

Myth Buster

PERSONAL ASSISTANCE



European Network on Independent Living



Acknowledgments

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If you have come across other misconceptions, not covered in this Myth Buster, please let us know and we will complete them. Thank you.

Layout: Marieta Vasileva

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European Network on Independent Living


December 2022





“Personal assistance is the number one thing disabled people should advocate for. If you have this, you can fight for everything else and live independently. It’s a game changer.”

Kamil Goungor, Personal Assistance employer



„You don’t need a university degree for the opportunity to have a huge positive impact on the quality of life of your fellow human. PA’s work offers you more than any degree can.”

Antonios Sotiropoulos, Personal Assistant

Plain Language Summary

This document is about personal assistance.

Personal assistance: this is support provided to disabled people by another person they have chosen.

Personal assistance helps disabled people to live according to their wishes.

This means that personal assistance helps disabled people to eat, get out of bed, take a shower, go to work, or go to a concert as they wish.

This document is called a myth buster.

Myth: this is something that many people believe, but that is wrong.

A myth buster first explains what many people think. Then it says what is correct.

The first myth explains the difference between personal assistance and home care.

- **Home care:** this is when a person is sent to take care of a disabled person in their home. The disabled person cannot decide who comes to their home or tell a carer what to do.
- Personal assistant is someone who is chosen by the disabled person. The disabled person tells their assistant what to do. They are the boss.

The second myth explains that personal assistance is for all disabled people. It is not just for those who use wheelchairs.

- All disabled people have a right to live in their own home and to do the things they like. This is called independent living.
- People with intellectual disabilities should also have their assistant, if they need one. Someone else can explain to the assistant what they have to do.
- The assistant can help the person with using money, getting on a bus or in any other situation where they need help.

The third myth says that children cannot have a personal assistant. This is wrong.

- Children live at home with their parents, but parents need to go to work or spend time with brothers or sisters. An assistant can help parents with taking care of their child.
- With an assistant, it is easier for families to do the things they like and not to be too tired.

The fourth myth says that all disabled people like to have their parents as assistants. This is wrong.

- Personal assistants help disabled people become independent. Sometimes, parents do not like their children to be independent, even if they are already grown up.
- This means that it can be better for parents not to be assistants.
- Some disabled people prefer not to have parents with them when they are on a date, for example.
- ENIL is not against disabled people having their parents as assistants, but only if this is something they really want.

The fifth myth says that it is cheaper for disabled people to be in an institution, than to have an assistant. This is wrong.

- Living at home and doing the things you like is a human right.
- This means that having a personal assistant is the right thing to do, even if it costs more money.
- Often, having an assistant costs less money.
- This is because the disabled person can go to work with an assistant and contribute to their community.

The sixth myth says that personal assistants need special skills. This is wrong.

- The disabled person should choose who they would like their assistant to be. It can be anyone they get along with.
- Personal assistants do not have to go to university or to be nurses. The disabled person should show them what to do.
- Self-advocacy organisations can help disabled people and personal assistants to do their job well.
- Other disabled people who use personal assistance can also help with sharing their experience. This is called peer support.

The seventh myth explains that governments should pay for personal assistants, not disabled people.

- This is because personal assistance helps disabled people live in their own home and do the things they like. This is their human right.
- It is important that the government gives enough money to disabled people, so they can have as much help as they need.
- Personal assistants also have to be paid well, in order to do their job properly.

The eighth myth says that personal assistants can hurt disabled people. This is wrong.

- It is dangerous for disabled people to live in institutions. It is much safer when they live in their own home.
- If a personal assistant is not doing a good job, they can be fired. The disabled person can find another assistant. This cannot be done in an institution.
- Self-advocacy organisations can help keep disabled people safe, by helping them understand what a personal assistant should and should not do.



Introduction

The European Network on Independent Living (ENIL) works on numerous topics and areas related to Independent Living, with personal assistance being always in the focus. Personal assistance is one of the main pillars of independent living, and one of the main tools we, disabled people, have to live with choice and control over our lives, in the community and out of institutions.

ENIL defines personal assistance as 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.

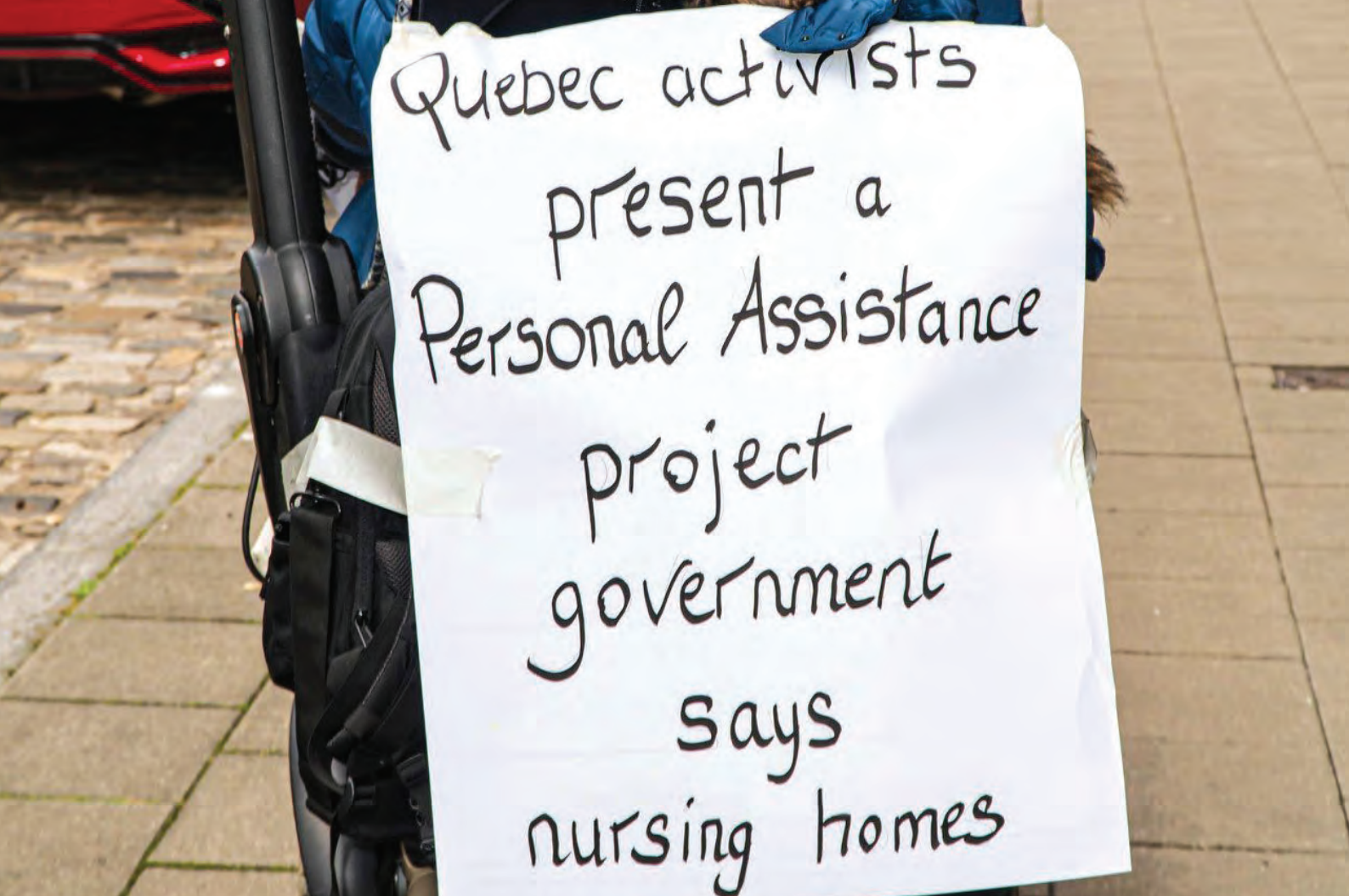
Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) requires States Parties to put in place personal assistance services, by stating that disabled people must “have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”. General Comment 5, on living independently and being included in the community, explains and defines personal assistance, in order to avoid misconceptions and misuse of the term.

This Myth Buster on Personal Assistance debunks some of the most common myths about personal assistance, and it is based on and inspired by the lived experience of the author and the contributors, by our everyday interaction with the disability community internationally, by our work with policy and decision makers at the European, national and local level, and of course by the UN CRPD and the General Comment 5.

ENIL decided to publish this Myth Buster, in order to raise awareness about personal assistance, and to address the various myths and misconceptions around it. We often read and hear about practices referred to as ‘Personal Assistance’, which are in fact something completely different, so we hope that this publication will contribute to a better understanding of personal assistance and everything related to this form of support. We also hope that, as a result of having access to more information, more disabled people will be interested in employing a personal assistant or advocating for this crucial support service..

This publication is aimed at

- **Disabled people:** with access to better information, more disabled people might advocate or apply for personal assistance.
- **Personal assistants and those who might want to become personal assistants:** the myth buster explains the importance of personal assistants for disabled people and how this job can be attractive for many job seekers, if well-funded and adequately valued.
- **National and local authorities:** while it is imperative that personal assistance is available to all, it is important that it is introduced in a way that facilitates independent living. This publication explains some of the most common traps that should be avoided.
- **European Union:** this publication can help ensure that the EU funded personal assistance schemes comply with the CRPD and the General Comment 5.
- **Anyone who would like to learn more about personal assistance:** after all, this is a compilation of the experiences of disabled people active in the independent living movement.



Quebec activists
present a
Personal Assistance
project
government
says
nursing homes

Myth

Any type of support provided in the home of the disabled person can be called 'personal assistance'.

Fact

While there are different ways support at home can be provided, personal assistance is specific in that it is controlled by the disabled person.

Therefore, we should refer to something as 'personal assistance' only if it satisfies the following criteria, set out in the General Comment 5:

- **The way personal assistance is funded.** According to GC 5, "funding for personal assistance must be provided on the basis of personalized criteria and take into account human rights standards for decent employment. The funding is to be controlled by and allocated to the person with disability with the purpose of paying for any assistance required. It is based on an individual needs assessment and upon the individual life circumstances.

Individualized services must not result in a reduced budget and/or higher personal payment.”

- **Who is in control.** As the GC 5 explains, “the service must be controlled by the person with disability, meaning that he or she can either contract the service from a variety of providers or act as an employer. Persons with disabilities have the option to custom design their own service, i.e., design the service and decide by whom, how, when, where and in what way the service is delivered and to instruct and direct service providers.”
- **The relationship between the disabled person and their assistant(s).** The GC 5 notes that “personal assistance is a one-to-one relationship. Personal assistants must be recruited, trained and supervised by the person granted personal assistance. Personal assistants should not be “shared” without the full and free consent of the person granted personal assistance. Sharing of personal assistants will potentially limit and hinder the self-determined and spontaneous participation in the community.”
- **Who makes decisions about what an assistant does.** According to the GC 5, one of the key criteria is the “self-management of service delivery. Persons with disabilities who require personal assistance can freely choose their degree of personal control over service delivery according to their life circumstances and preferences. Even if the responsibilities of “the employer” are contracted out, the person with disability always remains at the centre of the decisions concerning the assistance, the one to whom any inquiries must be directed and whose individual preferences must be respected. The control of personal assistance can be exercised through supported decision-making.”

Considering that home care (another type of support provided at home) is often mislabelled as ‘personal assistance’, ENIL has developed a comparison table explaining the main differences¹. Some of the main differences are that home care is most often provided by an agency, which means that the agency sends the ‘carers’ that are available and not necessarily the same ones every time. The disabled person does not have a choice. What the ‘carer’ does is also decided by someone else. Typically, ‘carers’ support a person with their basic needs inside their home; this includes help with eating, washing, taking medication, cleaning. Personal assistants, on the other hand, often support the disabled person outside of their home too, with going to a supermarket or a cinema, seeing friends, going to school or to work, even travelling.

Some people may prefer home care to personal assistance, to avoid making decisions, having to recruit staff and having responsibilities as employers. It is important that this is their genuine choice, and is not imposed on them. It is also important that peer support, administrative support and funding, is available to those who wish to use personal assistance, so that the responsibilities attached to using personal assistance and managing personal budgets are not too daunting. For example, some of the tasks, such as help with recruiting PAs or managing schedules, can be carried out with support from the local Center for Independent Living (with funding from the state) or by user cooperatives.

1. See: <https://enil.eu/explainer-difference-between-personal-assistance-and-home-care/>

It is also worth noting that, by definition, personal assistance cannot be provided in a residential care setting. This is because in institutions, the person is not in control of any care or support they receive, and cannot choose to, for example, fire their assistant should they wish to get someone different. The other criteria which characterise personal assistance also do not apply in a residential setting.

Finally, ENIL's Personal Assistance Checklist² can be used to develop or evaluate a system of personal assistance, to make sure it is in line with the CRPD and the independent living philosophy. Features of fake personal assistance, as opposed to real personal assistance, developed by Adolf Ratzka, are also helpful in understanding the difference between personal assistance and other types of support at home (see Table 1).

Related myths

- Disabled people should be grateful for whatever support they get.
- Having a personal assistant will cause a lot of disabled people to be more reluctant to do their daily routine on their own. They will become more lazy and less responsible for their actions.
- A personal assistant should take care of the disabled person.

2. See: https://enil.eu/wp-content/uploads/2022/03/Mladenov_Pokern_Bulic-PA_Checklist.pdf

Table 1: Common features of a fake personal assistance scheme

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1. Restrictions are placed on the choice of personal assistants or service providers. For example, the personal assistants' employer is limited to employing only certain categories of people, e.g., long-term unemployed people: or they can only engage a care agency from the authorities' predetermined approved list.

 2. Recipients have not been given any control over the funding.

 3. Direct payments are determined mostly on the basis of available income, but occasionally, on the degree of impairment. Therefore, in the former case, the provision of direct payments is limited to people with low incomes, or is means-tested so that it is free only to those with low incomes.

 4. The access to direct payments depends upon geographical residency. Therefore, the direct payment cannot be retained when the individual moves their residence to another area.

 5. There is an imposition of minimum or maximum number of assistance hours per week.

 6. The assistance is limited to personal care, i.e., washing, eating, etc.

 7. The funds are not sufficient to cover people's needs, including those involved in taking on the role of an employer.

 8. The imposition of a minimum and/or maximum age range for the personal assistance employer.

(Compiled by Jim Elder-Woodward³, adapted from Adolf Ratzka, 2018⁴)

3. Elder-Woodward, Jim (2023) Personal Assistance in Scotland: A Postcolonial Perspective, in *International Journal of Disability and Social Justice*, see: <https://www.scienceopen.com/hosted-document?doi=10.13169/intjofdissocjus.3.1.0114>

4. See video: https://youtu.be/s5ARX-_7ais



Myth

Personal assistance is only for people with physical impairments. People with intellectual impairments, autism or high support needs cannot manage their personal assistance.

Fact

Personal assistance is for every disabled person that needs support in order to be able to live independently with choice and control over their lives, irrespective of their impairments and other characteristics.

Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) states that::

“States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community”.

It requires governments to ensure that “persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”.

In addition, the General Comment 5 on Article 19 CRPD stresses that “persons with intellectual disabilities, especially those with complex communication requirements, among others, are often assessed as being unable to live outside institutional settings. Such reasoning is contrary to Article 19, which extends the right to live independently and be included in the community to all persons with disabilities, regardless of their level of intellectual capacity, self-functioning or support requirements.”⁵

Therefore, based on the above, but also on good practices we have seen in various countries (see, for example the work of JAG in Sweden), we can clearly say that personal assistance is for every disabled person that needs support in order to be able to live independently with choice and control over their lives. This includes also people with visual impairments, intellectual impairments, autism and those with multiple impairments, among others. The control of personal assistance can be exercised in various ways, one of them being through supported decision-making.

The support provided by the assistant will be different, based on the individual needs and circumstances of each person. For example, while someone with a physical impairment might use their assistant as their ‘arms’ or ‘legs’, a person with an intellectual impairment might use an assistant as support with using money, getting around with public transport, understanding complex information etc. Another person might need support with remembering to take medication, cooking, or keeping their apartment or a garden tidy.

When it comes to persons with different communication requirements, who use informal means of communication, the General Comment 5 asks that they be “provided with appropriate supports enabling them to develop and convey their directions, decisions, choices and/or preferences and have them acknowledged and respected” (para 17).

It is also important to note that not all disabled people need the same type of support and services in order to live independently. Therefore, personal assistance is not a tool every disabled person needs, and other forms of support must also be available (including, for example, financial support and assistive devices). This does not mean that disabled people who do not need personal assistance are able to live without support. Living independently involves a wide range of criteria for it to be possible, and there are many other barriers disabled people face in that respect (as described in the 12 Pillars of Independent Living⁶).

Related myths

- Personal assistance is a good solution only for persons with less extensive support needs. It is impossible to organise personal assistance for someone in need of support 24/7.

5. General Comment No.5 on Article 19 – the right to live independently and be included in the community, para. 21. Available at: <https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no5-article-19-right-live>

6. See: <https://enil.eu/independent-living/>



Myth

Independent living options, such as personal assistance, are not appropriate for disabled children⁷.

Fact

Experience shows that children and young people, as well as their families, can greatly benefit from personal assistance.

Independent living support options, such as personal assistance, are often available to adults only. This means that the only support offered to disabled children and their families occurs in segregated settings, such as special schools, children's institutions, day

7. This myth was firstly debunked in our Myth Buster on Independent Living (2014). Available at: https://enil.eu/wp-content/uploads/2022/03/Myths-Buster_2_for_web.pdf

care centres, institutional respite centres etc. This is especially true for children who have been diagnosed with having intellectual impairments or who have complex support needs. A lack of support in the family home or in mainstream educational settings can cause very stressful environments and can lead to a child being needlessly taken away from their families and peers. It also perpetuates the idea that 'special' services and institutions are necessary.

Independent living is not just for adults. It spans the full range of life experiences faced by disabled people, from early years and transition to adulthood, through to adult life and employment, extending into old age. The earlier an individual receives independent living support and has a chance to grow up in their family and alongside their peers, the more likely it is they will be confident and active as adults. On the other hand, early institutionalisation often leads to additional impairments and a lifetime spent in institutional care.

It is self-evident that personal assistance is not meant to replace the care provided by the child's parents or carers. Rather, its aim is to supplement it where needed, so that the child's parents or carers are able to work, spend time with their other children and get respite when needed. Personal assistance is also key to ensuring disabled children can attend mainstream education. If disabled people are able to experience independent living from a young age then they are afforded similar opportunities to develop their own life course and personal networks as their non-disabled peers.

Finally, one argument used to justify why personal assistance is not suitable for children is because they are not able to employ and manage their assistants. However, as evidenced by countries where children can have personal assistants, their parents or carers (with the support of Centres for Independent Living and similar organisations) are well placed to help ensure that personal assistants provide the type of support required by their child.



Myth

It is better for disabled people to have their family members as their personal assistants, because they know them best.

Fact

The experience of many disabled people proves that often, having a family member or a relative as a personal assistant, does not make the disabled person more independent.

Personal assistance gives disabled people choice and control over their lives, and makes it possible for them to live independently. It is a life changing factor for many. Disabled people are the employers and decide what they want to do, when and how, in the same way non-disabled people do.

However, in some countries, disabled people are forced to employ their family members as personal assistants, just because they get too little funding to employ someone from outside of their family. Sometimes, the funding provided is well below the minimum wage. In other cases, the hours funded per day are too low to find an assistant willing to do the job.

It is ENIL's view that disabled people should not be in a position where they have to employ family members, relatives or even friends as personal assistants. Experience from countries where employing family members as personal assistants is commonplace, shows that disabled people do not necessarily become independent. What this model does is bring additional funding to the household, or provide employment opportunities for parents or relatives.

A personal assistant is someone who is employed by the disabled person (acting as 'the boss') and follows their specific instructions, based on a contract agreed in advance. It can be difficult to employ your parents, husband or wife, children or friends and expect them to behave as an employee during the working hours, and after that to switch back to their other role (of a parent or a friend, for example). There are also situations, such as dating, intimate relationships, or going out with friends, when many people would not like to have their parent with them.

In the words of one of our members, an independent living activist from Scotland, there are benefits to not employing family members: "The personal assistant can also normalise family relationships, so the male carer can become the husband once more, or the female carer can become the wife. It is hard enough to discipline a personal assistant, then ask them to wipe your bottom, let alone disciplining your personal assistant and then giving them a loving kiss as a spouse."

Another activist from Hungary said: "Your personal assistant may be your friend, but you are primarily their employer."

ENIL accepts that some people – in many cases people with intellectual disabilities - might want to have their parent, sibling or another family member as a personal assistant. It is for this reason that ENIL does not call for a ban on employing family members. Where employing a family member is a genuine choice or preference of the disabled person, for whatever reason, it should be respected.

For people with intellectual disabilities who choose not to employ family members, it is important to have the peer support of other disabled activists and their Centers for Independent Living, as well as good cooperation with the families, who become part of the PA ecosystem, supporting with the recruitment and training of personal assistants, but not becoming assistants themselves.

Traditions and culture may also influence disabled people's choice of an assistant. While in some countries, it is deeply rooted in the culture to promote independence of one's child, in others, young people and adults may be expected to continue living in the family home and to have family members as assistants. In such cases, it may be difficult to say whether a disabled person chose their family member as an assistant, or if this was the result of pressure or tradition. In these cases, it is important to regulate personal assistance in such way to facilitate choice; for example, through empowerment, peer support and training on independent living (both for the disabled person and their family members).

Related myths

- A personal assistant should be your best friend.
- A personal assistant can do anything a disabled person wants them to do.



Myth

A personal assistance system is more expensive than placing disabled people in institutions.⁸

Fact

Whether personal assistance costs more or less should not be used as an argument to provide it or deny it. Independent living is a human right, and since personal assistance is for many people the only way to enjoy their rights, it should not be denied in order to make savings. However, even if economic arguments are being considered, there is evidence that personal assistance is still a better choice, financially speaking.

⁸ Based on a similar myth that was firstly debunked in our Myth Buster on Independent Living (2014)

It is often argued that, while living in the community is undoubtedly better than residential care, it is too expensive to provide independent living support, such as personal assistance, to everyone who needs it. There are a number of problems with this presumption.

First and foremost, independent living is a human right and cannot be denied because it is deemed to be too expensive. Secondly, the claim that independent living is always more expensive than residential care is usually made without any proof or analysis. For example, a study in Northern Ireland found that for every £1 spent on funding independent living (PA), the community benefited by £11.⁹ In terms of value for money, whether it is about people with low or high support needs, direct payments result in better quality of life measurements.

Unfortunately, the funding structure of health and social care services generally creates a financial incentive for local authorities to use residential care options. Those that do provide independent living options generally put a limit on how much support one person can get. Residential costs are determined on a group basis and it may be difficult to establish how money is allocated and what it pays for. Meanwhile, independent living requires resources to be allocated according to individual needs, in the form of individualised budgets (direct payments), which the disabled person can use to pay for their support. For the above reasons, and many more, comparisons of expenditure on institutional care versus independent living have proven very difficult. Independent living requires radical changes to the way in which services are delivered and funded, and does not work as just an add-on to existing services.

There is also a failure to see expenditure on independent living as a form of social and economic investment. In residential care, instead of supporting disabled people to actively contribute to their communities and society, resources are used in ways that maintain and create restrictions. This results in higher than necessary expenditure on social security benefits, as well as lost revenue from taxes that could have been paid by disabled people, were they supported to work and employ their personal assistants.

9. See: <https://ilf.scot/wp-content/uploads/2020/07/44188-ILF-NI-Impact-Evaluation-Report.pdf>



Myth

Personal assistants need training and medical knowledge. They should have specific qualifications in order to properly and safely do their job. Not everyone can be a personal assistant.

Fact

Disabled people should have the option to custom design their own service, which means deciding by whom, how, when, where and in what way the service is delivered to them. Some may choose trained professionals as their personal assistants, while others might find suitable people without any specific professional background or education. They might prefer people without any previous work experience, avoid those coming from the health sector, or even select another disabled person for the role.

Disabled people must have the right to recruit, train and manage their assistants, with adequate support if needed, and they should be the ones that choose the employment model which is most suitable for their needs. They can, if they wish, instruct and direct other service providers to formally employ their personal assistant, but they should remain in control of the overall service (i.e. to choose by whom, how, when, where and in what way the service is delivered to them). The control of personal assistance can be exercised through supported decision-making.

Personal assistants must be recruited, trained and supervised by the person who uses personal assistance. Disabled people know better than anyone else their needs and how they wish to be supported. Each disabled person is different and has different needs, so a universal training will not be very useful. If particular qualifications or additional training is required from personal assistants by the state, this may limit the pool of people a disabled person can choose, disqualifying a potential personal assistant that may lack a qualification (i.e. speaking the national language, having specific type of studies etc), but is the perfect option for the disabled person.

If any training is to be mandatory, this should be provided both to the disabled person and the personal assistant, on topics like the independent living values and philosophy, crisis management, employment legislation, working conditions etc. First aid training should also be available to personal assistants and should be encouraged. The practical part is learnt through the interaction of the two parties, and comes with practice. This includes handling medical equipment.

Considering that not every disabled will have the right level of education, experience, or skills needed to deal with the tasks involved in being an employer, Centers for Independent Living (CILs) and user co-operatives play an important role in making sure that personal assistance is accessible to everyone. In a user cooperative (see ULOBA in Norway, or STIL in Sweden), disabled people who employ personal assistants come together as employers and delegate the tasks such as training, recruitment, the paying of salaries and taxes to the co-operative. The co-operative can also support disabled people who employ personal assistants in the day-to-day supervision of a PA, time management, and any other administrative task. User cooperatives are funded by personal assistance employers with the funding they receive for administration (i.e. for managing of their personal assistance).

Related myths

- A personal assistant is responsible for the disabled person's decisions.



Myth

Disabled people should pay for their personal assistance.

Fact

The funding for personal assistance should be provided (in full) to disabled people by the state, and they should not be required to contribute to it financially.

Personal assistance is a right, enshrined in the UN Convention on the Rights of Persons with Disabilities, more specifically in Article 19, and as such should be available to every disabled person requiring support, in order to be able to live independently, irrespective of their social and financial status, the area they live, if they work or not, if they are married or not etc.

According to the General Comment 5: "To ensure that persons with disabilities enjoy an adequate standard of living (art. 28), States parties should provide, inter alia, access to support services that enable them to live independently. Therefore, there is an obligation on the part of States parties to ensure access to appropriate and affordable services, devices

and other assistance for impairment-related requirements, especially for those persons with disabilities who live in poverty. Furthermore, access to public and subsidized housing programmes in the community is required. It is considered contrary to the Convention for persons with disabilities to pay for disability-related expenses by themselves.”

Funding for personal assistance must be provided on the basis of personalised criteria and take into account the needs and the individual life circumstances of the disabled person. It has to be controlled by and allocated to the disabled person, in the form of ‘direct payments’ or ‘personal budgets’, with the purpose of paying for any assistance required. On the other hand, it must respect the human rights standards for decent employment of the personal assistants, and 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.

The lack of funding for personal assistance (whereby it is available only for some disabled people) may lead to higher costs in other sectors, such as health care. For example, in Scotland, 1 in 7 hospital beds are occupied by people who cannot get support in the community.

Related myths

- There is no need to introduce legislation on personal assistance. A personal assistance scheme can function effectively on a project basis as well.



Myth

Personal assistants could be potentially dangerous for disabled people, take advantage of them, harm them and provide low quality of services.¹⁰

Fact

Because independent living allows individuals to choose their support (the people that will assist them), it is much more likely that the support will be better suited to their needs. It is well documented that living in an institution can be much more dangerous for the person.

10. Based on a similar myth that was firstly debunked in our Myth Buster on Independent Living (2014)

Living independently is a fundamental human right, and personal assistance is an essential tool to achieve that. When used in a well defined and regulated scheme, personal assistance can be the only way for a disabled person to live independently and be safe. Living without the necessary support and not having access to services like personal assistance can even put a disabled person's life in danger.

Measuring the quality of service provision is an incredibly subjective exercise and it should be primarily based on the experiences of the person receiving the support, establishing whether it enables the individual to live as they wish and to realise their full potential. This is easier to ensure with independent living service options, because disabled people have much more choice and control over what their support looks like. Independent living support options allow disabled people to employ and train their assistants, and give them an option to fire them if needed. With 'direct payments' or 'personal budgets', disabled people can decide on their own support and that support is individualised. For this reason, it is much easier to control quality than in larger settings. Disabled people's organisations, such as Centres for Independent Living or user cooperatives, are available to support disabled people in this process, by providing information about employing personal assistants, helping with the administration of personal budgets, choosing the right type of support etc.

In institutional and residential settings, a "safe and protective environment" according to some, there are unlimited incidents of violation of the human rights of the residents. From the torture, abuse, isolation and over-medication, to the hundreds of deaths during a crisis situation (such as the COVID-19 pandemic, a flood or a war), or just because people were not being properly taken care of.

Human interaction can be potentially dangerous in any situation, and that is something that cannot be avoided in life. However, using a personal assistant is surely the safest option for a disabled person to live an independent and decent life.

Finally, disabled people's organisations, such as Centres for Independent Living or user cooperatives should, through peer support, empower disabled people using personal assistance to recognise abuse and give them the tools and support needed to report any abuse, if it happens, and to take other steps that are necessary.



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Glossary

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 defined in the General Comment 5 and the CRPD Guidelines¹¹ on Deinstitutionalisation, including in Emergencies as having some or all of these defining elements: obligatory sharing of assistants with others; no or limited influence as to who provides the assistance; isolation and segregation from independent life in the community;

11. Guidelines on Deinstitutionalisation, including in Emergencies (2022). Available at: <https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpd5-guidelines-deinstitutionalization-including>

lack of control over day-to-day decisions; lack of choice for the individuals concerned over with whom they live; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of individuals under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; a disproportionate number of persons with disabilities in the same environment; provision of housing and support in one package by the same service provider. By its very definition, Independent Living is impossible in residential settings.

When it comes to children, anything other than a family (including married and unmarried parents, single parents, same-sex parents, adoptive families, kinship care, kafalah, sibling care, extended family, and substitute families or foster care), must be considered an institution. “Family-like” institutions are still institutions and are no substitute for care by a family.

Institutional care refers to the ‘support’ residents receive by staff working in the institution. A residential care setting is terminology used by service providers to denote settings specifically designed for disabled people (such as group homes, service apartments, 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.

Supported decision making comprises various support options which give primacy to a person’s will and preferences and respect human rights norms. It should provide protection for all rights, including those related to autonomy (right to legal capacity, right to equal recognition before the law, right to choose where to live, etc.) and rights related to freedom from abuse and ill-treatment (right to live, right to physical integrity, etc.). Furthermore, systems of supported decision-making should not over-regulate the lives of persons with disabilities.¹²

12. General comment No.1 (2014) on Article 12: Equal recognition before the law. Available at: <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>

Useful resources on Personal Assistance

Fact Sheet on Personal Assistance (2022):

<https://enil.eu/personal-assistance/>

Fact Sheet on Independent Living (2022):

<https://enil.eu/independent-living/>

Explainer: Difference between Personal Assistance and Home Care (2022):

<https://enil.eu/explainer-difference-between-personal-assistance-and-home-care/>

Personal Assistance Checklist (2019):

https://enil.eu/wp-content/uploads/2022/03/Mladenov_Pokern_Bulic-PA_Checklist.pdf

Adolf Ratzka: True Personal Assistance vs Fake Versions (2018):

https://youtu.be/s5ARX-_7ais

Myth buster on Independent Living (2014):

<https://enil.eu/wp-content/uploads/2022/03/Myths-Buster-final-spread-A3-WEB.pdf>

Model National personal Assistance Policy: A project of the European Center for Excellence in Personal Assistance (ECEPA) (2004):

<https://www.independentliving.org/docs6/ratzka200410a.html>

Independent Living Research Network:

<https://enil.eu/project/independent-living-research-network/>



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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. For more information, see: www.enil.eu



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