

Comparing the Cost of Independent Living and Residential Care

A Survey by the European Network on
Independent Living

European Network on Independent Living
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About the European Network on Independent Living

The European Network on Independent Living (ENIL) is a Europe-wide network of disabled people, with members throughout Europe. ENIL is a forum for all disabled people, Independent Living organisations and their non-disabled allies on the issues of Independent Living. ENIL represents the disability movement for human rights and social inclusion based on solidarity, peer support, deinstitutionalisation, democracy, self-representation, cross disability and self-determination.

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1. Introduction

“Perhaps one day the question will no longer be, can we afford to invest in independent living, but can we afford not to?” (Zarb, 2003)

In 2014, as part of its Progress Action Grant funded by the European Commission, the European Network on Independent Living (ENIL) decided to carry out a small survey among its members and allies about the cost of Independent Living support (in particular Personal Assistance) in their countries and, compared to that, the cost of institutional/residential care¹. We realised that this would be a difficult task, considering the lack of available data, as well as the fact that there are many costs which are either difficult to quantify, or are simply hidden. However, as we are often pressed to provide information about the cost-efficiency of Independent Living vs. traditional care, especially in these times of austerity, we wanted to at least show how complex this issue is and at the same time set out some of the information that is available. We also wanted to make sure that what comes out of this survey is a conclusion that, regardless of the cost, Independent Living is a human right and the benefits of living independently in the community, with the appropriate support, will always outweigh any cost savings that may be made in institutional, residential or other traditional forms of care.

2. About the survey

The survey *Comparing the Cost of Independent Living and Residential Care* summarises the available information from eight countries: Belgium (Flemish part), Bulgaria, England, Iceland, Italy, France, Slovenia and Sweden, collected during 2014. It aims to provide information about the costs of institutional/residential care and whether disabled people in these eight countries are able to receive support to live independently in the community. In relation to support in the community, the survey looks at what such support entails, who is entitled to it, how it is funded, and whether it is adequate to facilitate the full inclusion and participation of disabled people in society. Information from the questionnaires is complemented by desktop research, looking at the availability of Independent Living supports, the cost of Independent Living, availability of data about the cost of Independent Living, benefits, barriers and personal budgets.

¹ Please see page 6 for the definitions.

3. Objectives of the survey

ENIL has come up with a number of questions to be answered as part of this survey. These are:

- What do we understand by 'Personal Assistance' and 'institutional/residential care' and why are we comparing them?
- Is Personal Assistance more expensive or cheaper than institutional/residential care?
- Can one compare the financial cost of Personal Assistance versus institutional/residential care?
- Are there any variations between the countries, individuals with different impairments, age groups, the way social care or health care systems are organised etc?
- What other factors may influence the cost of Personal Assistance and institutional/residential care?
- What are the important factors which should be taken into account by countries when deciding if to fund Personal Assistance as an alternative to institutional care, other than the cost?
- Is there need for further research into these questions and if yes, why is such research important?

4. Scope of the survey

Rather than producing a comprehensive study, which the questions above require, ENIL has carried out a small-scale survey in a selected number of countries (listed below). The aim was to highlight some of the important questions and complexities of this type of research, rather than provide a full picture of the situation in Europe and offer all the answers.

This research builds on *ENIL's Survey on Personal Assistance*², completed in 2013 (due to be updated in 2015). The 2013 survey looked at the legislation for and availability of Personal Assistance across Europe, how the service is funded, whether there are any access restrictions etc. Considering that in many countries funding is still tied up in institutional/residential care, this survey aims to show how it could be redirected to support Independent Living. The perceived cost of Personal Assistance is often used as an excuse not to provide Independent Living options, very often without any evidence to support such claims. Therefore, ENIL considered a survey is needed to address such misconceptions.

² Available at: <http://www.enil.eu/wp-content/uploads/2012/06/European-Survey-on-Personal-Assistance-Final.pdf>

The last part of the document summarises the main points from some of the research available on the costs and benefits of Independent Living.

5. Methodology and limitations

A total of eight countries have been chosen for the survey, ensuring a good geographical mix and the likelihood of obtaining the needed information. The countries covered by the survey are: **Belgium (Flemish part), Bulgaria, England, Iceland, Italy, France, Slovenia and Sweden.**

The survey is limited in that it has covered only a selection of countries. We have also relied on information provided by our respondents, which we could not verify through other sources; largely due to the lack of available data on the cost of Independent Living and institutional/residential care.

Furthermore, as noted in several studies (see page 22), there are many reasons why it is difficult to quantify the costs of both Independent Living and institutional/residential care. For example, when calculating the costs of institutional/residential care, it is important to take into account the cost of buildings and infrastructure, energy and maintenance. These capital costs, which can be substantial, are often excluded in cost comparisons, in place of the residents' costs which are easier to quantify. Another cost which is 'hidden' in institutional/residential care is the amount of voluntary care and labour that is often provided for all kinds of tasks and activities by residents and volunteers. For example, people often give up their time as volunteers to help serve meals, do odd jobs and many other voluntary roles. Residents may also be expected to help care for other, younger or less able residents, help maintain the grounds of the institution, or support the staff in other ways. This can be an enormous saving for the institution.

With regard to Independent Living, there is an important point about how one puts a cost on the quality of life and human rights. It is beneficial for society at large to have people living good quality lives with satisfaction and flexibility, which leads to good health and well-being. It is also a question of people contributing and participating positively in a mainstream society, and being active citizens. These are the types of 'benefits' that disabled people in institutional/residential care do not have, and something which cannot be quantified in monetary terms.

6. Definitions

Independent Living is the daily demonstration of human rights-based disability policies. Independent Living is possible through the combination of various environmental and individual factors that allow disabled people to have control over

their own lives. This includes the opportunity to make choices and decisions regarding where to live, with whom to live and how to live. Services must be accessible to all and provided on the basis of equal opportunity, allowing disabled people flexibility in our daily life. Independent Living requires that the built environment and transport are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services. It is necessary to point out that Independent Living is for all disabled persons, regardless of the level of their support needs.

Personal assistance is a tool which allows for Independent living. Personal assistance is purchased through earmarked cash allocations for disabled people, the purpose of which is to pay for any assistance needed. Personal assistance should be provided on the basis of an individual needs assessment and depending on the life situation of each individual. The rates allocated for personal assistance to disabled people need to be in line with the current salary rates in each country. As disabled people, we must have the right to recruit, train and manage our assistants with adequate support if we choose, and we should be the ones that choose the employment model which is most suitable for our needs. Personal assistance allocations must cover the salaries of personal assistants and other performance costs, such as all contributions due by the employer, administration costs and peer support for the person who needs assistance.

Deinstitutionalisation is a political and a social process, which provides for the shift from institutional care and other isolating and segregating settings to Independent Living. Effective deinstitutionalisation occurs when a person placed in an institution is given the opportunity to become a full citizen and to take control of his/her life (if necessary, with support). Essential to the process of deinstitutionalisation is the provision of affordable and accessible housing in the community, access to public services, personal assistance, and peer support. Deinstitutionalisation is also about preventing institutionalization in the future; ensuring that children are able to grow up with their families and alongside neighbours and friends in the community, instead of being segregated in institutional care.

An institution is any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size.

Institutional care refers to any residential care where: users are isolated from the broader community and/or compelled to live together; these users do not have sufficient control over their lives and over decisions which affect them; the

requirements of the organisation itself tend to take precedence over the users' individualised needs.³

A residential care setting is terminology used by service providers to denote settings specifically designed for disabled people (such as group homes, service apartments⁴, protected/sheltered homes and living centres), where people are grouped together depending on their labelled type/severity of disability. Such settings can cater for children and adults, and can be smaller (for example, for 6 people) or bigger (for example, for 30 people). It is a model of service which links the supports a person requires with a particular type of housing, thereby restricting people's choices about where and with whom they will live. Residential care settings, despite being physically placed in a city neighbourhood or a suburb, are often based on a 'one size fits all' model and can be as isolating as an old-style institution. Residential care and institutional care are often used interchangeably by Independent Living activists.

7. Summary of the findings

The findings are divided into two sections:

- Information about the cost of institutional/residential care; and
- Information about the cost of Personal Assistance.

Each section starts with the questions sent to respondents in the eight countries, followed by a summary of the responses received. Conclusions coming out of the completed questionnaires are then summarised at the end of each section.

7.1 Information about the cost of institutional/residential care

1. Do you know what is the cost of institutional/residential care per person in your country/region/local authority (whichever of these is relevant)?
2. Who funds an individual's placement in the institution – is it the state, the local authority or does the individual/their family have to pay in some circumstances?
3. Is the amount paid per person for the placement in an institution the same for all the individuals, regardless of their impairment, or does it vary? If it does vary, what are the reasons/factors for this variation? Please provide as much information as you can.
4. What does the amount paid to the institution cover?

³ Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care (2009), available at: [file:///C:/Users/ECCL/Downloads/2009-12-08%20Expert%20Group%20Report%20Final%20EN%20\(13\).pdf](file:///C:/Users/ECCL/Downloads/2009-12-08%20Expert%20Group%20Report%20Final%20EN%20(13).pdf)

⁴ A cluster of apartments in one building primarily offered to disabled people where 'support' is provided on a group basis.

5. If a person leaves the institution, does the funding follow them, or does it still go to the institution?
6. Do disabled people have a real choice between institutional/residential care or independent living with personal assistance?

Belgium (Flanders)

The average cost of institutional/residential care is 60,000 EUR per person/year. The amount is different according to the type of institution, but within a single type of institution the amount paid is the same for all individuals, regardless of type or 'severity' of impairment. The cost covers staff and overhead costs.

The funding does not follow the individual if they leave the institution, but is used to fund another individual's placement. Disabled people do not have a real choice between institutional/residential care and personal assistance. There are very long waiting lists for both, and a person living in an institution is not seen as a priority for personal assistance.

Bulgaria

The average cost of institutional/residential care is about 3,500 EUR per person/year. The amount paid varies according to the type of institution, but within a single type of institution, the amount paid is the same for all residents. This covers the staff and maintenance costs. The placement is funded by the central government and the residents pay a percentage of their income (i.e. disability allowance) towards the rent. Residents pay about 80% of their monthly income.

The funding does not follow the person but stays with the institution. Disabled people do not have a real choice between institutional/residential care and personal assistance, unless they have family and friends to support them, as there is virtually no alternative to institutional/residential care. There is a limited personal assistance programme in Sofia, available to a small number of users.

England

The average cost of institutional/residential care is 31,200 EUR per person/year. The amount is dependent on the required support and it covers staff and overhead costs. Placements are generally funded by the local authorities or the National Health Service (NHS), with the individual paying a contribution.

The funding does follow the individual if they leave institutional/residential care. However, many people are not informed of their options between residential care and personal assistance, and many people with mental health needs or people with

intellectual disabilities find it extremely difficult to access support services in the community.

France

The average cost of institutional/residential care is 91,000 EUR per person/year. The amount varies depending on the type and 'severity' of impairment. The amount covers the staff and maintenance costs. The placement is funded by the State.

The funding does not follow the individual. Disabled people do not have a real choice between institutional/residential care and personal assistance, especially those with high support needs – 'people dependent above 80%' are entitled to 5-6 hours of personal assistance, which is not sufficient for them to live in the community.

Iceland

The average cost of institutional/residential care is 50,000 EUR per person/year. This amount varies depending on the assessed support needs, but it is calculated based on overall costs of the service; for example, the costs of running a group home rather than what a specific individual requires/uses. The amount covers staff and overhead costs. Placements are funded by the municipalities and the individuals pay a contribution from their disability allowance.

In practice, if a person leaves an institution, the vacancy gets filled by another individual and so funding is tied to the building, rather than the person. Disabled people do not in reality have a choice between residential care and personal assistance, as the latter remains in an 'experimental' state and is generally insufficient to meet everyone's support needs. People with extensive support needs generally do not leave the institutional/group home setting.

Italy

The average cost of institutional/residential care is 48,000 EUR per person/year. The amount is not dependent on the type of impairment. If an individual is identified as being 'severely disabled', the state is expected to cover 30% of the cost of support, while disabled people who are 'simply lacking family support' must pay 60% of the cost. The State pays the balance, which covers the cost of staff and meals.

The funding is only provided if the individual stays in the institution. With the exception of North Italy, where there are more possibilities, disabled people in the rest of the country do not have a real choice between institutional/residential care and personal assistance.

Slovenia

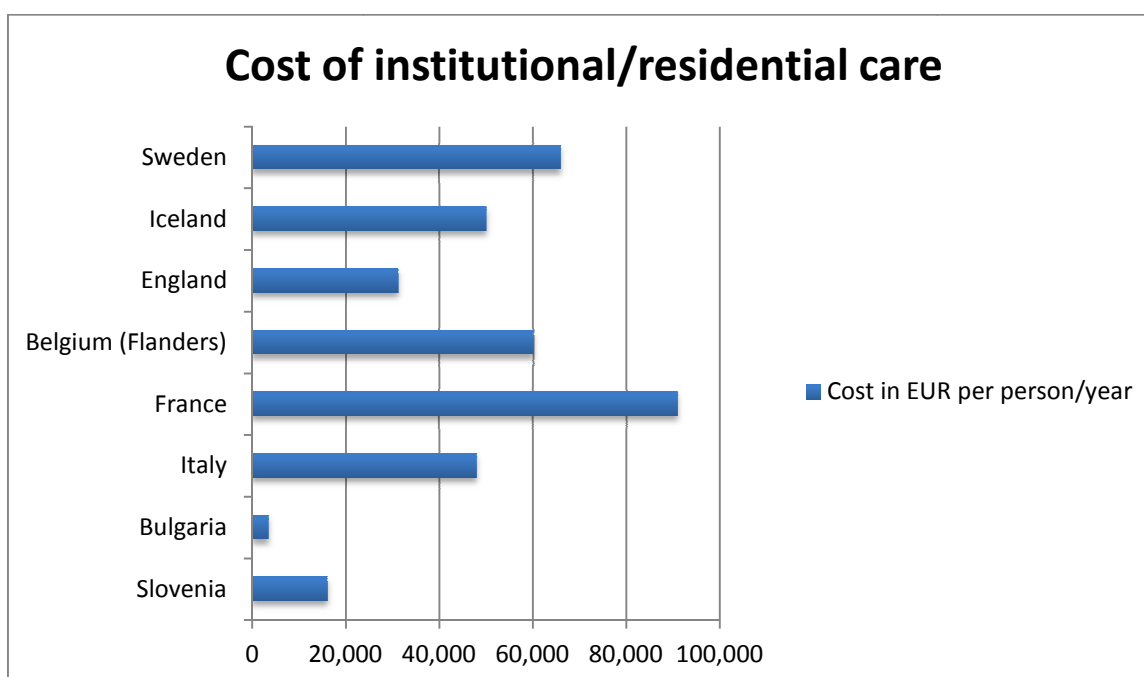
The average cost of institutional/residential care is about 16,000 EUR per person/year. The amount varies depending on the care category a person has been placed in. This covers staff and overhead costs. The placement in the institution is funded by the user, or their relatives, and if they are not able to pay - the local government.

The funding is conditional on the person continuing to live in institutional/residential care. It does not follow the individual if they leave. Disabled people do not have a real choice between institutional/residential care and personal assistance, because there are very few community-based services available. The only support provided outside of institutional/residential care is the disability pension, which is very small.

Sweden

The average cost of institutional/residential care is 66,000 EUR per person/year. The amount varies depending on the required support needs. The amount covers staff costs and the common facilities, with the individual paying rent on top of that. Placements are funded by the municipality.

If an individual leaves the institution, the funding does not follow them. However, they can apply for personal assistance instead. At the same time, not all people are granted personal assistance, with people who do not have a physical impairment often denied this type of support.



7.2 Conclusions

- a. In practice, funding is tied to buildings rather than people. This means that if the individual leaves institutional/residential care, they do not automatically get to use the same funding to pay for other types of support. In most cases, they would have to go through another assessment, to decide whether they are eligible for support in the community and if yes, how much funding they are entitled to.
- b. People with extensive support needs generally do not leave the institutional/residential care environment. In all countries surveyed, except for England and Sweden, personal assistance is not available to people who require extensive support, unless their family members can provide informal support along with the formal personal assistance support.
- c. Persons with disabilities can in theory choose between institutional/residential care and personal assistance. However, there are many barriers to this in practice. The reason for this is that, what is offered in terms of support, is generally insufficient to meet everyone's needs. For example:
 - Personal assistance is not offered by all local authorities;
 - Personal assistance in many countries lacks a legal basis and remains in an experimental state;
 - A very limited budget is made available to local authorities, resulting in the restricted availability of personal assistance schemes; and
 - Where personal assistance and other community supports are available, many people are not necessarily informed of the choices available to them.
- d. Of those surveyed, in many countries the funding provided for placement in institutional/residential care is not calculated based on the support needs of the individual, but rather the overall costs of the institution. In addition, the amount of funding allocated is not reviewed regularly, if at all (despite the individuals' changing needs over time).

7.3 Information about the cost of Personal Assistance

1. What amount do disabled people receive to employ a personal assistant(s) in your country/region/local authority (whichever of these is relevant)?
2. Do disabled people receive the same amount of funding if they are employing family members as personal assistants?

3. Who funds personal assistance costs - is it the state, the local authority or does the individual/their family have to pay in some circumstances?
4. Is the amount paid the same for everyone or is it based on their support needs?
5. If it is based on their support needs, how are these determined? [If there is an assessment, how often do disabled people need to have them?]
6. How is the money for personal assistance paid – as a direct payment, personal budget, or through a provider?
7. Do you consider the amount paid for personal assistance adequate? For example, what is the hourly rate and how does this compare to minimum wage? Or, is the number of hours of personal assistance enough to cover disabled people's needs?
8. Is there a stipulation about what the amount paid for personal assistance can be used for – e.g. personal care, housework, employment activities, social activities etc.?
9. Is personal assistance available to everyone who needs it, or does it depend on where they live, the type/severity of their impairment or anything else?
10. What housing options, if any, are available to people who choose not to live in an institution (e.g. social housing, supported housing)?
11. Is there any funding available to disabled people to support their housing needs (e.g. to help with the cost of renting a flat, for adaptations of the flat)? What is the amount of funding available? How is this amount determined?
12. Does funding to support housing needs come from the same (or a different) source as funding for personal assistance? Are they linked in any way?

Belgium (Flanders)

The cost of personal assistance is between 9,500 EUR per person per year and 45,000 EUR per person per year, depending on the category of impairment (disability). The budget holder is allowed to spend a maximum of 5% of this amount on indirect costs, while the rest is spent on wages. The total amount is dependent on the individual's level of support needs, which is decided by a multidisciplinary team. Personal assistance can be used for personal care, housework, employment activities and social activities.

Personal assistance is funded by the Flanders local authority, and is paid directly to the individual or to a guardian, if the individual is deemed not to have capacity.

The budget holder is free to determine the personal assistant's salary, but has to respect the minimum wage. Most commonly, personal assistants are paid at least

10.43 EUR per hour (this can go up to 30 EUR per hour if the work involves specialised skills). However, the overall budget is usually insufficient for people with high support needs, who are often forced to go to institutions/residential care or rely on family members. Theoretically, no one is excluded from applying for personal assistance, however there are huge waiting lists for both personal assistance and for residential care placements.

Rent subsidies and social housing are available to people who have low incomes. There is also funding available for housing adaptations. The budget for personal assistance and housing supports are not linked.

Bulgaria

Personal assistance is only available on a project/programme basis. One such project in Sofia provides for an hourly salary of 2 EUR, while an EU funded project pays 1.20 EUR per hour. Both of these projects involve a complex needs assessment, which is being carried out by a panel of professionals. The number of personal assistance hours available per person is very limited. Personal assistants are required to report their time by activities, based on the functionality factors identified in the needs assessment.

The Assistant for Independent Living Regulation project is funded by the Sofia municipality, while the Alternatives Scheme project is funded by the European Social Fund (ESF). The money for personal assistance is always paid to the disabled person through a service provider.

The amount paid for personal assistance is not adequate to hire assistants on the open labour market, which means that this funding often becomes a 'welfare benefit', used to support family budgets, without changing the status of the disabled person. Personal assistance is offered to a very limited number of people, based on their geographical location and the financial status of the municipality they live in. Only people 'with a certified medical condition of 90% and more of lost ability to work' are eligible for personal assistance.

There is social housing offered to low-income families by the municipality and extra points are awarded for having an impairment. There is no assistance offered to disabled people to pay rent on the open housing market. There is a small allowance available to disabled people for housing adjustments; however, the process is very complex, so few people apply for this allowance. Funding for personal assistance is not linked in any way to funding for housing supports.

England

The amount of funding for personal assistance depends on the needs of the individual, which are assessed by the local authorities.

Personal assistance is generally funded by the local authority, and is paid either directly to the individual, family member or through a provider. Most personal assistants are paid between 7.50 GBP and 11 GBP per hour (app. 10 – 14 EUR per hour). There is no stipulation as to how this money should be spent.

Personal assistance is available to people who live in their own home. In recent years, local authorities have been cutting spending on social care, resulting in reduced personal assistance budgets and preventing people with lower support needs from accessing publicly funded support.

There is a range of housing options, including social housing, rent subsidies for private rental market and housing adaptations supports (the latter is only available if the disabled person does not live with a non-disabled person). Personal assistance budget and housing support budget come from a different source and both are administered by the local authority.

France

If personal assistance is paid directly to the user, they get paid up to 12.39 EUR per hour; for a proxy service (with the administration carried out by a service provider), the amount is 13.63 EUR per hour, and if personal assistance is paid entirely through a service provider, then it is paid at a rate of between 17.59 EUR – 30 EUR per hour. On average, people are entitled to 5 – 6 hours of personal assistance per day. The amount paid depends on the user's support needs, which are assessed by the local authority. Personal assistance covers personal care only and one hour is granted for social activities.

Personal assistance is funded by the local authority, but can be compensated up to 34% by the State. In most cases, personal assistance can only be paid via a service provider.

Most commonly, a personal assistant receives the minimum wage (7.47 EUR per hour). However, the hours granted are usually not adequate and only cover basic needs. The availability of personal assistance is dependent upon 'severity' of impairment and where the person resides.

Rent for private and social housing can be subsidised according to the income of the individual. Also, there is funding available for housing adaptations.

Iceland

Personal assistance is budgeted at about 19 EUR per hour, of which 85% is for wages for the personal assistants. The basic amount is the same for everyone, but the number of hours is dependent on the needs, which are decided by a group of

experts at the municipality level. There is no stipulation as to how the money for personal assistance should be spent.

The majority of the funding for personal assistance comes from the State, which is paid to the municipality, which in turn pays the personal assistant wages either directly to the individual or through a provider.

Personal assistants get paid a similar wage to other unskilled workers. The availability of personal assistance depends on the place of residence and available budget.

There are social housing options available and housing provided by disabled people's organisations. There is also a budget for housing adaptations if the disabled person lives alone, as well as rent subsidies.

Italy

The amount provided for personal assistance is up to 10.87 EUR per hour (between 500 EUR and 2,000 EUR per month) and is only available in a few regions for people with '100% gravity of illness'. The amount allocated depends on individuals' personal needs and personal income. Personal needs are assessed by the social services, within the limits of available funds. Personal assistance can be used for personal care, housework, preparing meals, etc.

The State provides a social fund and a health fund to the local regions in Italy and in 10 of the 21 regions independent living is offered from these funds. A personal assistance budget is normally given directly to the user, if the person is 'able to self-manage', and if not, 'it is delivered to the guardian'.

On the whole, the personal assistance allowance is not sufficient to cover an individual's personal needs. In some regions, the maximum number of hours provided for is 25 hours per week, while in very few regions individuals can receive 24/7 personal assistance. In many cases, personal assistance is only available for a few hours and the person is forced to rely informally on family, where possible. Personal assistance is very dependent on where an individual lives, but residential care is still largely used throughout the country.

In some regions, housing and co-housing supports are offered. There is a very limited budget in several regions to support housing adaptations. Some municipalities support individuals with low income to pay their rent and disabled people 'have a higher score due to social disadvantage'. The funds for housing needs and personal assistance are not linked. Each municipality is economically independent (i.e. is responsible for administering their own budget).

Slovenia

Personal assistance is only available through a limited number of social welfare programmes. The average cost of personal assistance is 8.34 EUR per hour. A family member cannot be employed as a personal assistant. Agencies which administer personal assistance programmes do not receive funds based on the number and needs of disabled people involved in the project, with each agency setting their own priorities and standards for assessing disabled people's needs. Each agency also decides what the funding for personal assistance should cover.

Personal assistance is funded mainly through public tenders and through contributions and donations. Personal assistance is paid through service providers, not personal budgets.

The amount of resources allocated through the tender is decided by the authorities. As a rule, personal assistance is underfunded and the wages received by personal assistants are about 15% lower than for other caregivers. This results in those who receive personal assistance also having to rely on informal support from friends and family in order to receive the support required to live in the community, as opposed to institutional/residential care. With regard to eligibility, personal assistance is very limited and is not aimed at those with high support needs.

There is a limited number of apartments made available to people with physical impairments and those with sensory impairments. Disabled people can apply for a rent subsidy of up to 80% of their rent. Funding for personal assistance and housing support come from different sources.

Sweden

Personal assistance is paid at the rate of 29 EUR per hour, and is assessed by the National Social Insurance Agency. A total of 87% of the personal assistance budget is for wages of the assistant.

The municipality funds the first 20 hours/week and the State pays the rest. The average hours provided are about 110 hours/week. Personal assistance is paid either directly to the individual or through a provider.

At the moment, the budgets for personal assistance are mostly adequate. Personal assistance covers basic needs including personal care, communication and support with personal needs such as eating.

There are different forms of supported housing available and rent subsidies for people with low income. Housing adaptations are also available.

7.4 Conclusions

- a. In countries where personal assistance is legislated for, such as Sweden and England, authorities have reduced the funding provided for personal budgets and as a result, the eligibility criteria have been restricted. In England, this has resulted in people with lower support needs not being eligible for personal assistance and having to rely on family and friends for the support they require. In Sweden, although the law with regard to personal assistance has not been changed, the guidelines have been revised, resulting in many individuals losing hours after being reassessed.
- b. There is a definite hierarchy among people accessing personalised support services. People with intellectual disabilities, mental health conditions and older people with support needs are either not eligible or find it extremely difficult to access support outside of institutions/residential care.
- c. In all of the countries, personal assistance services are provided in parallel with institutional/residential care provision.
- d. Countries that do provide some level of personal assistance require a regular assessment of each individual's support needs, determined by an assessment tool. For example, in England, calculating 'individual needs' looks at support within residential care, such as nursing needs, personal care, and if someone requires a 1-1 or 2-1 level of support. With regard to personal assistance, assessment of needs not only takes into account personal care and assistance within the individual's home, but also support accessing the community and work/educational needs.
- e. Individuals receiving personal assistance have more choice and control over what services they spend their budget on and can have more flexibility with the support they receive on a day to day basis.
- f. From the evidence available, there appears to be more transparency with data on financial costs of personal assistance provision as opposed to costs of institutional/residential care.
- g. In Iceland, housing options are only available to people who are living alone (excluding those under 18). Moreover, individuals living in group homes are not eligible for personal assistance.
- h. In countries such as Slovenia and Bulgaria, personal assistance is provided through a social welfare programme and these are time limited and underfunded.

- i. There is no consistent understanding about what personal assistance and housing supports are. Personal assistance is frequently confused with home help and group homes are viewed as housing support options for individuals, when they are an example of institutional/residential service provision.
- j. Implementation of personal assistance is limited by a lack of resources and regional interpretation of national policy.

8. Research on the costs and benefits of Independent Living

8.1 Availability of Independent Living support in the European Union (EU)

- Across the EU, many disabled people still have to rely on family members to provide care and support, rather than “a system which promotes and supports Independent Living”. (ANED, 2010)
- There is a gap between a commitment to independent living in national strategies and what happens in practice. The main reasons for this are: lack of resources at the local level, how strategies are implemented at the regional level, lack of political leadership, lack of policies to implement the strategy, and assessment processes that are not focused on individual needs. (ANED, 2010)
- In most countries covered by the Academic Network of European Disability Experts (ANED) researchers, self-directed support is available in combination with other services. Only in one country is self-directed support the norm, while two countries were found to provide no support at all. (ANED, 2010)
- There is still little access to independent living support, even in countries where in theory everyone is entitled to it. This is mainly due to limited resources, but also the way in which disabled people “are allowed to use these resources to organise their support”. (Zarb, 2003)

8.2 Costs of Independent Living

- Zarb argues that independent living is the most cost-effective way to support disabled people “because assistance is precisely matched to individual needs and, over time, is also likely to help reduce the overall level of demand on both social care and other public services.” According to him, investing in independent living is also likely to reduce reliance on informal care and charity. On the other hand, failure to support independent living results in disabled people’s exclusion from social and economic life. (Zarb, 2003)

- In relation to calculating the cost of independent living, Zarb argues that there is too much focus on the actual costs, while too little attention is paid to the potential benefits. He notes that investing into independent living should be viewed as a social and economic investment, with potentially universal benefits for the entire society. Zarb explains that by pointing out that disabled people play a variety of different roles – they are customers, workers, students, parents, taxpayers and voters, and community members. (Zarb, 2003)
- Zarb points out that “economic considerations should not be the only justification for investing in independent living”. Rather, public investment decisions should be guided by criteria based on human rights and social justice. The best way to illustrate this is looking at the consequences of the lack or absence of independent living support, which is often placement into institutional care. (Zarb, 2003)
- Hurstfield et al found the key factors which influence the costs to be “types of settings, types of care, types of impairment and extent of severity.” (Office for Disability Issues (ODI), 2007)
- Hurstfield et al point out that setting up independent living supports does involve “considerable transformational costs in order to finance workforce development and administration of the new system” in the short term. This is not helped by the fact that considerable resources are currently tied up in institutional care. Therefore, a one-off investment may be needed, as well as “adequate emotional and practical support to individuals, so that they are properly equipped to manage their own care”. Interestingly, their research has shown that, in the long term, the savings are likely to be felt more by emergency and acute care services, rather than local authorities and service providers, even though *they* need to make this upfront investment. For this reason, it is considered necessary to explore how some of the savings can be passed on to service providers and local authorities, in order to motivate them to embrace implementation of independent living support. (ODI, 2007)
- Overall, given the “inherent inefficiencies involved in traditional care provision“ (such as inflexible block contracts, inflated agency charges and an assessment system which can result in individuals receiving over and above their care requirements), independent living support mechanisms were found to result in reduced costs. Therefore, despite the need for transitional (i.e. transformational) costs, one needs to adopt an “invest to save” approach. (ODI, 2007)
- Hurstfield et al in the UK point out that investing into independent living is likely to lead to long-term benefits both for the state purse and the society; mainly

due to reduced reliance on health and social care services and the reduction in overall dependency on informal support. They note, however, that at the moment there is a lack of robust figures to substantiate this claim. At the same time, they state that some preliminary conclusions can be drawn from the available research, and these are that “the delivery of Independent Living support to disabled people is more cost effective, or at least no more expensive, than traditional care provision”. Some of the examples provided for this from the UK are as follows:

- It costs local education authorities considerably more to send young disabled people to out-of-authority residential schools rather than facilitating their further education within their community.
 - The overall costs of enabling parents with intellectual disabilities to care for their child, through the use of advocacy and support services, are less than the costs involved in putting the child through the adoption process.
 - The costs of provision of advocacy support to help disabled individuals remain in employment are smaller than the costs the state would have to provide if they were unemployed (in which case there would be the cost of benefit payments and a loss in tax revenues). (ODI, 2007)
- Based on one case study, the cost of residential care can be marginally lower than independent living support, if we are looking at people with complex support needs. This is because typically residential institutions would have lower staff ratios than would be required in the community. It was pointed out, however, that the savings were “marginal” and “may reflect the different cost of service provision in the two local authorities”. Also, the disabled people involved in the study pointed out that “the qualitative benefits, in terms of enhanced freedom and control over their life, more than offset the minimal extra costs at individual level”. (ODI, 2007)
 - An important lesson to emerge from research is that “investment in long-term sustainable projects, rather than small pilots is more likely to realise the potential benefits and economies of scale”. This requires cooperation between different parts of the Government, which should result in the “development of a strategic view on the aggregate savings that can be made through the implementation of Independent Living”. (ODI, 2007)
 - Research carried out in the U.S in the late 1990s found that the average cost per person per year in state institutions was \$104,000, whereas for those living in the community it was \$30,000. While some European studies confirmed that costs of living in the community were lower, others found that this was not

always the case. It may also be linked to the fact that “the worst institutions will reduce their running costs to unacceptable levels.” (Jolly, 2009)

- Related to the previous point, in a major European study looking at the outcomes and costs of deinstitutionalisation, Mansell et al found that “community-based models of care are not inherently more costly than institutions, once a comparison is made on the basis of comparable needs of residents and comparable quality of care”. (Mansell, 2007)

8.3 Availability of data about the cost of institutional care vs. Independent Living

- When trying to understand the extent of available data and research on the cost of institutional care and Independent Living supports, some conclusions can be drawn from the work done by ANED. As part of a Europe-wide study on independent living, they set out to establish: a) if there was any evidence of comparison of the overall expenditure, or the average cost per person; and b) if any major investments are still being made to develop residential institutions rather than moving away from them (e.g. construction of new institutions, or development of old ones). The conclusion of this research was that:
 - Data relating to community-based living arrangements and independent living were often combined/confused under one heading such as ‘people living at home’ (France), accessing ‘home-care’ (Latvia), living in ‘residences’ (Denmark), or living in ‘autonomous residences’ (Portugal).
 - There appears to be very little published research on costs and benefits of independent living. The analysis has highlighted studies conducted by researchers in the Netherlands, Germany, France, Spain, Italy and Sweden, but these relate solely to fiscal costs/savings, rather than assessing broader benefits, including downstream costs and benefits. Clearly this is an area where there is huge scope for more significant research to be undertaken within and across member states. In the United Kingdom, although not mentioned in the report, a significant piece of research has been carried out in this area (Hurstfield et al (2007) ‘The costs and benefits of independent living’).
 - In relation to the evidence of outcomes and effectiveness of Independent Living, ANED points to the lack of “published research on cost/benefit issues” and research which would “look at *savings* rather than costs/benefits”. (ANED, 2010)

- Gadsby notes the lack of cost-effectiveness analyses of Independent Living supports (such as personal budgets) in the short-term and their complete absence over the long-term “in all countries”. (Gadsby, 2013)
- Hurstfield et al highlight gaps in the availability of cost and benefit data in relation to independent living supports vs. traditional care in the UK. This is especially the case when it comes to quantifying social benefits as a result of independent living support, such as data on the benefits of increased participation in employment and education. They note that “whilst many studies have been able to capture some of the immediate benefits of independent living options for individuals, very few have managed to deploy robust methods to value benefits quantitatively.” As one of the reasons for this, they add, is the “relative recency of the Independent Living agenda both in terms of research and implementation”, which makes longitudinal analysis, looking at the long-term cost and benefit impacts, impossible. (ODI, 2007)
- Another difficulty when comparing costs and benefits pointed out by Hurstfield et al are the “fundamental problems with quantifying benefits, in particular, when they relate to improvements in quality of life or physical and emotional well-being”. In other words, researchers are struggling with “attributing values to qualitative costs and benefits”. At the same time, the research that is available points to significant costs of not addressing the barriers by disabled people. (ODI, 2007)

8.4 Barriers to Independent Living

- A “perceived prohibitive level of expense required to support independent living in the current economic climate” was found to be one of the factors impeding progress towards Independent Living by ANED. (ANED, 2010)
- Zarb observes several key barriers to Independent Living:
 - The fact that “current debates about public investment in support of disabled people are flawed by the traditional assumption that residential care should nearly always be the option of ‘first choice’ for the majority of older and disabled people requiring higher levels of support”.
 - The lack of support for independent living as a human right, as well as a limited understanding of independent living, where disabled people are seen only as users of support services.
 - The fact that simultaneous action is needed across many sectors, such as education, transport and employment, in a situation when “public support systems typically have great difficulty linking all of these actions

together” and “tend to have different administrative functions to deal with them separately”. He gives as an example direct payments, which may be provided to disabled people for assistance at home, but not at work. Similarly, they may be able to use assistance with travel to go to school or to the shops, but not to social or leisure activities. In practice, all these restrictions result in disabled people having to organise their lives around the support services that are available, rather than vice versa. (Zarb, 2003)

- Hurstfield et al pointed to “resistance towards change within the social care sector” and “silo thinking” as one of the barriers to implementation of independent living, with many people having a vested interest in maintaining the existing institutions, processes and workforce skills. (ODI, 2007)

8.5 Benefits of Independent Living vs. residential care

- Hurstfield et al point to “extensive qualitative evidence on Independent Living benefits and the considerable improvements in terms of physical and emotional well-being”, adding that these benefits (which include improvements in health, satisfaction, participation in society, motivation and self-esteem) significantly outweigh those that can be achieved through “conventional forms of support”. Those interviewees in receipt of conventional support commented on the absence of choice and control, restricted access to social and labour market participation, emotional distress, over-reliance on friends and family and the general culture of dependency it breeds. In stark contrast, those experiencing Independent Living provision spoke of the equality that they felt, improved social, recreational and professional opportunities, enhanced confidence and mental health, freedom with which to make life decisions, the flexibility in provision and its sensitivity to individual circumstances. (ODI, 2007)
- Jolly has highlighted a large number of studies looking at the effects of moving away from institutional care to living in the community, which note the following benefits for disabled people:
 - Improvements in the quality of life and self esteem, as well as improvements in communication, academic and social skills.
 - Increase in the physical health and life span, with those living in the community securing health and longevity gains.
 - Immeasurable gains in terms of self determination and choice, independent living, sociability, employment, leisure and training.

- Positive outcomes for individuals living in the community in terms of social contributions, economic contributions and health outcomes which represent a long-term cost saving on health system and other state resources. (Jolly, 2009)

8.6 Personal budgets

Several studies have looked at the use of personal budgets and direct payments (most notably the Expertise Centre Independent Living, 2009), and whether self-directed support has any effects on the cost of support (both in social care or health care). Below are some of the lessons that can be drawn from the existing research:

- Looking at the Netherlands, Gadsby found “some evidence to suggest that individuals with a personal budget may spend less on their care than those receiving agency-directed services”. The budget they receive is also 25% lower than the equivalent costs of care in kind, as there are considered to be fewer overheads. In addition, each year around 10-15% of budget holders repay some of their annual allocation. However, he points out that “there is no evaluation to examine whether budget holders are getting a comparable level of care from the reduced levels of funding; or indeed whether some of the costs are being displaced to elsewhere in the system.” (Gadsby, 2013)
- Looking at research carried out in England, Gadsby noted that “across all user groups combined [...] there is some evidence that individual budgets are more cost-effective in achieving overall social care outcomes. However, there is virtually no reliable evidence on long-term cost implications for individual budget schemes in the UK or elsewhere”. (Gadsby, 2013)
- Gadsby noted one further difficulty in comparing experiences of personal budgets, related to the way health and social care are funded. For example, in England, healthcare is not means-tested, whereas social funding is “dependent on individuals’ contributions, and individual budgets can be topped up”. (Gadsby, 2013)
- Research by the Health Foundation noted the difficulty in evaluating “the cost or value for money of personal budgets given the paucity of outcomes, information and accurate costings available.” Using the U.S. as an example, they pointed out that the number of studies fail to consider the start-up costs of new schemes, the unpaid care and support provided by family members, or the uncompensated expenses in traditional care. This does not seem to be different in the EU, where a review of personal budgets in social care found that “almost all schemes have underestimated implementation costs, perhaps partly due to unpredicted demand and unmet needs.” (Health Foundation, 2010)

- Looking at the benefits of introducing personal budgets – i.e. of allowing individuals to decide how their budgets should be spent – Gadsby concludes that, at least in theory, they offer “more choice, control and flexibility to the budget holder”. Moreover, they place a responsibility on the individual to “identify and potentially source the most appropriate services, and to varying degrees, manage the budget and be accountable for how it is spent.” Added to this is the economic argument, according to which giving budget holders a greater degree of choice can act as a “driver for efficiency”. For example, in Sweden, the personal budget scheme has resulted in lower costs by allowing individuals to employ their personal assistants in the open labour market - which proved to be cheaper than in the public sector. (Gadsby, 2013)
- In the Netherlands and Belgium, however, the introduction of personal budgets resulted in increased costs, as the demand was much higher than expected. For example, in Belgium, requests for personal budgets were made by non-institutionalised physically disabled people who previously did not make much use of public services. As a result, in the Netherlands, both access to the scheme and the scope of what the budget covers were significantly restricted; in Belgium, the number of new budgets approved each year was limited, thus creating long waiting lists of people waiting to become budget holders. (Gadsby, 2013)
- In the U.S., according to the available research, “self-direction [...] has been found to promote a more preventative approach to care by providing greater access to support services. This is associated with a shift away from costly, acute interventions.” (Gadsby, 2013)
- Gadsby concludes that “overall, whilst personal budget programmes have been piloted without incurring considerable expense, there is little evidence to suggest whether (and to what degree) they are cost-effective in the long term. Moreover, there are some important concerns around longer term implications and their future sustainability.” (Gadsby, 2013)

9. Conclusions

- a. There is a lack of available data about the cost of institutional/residential care and Independent Living supports, and where some data exists, what is included under community-based supports and Independent Living may also include different forms of residential care;

- b. Considering that Independent Living is a relatively new concept in many countries (where it exists at all), there are as yet no cost-effectiveness analyses of Independent Living supports over long-term;
- c. It is difficult, if not impossible, to quantify all the benefits of Independent Living, which are many and evident;
- d. Public investment decisions should be guided by criteria based on human rights, rather than what may or may not be cheaper; this, in addition to the fact that Independent Living is not necessarily more expensive than residential care and the fact that the lack of Independent Living supports most commonly results in long-term institutionalisation and additional human rights abuses against disabled people;
- e. Countries should be prepared to adopt an 'invest to save' approach, since there will be additional costs (the so-called 'transformational costs') when introducing personal budgets and other types of Independent Living supports;
- f. Investment in long-term sustainable projects, rather than small pilots is more likely to realise the potential benefits of Independent Living and result in cost savings over the long-term;
- g. There are still many barriers to Independent Living, not least 'silo thinking' and resistance to change within the social care sector, with many people having a vested interest in maintaining the existing institutions, processes and workforce skills.

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