

MANIFESTO PERSONAL ASSISTANCE

Right to personal assistance for every person with a disability

Brussels, 15 December 2021

With this manifesto, we invite policymakers to bring personal assistance out of the shadow and strengthen the right to personal assistance.

ABOUT PERSONAL ASSISTANCE AND DIRECT FINANCING

What is it?

Personal Assistance is support under the control of the person with a disability in the context of an independent life in society. The assistance to the person with a disability is personal if the person with a disability decides who acts as an assistant, what support the assistant provides, where, when and how the assistant provides support. It is personal if only this one person is supported within the assistance time.

In a number of countries or regions, there are legal systems that allocate a budget to persons with disabilities to organise personal assistance. This is called direct funding: the grants go directly to the person. The rightholder receives an individual, tailor-made budget and can use it to pay for the support that is needed.

Personal assistance and direct funding are part of an important evolution in the pursuit of an inclusive society, which also focuses on integral accessibility, providing reasonable accommodations in all areas, a decent income and so on. The right to personal assistance is expressed in Article 19b of the UN Convention on the Rights of Persons with Disabilities (CRPD) and further elaborated in an explanatory text of the UN Committee.

A powerful story we can be proud of

The possibility of direct financing arose in Flanders on 15 December 2000, with the approval of the Decree on the Personal Assistance Budget (PAB), the culmination of a years-long struggle between people with disabilities. Flanders became an exemplary region in Belgium and Europe. From 2016, the principle of having your own budget to organize your support was extended to the Personal Budget (PVB) within stage 2 of the Person-following Financing (PVF).

Personal assistance proved to be one of the most important keys to inclusion in Flanders over the past 2 decades. Hundreds of children, young people and adults who acquired a disability before the age of 65 built their lives in the middle of society with the help of personal assistance. It gave them opportunities to live in society, go to regular school, take up a regular job, establish relationships with other people without depending on them for care. Very normal things that were unfeasible without personal assistance. Personal assistance gives people the right to make decisions and therefore allows them to maintain their human dignity. Personal assistants do a top job.

And yet: a bird that is not allowed to fly?

However, the reality of personal assistance remains too small and invisible after 20 years. In the first 15 years after the creation of PAB, the share of direct financing in the expenditure of the Flemish Agency for Persons with Disabilities (VAPH) fluctuated around 5%. After the introduction of PVF, this changed very little. Currently, it's about a 7-8% cash budget relative to the total. It is not known how much of that share of cash budgets really goes to personal assistance. After all, personal assistance only includes those methods of spending in which the person himself or herself determines who assists him or her, when, for what, how and where.

It is a painful observation that personal assistance does not really get off the ground. On the other hand, it does not surprise us. Personal assistance and the job of personal assistant are still unknown to many, there are prejudices, and the thresholds for exercising the right to personal assistance are too high. For example, the budget levels are not up to scratch, there are long waiting times to obtain a budget and many are not even eligible for a budget. Moreover, it is currently difficult for many to work with, there is insufficient training and coaching for budget holders, the exchange of information and social support by other persons with disabilities is not encouraged, and safety nets are lacking for those who find it more difficult to organise personal assistance themselves.

We must therefore conclude that the right to personal assistance is still being violated in Flanders. As a result, many people remain dependent on the goodwill of family, friends and volunteers, collective care organizations and the social network. Shortages in personal assistance deplete the social network around the person, and can lead to social isolation and loneliness. Other rights are also affected, such as the right to personal autonomy and equal opportunities for free choice, the right to participate in society on an equal basis with other citizens and the right to a good standard of living and social protection. Because people have to bear the costs of support themselves, their current and future income position weakens.

CALL

We make a warm and urgent appeal to all policymakers to change this. Targeted policies with a clear vision can make the transition to equal opportunities for a life in society possible, as also expressed in the UNCRPD. In a general and coordinated plan for the inclusion of persons with disabilities, personal assistance plays an important role. We see the following action lines for this:

1. Focus on sufficient and qualitative personal assistance

» **Raise awareness and actively address prejudices.** Both among people with disabilities and among the general population, personal assistance is too little known and the image of the job of personal assistant is often too one-sided. What the job entails and who is eligible for a particular assistant job vary greatly depending on the needs and expectations of the budget holder. The various policy makers involved can each work on this within their sphere of influence. The ministers of welfare, work, education and equal opportunities can work together from their key positions within an awareness plan.

» **Clear language for personal assistance and inclusion.** Clearly support and defend the paradigm shift towards inclusion in society in public. Giving positive attention and speaking appreciatively about the job of personal assistant.

» **Fine-tune budget levels.** The individual budgets must be high enough to meet the support needs, to hire personal assistants themselves, to give them sufficient remuneration, to reimburse seniority and to be able to keep them. This is currently not the case with many budget holders. This compromises the continuity of support. It takes a lot of energy to find and train personal assistants again and again, to build a professional relationship of trust and good relationship.

» **Better financial support for choices to arrange support yourself.** Less money is allocated for those who organise the support themselves than for those who go to live at a facility. People have to make adjustments themselves for years because their personal budget is not sufficient. They can often offer their personal assistants too few interesting conditions. However, if these budget holders go to a facility, there is additional budget available in the welfare budget for things like overhead costs and staff seniority. It would be a clear positive signal and actually support people to do it themselves if their budgets were increased accordingly.

2. Improve access to personal assistance

» **Eliminate the waiting list and guarantee the right to personal assistance.** The right to personal assistance remains a dead letter if people only receive a budget (or additional budget increase) after years of waiting. In the meantime, their savings have run out, they have been forced by the situation to live in a residential care centre, their physical and mental health or that of their family has deteriorated, and so on. Their carrying capacity deteriorates so much that they eventually make a forced choice for a facility. We call for this negative spiral to stop and to dare to choose to strengthen people. That is the only sustainable and ethical option.

» **Also give people with low support needs access to a budget.** Many people could improve enormously their participation if they could get personal assistance, but are currently not eligible for a personal budget. They are denied access to Stage 2 of the Person Following Funding and must draw their plan with home care organizations, services directly accessible help, family, friends and volunteers. The supply-driven financing of home care organizations and directly accessible help are constantly being strengthened. We call for them to also be given opportunities for self-management, as the philosophy of person-to-person financing aims to do. All persons with disabilities and a continuing need for personal assistance should be able to benefit from a budget tailored to their needs. This is a choice for more opportunities to become independent of collective care organizations and social network.

» **Reduce the waiting time for PAB for children and young people to zero.** Those who wait for a PAB still have to wait much longer than for a place in an institution.

» **Eliminate age discrimination.** Ensure that people who acquire a disability after the age of 65 can also exercise their right to personal assistance.

» **Take responsibility for personal assistance together.** Personal assistance is necessary for full participation in various areas: education, work, filling in free time, mobility, and so on. Within all areas of life, people should be able to easily deploy sufficient personal assistance. At the moment, that often doesn't work. In practice, people have to opt for support in one area of life at the expense of another. Shortages in one domain affect the other domain. Guaranteeing the right to personal assistance is therefore a matter for everyone (not just the minister of welfare). We call on all policy makers in charge of the different life domains to coordinate this, based on a joint responsibility, so that sufficient personal assistance is possible in all areas of life in order to live and participate in society. This is how we make the UNCRPD a reality.

Supporting people to organise personal assistance

» **Remove barriers to organize your own support.** Real accessibility of personal assistance means that people can easily organize it themselves. Now it is too difficult for many people. Because of too difficult language in official communication and regulations, too many and too complicated administrative obligations, people tend to buy care from a healthcare organization that handles it further. As a result, they refrain from working with personal assistants. Dependence on services and organizations that assist the budget holder can also be limited. Policymakers can start a process towards more simplicity in consultation with budget holders.

» **Training and coaching for employers.** A good employer-employee relationship is essential. Policymakers can facilitate this by funding initiatives that organize education, training and coaching for budget holders. In this way, people with disabilities can strengthen themselves to be a good employer. For some people, for example because of disability, extra support is needed in the relationship with the personal assistant. Often a parent takes this with them, but that is not always feasible or desirable. In these situations, there may be a need for extra intensive and permanent coaching.

» **A safety net for those who cannot take up the organization themselves.** The right to personal assistance is even more vulnerable for those who, for example because of disability, find it difficult to organise the support themselves. Usually, a parent or other person from the social network records this. They often also play a role in managing personal assistants. If these people lack or have too little capacity, the organization of the support also threatens to become impossible. Then it becomes very difficult to continue to live independently of collective healthcare providers. We call for solutions to such situations, and to build a guarantee that personal assistance does not have to be stopped and that the person's choices about his or her support are safeguarded.

» **Facilitate social capital and peer counseling.** Social support is essential to strengthen people in their daily exercise to live and participate in society. However, social networks are now under more pressure than ever due to all kinds of factors. In addition to mutual assistance in family and friends, people with disabilities should also be able to exchange more experiences and support with each other. The government can facilitate this by funding peer counselling initiatives, where people with disabilities can inform and support each other.

LEARN MORE

This manifesto is an initiative of the Working Group on Support Policy of GRIP vzw, in which (experiential) experts determine the vision and actions of GRIP about support based on years of involvement, knowledge, experience and analysis. We are convinced that many people will recognize themselves in this manifesto and support its content. This manifesto therefore wants to offer recognition to all these people, without assuming to represent the voice of everyone who uses personal assistance or is on the waiting list for a budget. This manifesto was originally written in Dutch and published on the GRIP-website. You can download it here:

https://cdn.digisecure.be/grip/2021121422453544_211215-def-manifest-persoonlijke-assistentie-2021.pdf

As a contribution to more awareness, an understanding and a more positive image of personal assistance, we published a brochure about this in 2021. In **'#inclusion#personalassistance: grip on your life'** we show what personal assistance is, how it works and what it means for inclusion. We do this on the basis of duo interviews of a person with a disability and his or her personal assistant, with some extra explanation each time. A digital version of the brochure can be downloaded free of charge at www.gripvzw.be

In 2011 GRIP wrote the **Manifesto Personal Budget**. This became a joint manifesto in May 2011, signed by dozens of associations of persons with disabilities (see [20181120112618519_120615-joint-manifest-pgb.pdf \(digisecure.be\)](https://cdn.digisecure.be/20181120112618519_120615-joint-manifest-pgb.pdf)). The principles remain relevant today:

- We want equal rights and equal opportunities
- We want to control our support ourselves
- Direct financing increases our autonomy

GRIP vzw | Vooruitgangstraat 323 | T. 02/ 214 27 60 | e-mail: info@gripvzw.be
Company number 0474368206 | RPR Brussels