we have emphasized the role that labor market participation can play as a catalyst for the possibilities of social integration.

Moreover, we have noted the importance of the inclusion of employment with the guarantee that, at the bare minimum, medical recognition of disability is maintained. This is not guaranteed uniformly in all systems. The finality of (re)employment to an 'outflux' still accounts for an essential part of legislation concerning primary disability and invalidity, whereas in other social security systems, as well as in the social assistance system, more extensive options exist that allow one to, at least, be able to fall back on medical recognition of disability, with its associated potential derived rights, after a longer period of employment. And in terms of the existence of 'intermittent disability', these findings emphasize the need for flexibility. Since final disability is the consequence of a more (complex) interaction between the individual and his/her environment, legislation should accordingly foresee such possible 'ups' and 'downs' during the lifespan of people with a disability.

3.2 Towards a more effective system of allowances

These results indicate that the current system of allowances doesn't succeed sufficiently to cover the extra costs of persons and households with beneficiaries IVT/IT. The level of these extra costs depends on the way the standard of living is operationalized. However, this does not imply that the allowances should be increased by these amounts in order to cover the additional costs of disability.

Covering the extra costs may occur through three kinds of policy measures: (1) increasing the income, (2) reducing expenditures and (3) improving the services. Probably actions are required in all three areas. Since Belgium has ratified the UN Convention on the Rights of Persons with Disabilities, we advocate a public debate on a reform of the current system of allowances and on the three kinds of policy measures based on this guiding framework. The Convention recommends that all fundamental rights and freedoms of persons with disabilities are respected and the inclusion of people with disabilities is supported:

- in all areas of life
- by removing all contextual obstacles that exclude people with disabilities from the societal, economic, policy and cultural life
- but also by ensuring adequate access to resources, goods and services
- so they can make their own life choices autonomously and independently of others

The UN Convention advocates an effective social protection for all persons with disabilities to realise a decent standard of living. With regard to increasing the income, we support the claim made by the Government Statement (2011) and the second National action plan to combat poverty (2012) to increase welfare allowances (at least) towards the European poverty line.

In various policy domains, the expenditures of beneficiaries could be limited. For example, by mitigating the personal contribution of the beneficiary in health care costs, the fight against energy poverty, or by increasing financial and physical accessibility of social housing. Optimizing public services is another possibility to reduce costs. Especially mobility policies could be improved. This type of action can only be taken by a transversal policy approach which pursues inclusion policies in each policy domain. With regard to increasing the income we also wish to emphasize one essential domain namely realizing an increased labour participation by providing jobs adapted to the disability.

In addition to these generic measures targeting all persons with an IVT/IT allowance, we want to point to two specific vulnerable groups. The first are people with a moderate disability. This group is protected the least. They have significantly higher additional costs which are less covered by the current system of allowances, unlike persons with severe disabilities. This study is not an evaluation of the criteria on which the amounts of the integration allowance are calculated. Nevertheless, the results suggest a 'gap' between people with moderate and severe limitations in daily living. These results demand a debate on the criteria which guide the allowance's calculation. A second particular vulnerable group

are single parent families where the parent is entitled to an allowance are another particularly vulnerable target group. They face the greatest poverty risk and experience the highest degree of severe material deprivation.

The study also shows that a more integrated approach towards disability is needed. The lack of social participation can partly be improved by a higher income so they can participate more in activities. The question arises whether increasing the income is sufficient, especially considering that this is a group in society that appears to be vulnerable in many areas. This is partly reflected in the high number of beneficiaries who are unable to manage administration and finances themselves. To realise this integrated approach is to stimulate regular social services (public centres for social welfare and social services of the mutuality) to implement inclusion policies and to pay more attention to the social participation of this target group. It's also important to attain to a better coordination of the social care for this target group, for instance by introducing case management models. An additional road is including disability as an essential focus in the federal, regional and local policies to combat poverty.

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