



# INFOSHEET IRELAND

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## **THE PURPOSE OF THIS INFOSHEET**

The goal of the Expertise Center Independent Life is the gathering of expertise on direct payments in Flanders and Europe.

A first report entitled "Direct payments in care. Actual situation in 8 European countries" was published in February 2008. It contained an overview of the way in which direct payments are organized in the Netherlands, Germany, Sweden, the United Kingdom, Spain, France, Norway and Finland.

We would have liked to extend the research to all European countries, but we lack the means to that end. That is why we have asked some experts in the field of direct payments to give a brief overview of the current situation in their respective home countries. As a support we have used a questionnaire. Thanks to the people that have responded to our emails we have been able to gather this extra information.

As a result this text does not pretend to be exhaustive. The idea is to just give information about the most important initiatives of direct payments in different European countries.

Nuala Crowe Taft, a Development Consultant with a special interest in disability human rights gave us the following information.

## **CURRENT SITUATION IN IRELAND**

### **GENERAL INFORMATION**

**1. Is there, on a national level, a law that regulates direct payment?**

No, there is not

**2. Is there on a regional or local level a law that regulates direct payment?**

No, there is not, some regions have arrangements, but they are not law.

**3. If a system of direct payment lacks, how is the support for disabled people arranged?**

Although there is not a law for direct payments, there is the possibility to use some kind of personal assistance. Some general information about this service:

- People who have personal assistants have their service delivered through a government approved service provider. Therefore the service provider is the employer, even though the disabled person supervises the service.
- People are to some extent allowed to negotiate the support that is offered to them. After assessment they are approved for a certain number of hours, and they can then appeal this, but the process is slow and it is difficult to get an increase in the hours.

- There is a waiting list for assessment. The disability act (2005) includes the right to assessment, but it is being implemented very slowly. Most people on the list will have to wait several years for assessment if they do not already have personal assistant services.
- If a person has approval by the Health Service Executive for hours, the hours are provided without cost to the service user, but if a person needs more hours, they may have to pay for the hours until they are reassessed. If you have not been assessed, you must purchase hours until your assessment comes through.

## QUESTIONS ABOUT DIRECT PAYMENTS:

As said in Ireland, there is only a regional arrangement (not a law) on direct payments and to some extent personal assistance. In the following text Nuala Crow gives answers to the questions, either considering the regional direct payment, or personal assistance, or both, depending on what is more appropriate:

### 4. Who can and who cannot receive direct payment? How is this defined?

- **Is there a minimum or maximum age?**

At present adults under 65, - but there is no national law that respects the right to direct payments. Some individuals have arrangements with their local health service providers.

- **Is this budget merely meant for disabled people, or also for health care and care for elderly people?**

There are regional arrangements whereby individuals can apply for 'home care packages' which include some care hours, but this is not really 'independent living'.

- **Is the budget also for people with an intellectual disability? Is there a special arrangement for these individuals?**

No. The Microboard association of Ireland was established to pilot direct payments for people with intellectual and other disabilities, but whilst the pilot was successful in terms of proving that persons with an intellectual disability can manage their own affairs with support, the organization did not manage to obtain direct payments for any of the participants.

### 5. On what basis is the height of the budget determined?

- **Is this on an individual basis, depending on your specific disability and need of support?**

Individual basis for those assessed.

- **Does your own income have an influence on the height of your budget?**

It does for the Home Care Package, not for personal assistants.

- **Does the budget cover the costs you have to make for the necessary support? Or are you expected to contribute a part yourself?**

Currently people receiving personal assistant hours have to contribute additional costs – as the payment does not take account of the cost of travel etc.

**6. Is the budget considered an income, meaning you have to pay taxes on top?**

No. Not as it currently is.

**7. Does the budget go entirely to the disabled person him- or herself? Is there a possibility that the money goes to a third party like the government, a co-operative, a care office etc.?**

The budget goes almost always to a third party. Some local health offices have paid money into an account for an individual to buy services, but generally only as a last resort – and when no service provider will deliver the service in the area.

**8. Does the direct payment come in cash or as a voucher?**

Neither. Just hours of service – and the recipient signs accountability forms for the service providers.

**9. Do you have the right to determine the content of your support? Or does the government determine what you have to use the budget for?**

The government determines.

**10. Does a Personal Assistant need to fulfill special criteria established by the government? E.g. does the assistant need to be unemployed for a certain amount of time, or does he/she need to have a certain certificate?**

Many personal assistants are engaged through community employment schemes, but not all. All personal assistants engaged through service providers must undertake training in health and safety and manual handling.

**11. Can you hire family members or neighbors as a Personal Assistant?**

This seldom happens due to the way the personal assistants are engaged through service providers. Some organisations (e.g. Muscular dystrophy Ireland) manage a service that provides 'home care supports' – and in this instance many of the employees are family members, - but this is not 'personal assistance' in the same way that we understand as part of the Independent Living Philosophy.

**12. Can you pay aid instruments with the budget or is this paid by a separate regulation and funding? There are separate processes for applying for funding for personal aids.**

**13. Can you yourself determine when you get your support, for example at night, during the weekends, etc?**

To some extent, - but generally this is worked out at the assessment – based on the assessors understanding of your need. Once a person has been granted hours, they can sometimes come to agreement with their own personal assistants to change how those hours are used, but there is not a lot of scope for moving hours around.

**14. Can you yourself determine where to get your support, for example at home, at work, in class, in a collective housing etc.?**

Disabled people who live in community homes are currently (ironically) not considered to be 'living in the community' – therefore they do not receive community living supports, such as personal assistants. This is a big problem for people trying to move from institutional care to independent living, as they have to be living 'out in the community' before they can apply for assessment for personal assistant services. It is currently not a fair system. Care provided in institutions is seldom within the direct control of the disabled person, and they are subjected to collective mealtimes, bedtimes etc. There are efforts to move everyone to the community – but again, it is a slow process and there are obstacles (system barriers) such as the one I mentioned above.

**15. What is the minimum and maximum budget? What is the average budget?**

The maximum or minimum budget is not known. It is worked out in 'hours' rather than money, and some people have 24 hour personal assistance (therefore four or more personal assistants are supervised by them).

**16. How many people receive a means of direct payment and how long does this possibility exist already?**

This information is not available. The Health Research Board is asked to assist the Center for Independent Living to obtain this information. It would involve collecting information from all health area managers and also from some not for profit agencies who act as 'fiscal intermediaries' for individuals receiving payments. All these arrangements are individual – and not quite part of the system.

**17. How is the payment periodically arranged? Once a year, every 3 months, each month etc? Do you get this budget in advance or do you need to pay it first yourself, while the money is paid back to you afterwards?**

This depends on the service provider, but Personal Assistants are paid weekly and monthly depending on the employer.

**18. Who pays the budget ? Can you give us an address or contact data?** The Health Service Executive, disability services.

**19. Are you free to spend the budget the way you like? Do you need to prove how you spend your money and if so, how do you have to do that? Do you need to show a contract, bills etc?**

Disabled people sign work sheets for the personal assistants and they are then submitted to the service providers (usually).

**20. Do you get any support from a department or organization while managing your budget, as to the difficulties you experience in being an employer, your negotiations**

**with services? Is there a special treatment, extra support for people with a mental disability?**

Many voluntary organisations have services that provide support. There is an urgent need for more. The government also provides some 'personal advocate' services through the Citizen Information Board.

**21. Is there a problem in finding adequate staff, personnel, or services?** Yes.

**22. Does it take a long time between the application for support and the actual reception of a budget. Is there a waiting list?** Yes, see the National Physical and Sensory Disability Database for an annual update regarding the waiting list, available on the web.

**23. How do the government, the users, the institutions evaluate the system of direct payments? How are their reactions?** There is no large scale research yet carried out.

**24. In what way does direct payment influence the macrobudget?**

There is no quantifiable research done yet. We often cite the research from the UK where it is obvious that the state can benefit by the increased employment of disabled people.