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Towards a People's Europe

A report on the Development of
Direct Payments in 10 Member States
of the European Union



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Towards a People's Europe

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PREFACE

The purpose of this report is to review the introduction and development of 'Direct Payments', a term used to include a range of approaches which directly fund disabled and older people to employ their own personal assistants and organise their own care. These developments by social services whose aim is to enhance the independence of disabled and older service users are significantly changing the traditional relationship between service provider and service user in Europe.

As such, this change in service relationship may be viewed as marking one of the most important developments of the European social model of the last fifty years.

The European Social Network, a recently established independent forum whose members, the directors of public social services, are largely responsible for implementing these changes, proposed to the European Commission that here was an important example of social inclusion in a people's Europe with potentially far reaching consequences for the shape of social protection in the future.

The objectives of this review are threefold; firstly to simply map the extent and type of Direct Payments systems in the European Union, to compare these systems as far as we are able, in terms of eligibility, assessment and quality, employment and financing and to identify a series of key questions for further investigation.

The report is divided into two parts; Part One provides the background and comparison of Direct Payments in the member states provided, and Part Two comprises a detailed country by country description of Direct Payments followed by a legal reference section and acknowledgments.

We should like to thank the National Centre for Independent Living in London, the European Network for Independent Living in Stockholm and Age Concern, whose advice and information with regard to personal assistance programmes in Europe, has been much appreciated.

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Part One

Analysis and Summary

1.1 INTRODUCTION

The last decade has seen widespread change in social welfare across Europe, of which the most significant feature has probably been the shift from institutional to community based living for those with a range of disabilities. Services for older people too have progressively moved away from the widespread use of long term hospitalisation to social and health based community care.

Whilst these developments have been welcomed by service users, they have nevertheless remained largely service-led responses to individual need with little, if any, control exercised by the users themselves, so that whereas most of us experience life as active citizens and consumers, the experience for most clients had remained relatively passive.

Over the past 5 to 10 years, however, much recognition is due to service users who in a number of countries have vigorously campaigned for this relationship to be changed so that they might become equal partners able to manage their own personal support systems or '*personal assistance*' the term most used within the philosophy of independent living in Europe today.

A declaration on the right to personal assistance, known as the '*Strasbourg Resolution*' had been passed at a special meeting of 14 countries held at the European Parliament in 1989, but whilst good social work practice has for some time emphasised the importance of client self determination, through participation in assessment and varying degrees of choice from a menu of available services, the concept of clients taking on the responsibility of managing their own personal assistance is a relatively recent development.

Tracing the legislative origins of what has come to be known as Direct Payments is not a simple matter for whilst much change is recent and distinctly specific to cash payment for service users, other older legislation has sometimes been updated to include new Direct Payment provisions. (A list of European social services law specific to Direct Payments can be found at the end of Part Two.)

A definition is perhaps required here. Direct Payments means that the service user is funded to pay for their own service directly through cash, cheque or vouchers or in some other way authorising payment to a personal assistant or service provider. In most cases this involves service users directly employing their own personal assistants. Where the service user has difficulty managing this responsibility, some systems allow a member of the person's own family to exercise this role. In some circumstances, a number of service users have organised themselves into self help co-operatives (centres for independent living), to provide information, advice and support.

This report has chosen to focus on direct payment for personal assistance which appears to offer service users significant decision making responsibility and as such marks a distinctive move towards their empowerment as consumers in a more pluralist welfare environment.

1.2 ELIGIBILITY

There are, as might be expected, both similarities and differences in systems and approaches to Direct Payments reflecting a range of priorities in social and health care in European countries.

From the evidence presented to the network, what all schemes appear to have in common is a system of directly funding in cash or kind (e.g. vouchers) to physically disabled adults who directly

manage (or indirectly with assistance from agencies, local authorities or third persons as may be necessary) their own personal assistance. This means that service users have defined choices about who they employ and when they provide assistance. Service users are involved in the assessment of their own needs and enter into agreement with their assessors about their care plan. They will also have access to some form of complaints procedure.

In analysing the differences between countries, there would appear to be broadly three types of Direct Payments. Firstly where it is part of a standardised national insurance system providing a financial alternative to a range of health and social direct services, for those with a health and/or social need irrespective of disability or age. The prime example of this system is in Germany.

The second type, influenced by the disability movement, focuses specifically on services for physically disabled people and their need for personal assistance. The introduction of *Support and Services Act 1994* (for persons with functional impairments) in Sweden, though a voucher based system, nevertheless marked an important milestone for promoting independent living for disabled people in Europe and has become a model for others in this regard. This type tends to have an emphasis on individually tailored care plans and a relatively non-standard approach both to payment and services. It should be noted that such schemes also often include those with learning disabilities (mental handicap) but tend to have an upper age limit upon application of 65 years or the equivalent pensionable age. Existing service users are however not excluded from continuing to receive Direct Payments upon reaching the pensionable age.

The third type of Direct Payments is that designed specifically for older people. This largely differs from the second type in that it is essentially a community/domiciliary alternative to residential nursing or care home for very dependent people. It is this type of direct payment with the largest use of employed family members and where, on occasion, family members can be nominated budget holder in place of the service user.

Eligibility naturally reflects these differences with more or less standardised procedures using clearly defined criteria. The German social insurance model carefully defines categories of need and allocates hourly costs accordingly. The issue of scale also features in the design of systems and whilst the French PSB is not an insurance based model, its national scale (100,000 service users after 12 months of operation) means it inevitably must share some of the standardised features of the German model.

Most countries employ an eligibility threshold either in minimum service time or level of dependency. In Germany, the threshold is 1.5 hours of personal assistance per day, in Denmark 20 hours per week and in the Netherlands 3 months. In France (PSD) the elderly person will need to be very dependent according to a national elderly independence scale.

Figure 1

Eligibility	Austria	Belgium	Germany	Denmark	Finland	France	Italy	Netherlands	Sweden	UK
Older people	Yes	No	Yes	No	Yes	Yes	No	Yes	No	No
Disabled people	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Threshold	50 hrs per month	7 hrs per week	1.5 hrs per day	20 hrs per week	None	Elderly dependency level 1-3	None	3 months	None	Variable

1.3 ASSESSMENT AND QUALITY

Individual need may be assessed within a health and/or social care framework and accordingly eligibility for assistance may be uniquely related to personal/health care at home or to a wider range of assistance for work, leisure or cultural participation. Where services are focused on older people and on severely disabled people (e.g. France, Germany and Denmark) health plays a stronger part in the assessment. In Germany it is essentially a health-led assessment and monitoring (6 monthly) process. In France the assessment is carried out by both health and social professionals working together and in Denmark the local authority may also involve a nurse.

Those schemes which also enable personal assistance to be used for a wide range of social/employment/cultural activities outside the home (Sweden, UK, Denmark) tend to have social/community model of assessments.

Who is responsible for the assessment and quality control also tends to reflect the interests of the funding agency. For insurance based systems of funding in Germany, Austria and the Netherlands (Netherlands use a combination of insurance local authority payment and personal finance according to the particular service) assessments are carried out by independent agencies appointed by the care insurers.

In the UK, France, Finland and Denmark it is the local authority that takes responsibility, whereas in Sweden it is the local authority for needs of less than 20 hours per week and the Social Insurance Office of central government for over 20 hours per week. In Sweden, quality control is the responsibility of national government via the National Board of Health and Welfare, carried out on a regional basis.

How the quality of Direct Payments should best be monitored, given that it is purposely established to promote service user independence, is not easily resolved. The well being and protection of the service user and their assistant(s), together with the need to ensure financial priority, has to be reviewed. Current approaches tend to involve annual home visits, but there is concern that this may not always be sufficient and that adequate preparation followed by on-going monitoring and support also need to be built into the system.

Disabled service users believe that they should be able to carry out a self-assessment of their own needs in the first instance, and then negotiate with the local authority as to which direct payments they need to become more independent.

Figure 2

Coverage	Austria	Belgium	Germany	Denmark	Finland	France	Italy	Netherlands	Sweden	UK
Mandatory	Yes	No	Yes	No	Yes*	Yes	No	Yes	Yes	No
Participants	300,000	Pilot (15)	1 million	200	2100	100,000	Pilot Not known	20000	43000	Not known
* in connection with service accommodation. Otherwise at the discretion of local authority.										

1.4 EMPLOYMENT OF PERSONAL ASSISTANTS

A driving force behind the introduction of Direct Payments was the recognition that the traditional pattern of service provision in people's own homes was inflexible with service users frequently obliged to accept assistance not at a time of their choosing or need.

All countries surveyed in this report offer service users a choice of employing a provider/personal assistant although this choice is related to the extent to which the social market has developed and the regulations of the funding agency, usually the local public authorities.

The growth of a new independent '*care market*' appears to have been stimulated by direct payment service developments in Germany, Austria, Netherlands and France and to a lesser extent in Sweden and Denmark. In all countries this is regarded, so far, as a relatively fast growing though piecemeal market development of small companies and individuals. Clients in the above countries have taken to engaging or directly employing personal assistants or companies themselves or through agencies. Uniquely in the UK system, direct payment clients cannot exclusively use their local authority as unique provider of their personal assistance, but must seek independent services or individuals. They can however use the local authority as part of a package of care.

It appears that service users in the Nordic countries generally retain such a positive attitude towards their public services, (regarding them as reliable and of high quality) that when given the choice (although limited) of independent providers, service users tended to prefer the local authority. Also specific to the Nordic countries and particularly Sweden, is a tradition amongst some disabled persons of co-operatives and one of the consequences of Direct Payments there has been that some co-operatives have been able to pool their income from this source to employ their own administrative and care staff in agreement with the local authority.

Whilst medical staff employed by Direct Payment schemes in all countries are trained, this is frequently not the case with personal assistants. It must be said that some service users would prefer to train their own assistants and are wary of what may appear to be a re-institutionisation of independent living.

Figure 3

Providers	Austria	Belgium	Germany	Denmark	Finland	France	Italy	Netherlands	Sweden	UK
<i>Own family</i>	Yes	No	Yes	Yes	Yes	Yes*	Yes	Yes	Yes	No
<i>Commercial</i>	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
<i>Local authority</i>	Yes	No	Yes	Yes	No	Yes	Yes	No	Yes	No
<i>Not for profit</i>	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
<i>Self Employed</i>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
* in France a client's spouse cannot be employed as their personal assistant.										

In many countries traditionally unpaid care has been provided by family members and sometimes friends and neighbours and regarded as a natural duty although in reality this responsibility fell largely on women and often the daughter or daughter-in-law. In most countries family members can now be paid to care.

In Sweden, for example, a parent can be employed to care for their disabled or handicapped children. This can however mean that the parent's employment career for example and financial well-being becomes dependent on their supporting their child, who may one day wish to leave home and live in a group home, thereby depriving the parent of that income.

In France, in contrast, whilst relatives can be employed, this cannot include the client's spouse (or partner if unmarried). The similar dilemma can occur where an elderly parent is being cared for by the daughter, for perhaps 10 years, after which the parent dies and the daughter ceases to be paid and worse, is unskilled and unemployable.

These examples do not mean that family should not be paid for caring (for it is difficult to envisage a situation where countries would withdraw this right) but rather that support and training should be available to situations of paid family caring. For obvious reasons there appears to be a particularly strong correlation between the employment of family members as carers where the client is an older person.

Whilst the advent of Direct Payments has undoubtedly brought benefits to service users, there are as has been described above, consequences for employment in the home care sector. On the positive side, the development of Direct Payments has provided a large number of work opportunities particular suited to people already caring in families, in local neighbourhoods and people wanting part-time and perhaps short-term employment. Indeed in France the introduction of PSD (Direct Payments for elderly persons) was in part conceived as an employment measure.

There are however concerns that there could be future dangers for both service users and personal assistants from an unregulated home care market based on an untrained, fragmented and vulnerable work force. This is simply to recognise that service users and their assistants should be afforded a minimum of protection and training in often difficult physical and emotional forms of employment. Many directors felt that this was the best guarantee of service quality.

The development in the UK, of new non-government organisations or companies run by service users to provide employment services, insurance, help lines and training may offer one appropriate model of support and development for service users and personal assistants.

1.5 PAYMENTS AND FINANCING

Complex funding arrangements employed in different countries have meant that providing reliable comparative information about payments and indeed the cost to local authorities or other funding agencies is fraught with difficulty. This complexity can be found for example, in the way personal assets such as housing are valued and then related to the allocated care budget and again hourly payments depend both on the level of need and therefore type of assistance and also the qualification of the assistant or other personnel.

Paying for care

There appears from this review however to be three principal methods whereby Direct Payment service users can pay for personal assistance. They may choose a particular service from an approved provider and the provider bills the funding authority/agency and is paid by them directly (option 1: Germany + France + Denmark).

As second approach offered in Scandinavian countries is to issue a voucher for payment by a provider of their choice. Uniquely on the basis of quality and individual preference for there is no price competition between providers. Vouchers are widely used for educational and day nursery services.

The third approach is to provide the client with cash with which to pay for services. This is now possible in the UK and Denmark, but in France, Germany, Austria and the Netherlands whilst

service users can opt to be paid directly in cash, in so doing they receive a smaller sum than the in kind value of the service they would otherwise receive from a nominated provider, e.g. In Germany a client assessed as requiring the equivalent of DM 750 worth of service would receive DM 400 if they opted for cash instead. Despite this, 8 out of 10 German clients choose cash payments. In the Netherlands once the budget is agreed, 20% is deducted for administration savings for those taking up Direct Payments.

In Denmark the price of a unit of service is the same whether it is paid for in cash or comes in kind from a private or public provider.

Only France and Netherlands undertake specific financial assessments with regards to Direct Payments. Particularly rigorous in this regard is the French system which can take a charge on the assets of future generations of the service users family. The UK whilst not assessing Direct Payments, does assess users for community care services which may have a similar effect.

Financing

In pure insurance schemes (Germany), allowances are calculated according to a pre-set national table of need and cost per hour with no financial limits on local authorities. In France local authorities (Departements) administer this national scheme but are financially subject to managing within their budgets. In Sweden, the regional authorities pay for care if the service user is assessed as needing more than 20 hours of care per week, if less it is the responsibility of the local authority. They have discovered that as in Denmark that although there had not been a dramatic growth in numbers of direct payment service users that the cost per user has been higher than predicted.

Figure 4

Financing	Austria	Belgium	Germany	Denmark	Finland	France	Italy	Netherlands	Sweden	UK
<i>Means tested</i>	No	No	No	No	No	Yes	No ^{*1}	No	No	No ^{*2}
Method of Payment*										
<i>Cash/cheque</i>	Yes	Yes	Yes	Yes	–	Yes	Yes	Yes	–	Yes
<i>Vouchers</i>	–	–	–	–	–	–	–	–	Yes	–
<i>Giro transfer</i>	–	–	–	–	Yes	–	–	Yes	–	–
^{* 1} National allowances are not means tested, local funding is. ^{* 2} Direct Payments are not specifically means tested although community care services generally are means tested.										

For the future, should Direct Payments become a mainstream and larger scale activity in European countries where that is not presently the case, ensuring equity within fixed local authority budgets may become a significant issue.

1.6 SUMMARY

The authors of this report are firmly of the view that Direct Payments has a number of important benefits to service users and to social services. They are convinced that it increases people's independence, self-respect and responsibility and it enables services to be better targeted on individual need.

Whilst many view Direct Payments as a success for adult physically handicapped people willing and able to manage their own personal care, there were some doubts that it could easily be extended to such services where clients might have experienced considerable problems in managing their own lives in the first instance. The overall view however, was that this option should be available to all those who can adequately benefit from it, regardless of age or disability. In that context more work probably needs to be done to evaluate the experience of existing service users and the social services in those countries responsible for implementing and monitoring mainstream Direct Payment services, particularly for older people.

Whether Direct Payment is more expensive than directly provided services also received a mixed response. The overall view is that it is at least as expensive with several countries indicating that they had experienced increased costs in terms of more hours being assessed per client (Austria, Sweden), though fewer total clients than anticipated (Sweden, France) and in more complex administration (Germany, Denmark).

Concern about the possible misuse of public finances by individual service users did not in fact raise undue concern although it was felt that better preparation of clients to take on employment responsibilities and better quality monitoring and ongoing support was important.

In a number of countries, both where families are employed as carers and in others where this is being considered, there seems to be concern that employing your family to care for you can be problematic, although where the service user is elderly, the exclusion of a relative who wishes to care, from being paid to do so, may not be seen as contributing to supporting families and maintaining intergenerational solidarity.

Directors of social services believe that creating an inclusive Europe means working with their disabled and dependent older clients to provide opportunities for them to manage their own personal assistance. For those with a disability this could facilitate access to work and to social and cultural participation as well as providing personal care. For all this should be a liberating experience, which treats service users with dignity and respect in a relationship of partnership.

For the future the authors of this report propose that following this initial mapping exercise undertaken by the European Social Network in 1998, that further work be undertaken to review in more detail the extent to which the systems described offer independent living have met the needs and preferences of service users and to how a European wide approach to service quality for users and employment protection for employees might best be developed.

The key questions proposed are as follows:

1. Should direct payment systems adopt the same approach for disabled service users as for elderly people?
2. How best should mandatory systems of Direct Payments be financed in the future to ensure service equity?
3. How can service users best participate in their own service assessment and quality?
4. How can the longer term employment prospects and protection of personal assistants, including paid family members, be best promoted?

This report believes that the recent development of Direct Payments within the Member States has significant consequences for the modernisation of social protection. It reflects the Amsterdam Treaty's welcome inclusion of disabled people in its provision on social policy and employment and offers practical evidence of changes in social services which should be supported as contributing towards making a people's Europe a reality.

Part Two

Country Profiles

2.1 AUSTRIA

Dr. Werner Pröbsting

Background

On the 1st of July 1993 the Law for Financial Arrangements for Care in the Federal Government and the new Federal Provinces came into force. This revision primarily brought about a standardisation of conditions for claims in Austria (that is to say a revision of the arrangements for the settlement of claims arising from additional expenditure associated with Care).

Until 1.7.93 there were a large number of governmental and provincial legal requirements at the beginning of the process for settling claims relating to additional Care expenditure which arose from the varying conditions for claiming and allowed for differing payments for comparable situations of need within Care. The *Law regarding Financial Arrangements for Care* will ensure that people in need of Care in comparable situations will be granted the same kind of payments under the same conditions for claiming.

The goal of Care Provision is to settle claims relating to additional Care expenditure for people with physical, mental or psychological handicaps as well as sensory handicap at one flat rate in order to enable a self-determined and need-oriented lifestyle. Decisions will no longer be made according to the principle of causality but rather according to the principle of future need. In addition, the principle of independent income relating to the payment of money for care will apply.

A Federal agreement has been drawn up between the Federal Government and the Provinces in accordance with *Article 15a of the Federal Constitutional Law 1920* in the 1929 version in order to ensure that the Law for Financial Arrangements for Care is as extensively uniform as is possible within the *Federal Government and the Provinces (BGB1. No. 866/1993)* which makes it the obligation of the Provinces to enact the same kind of conditions according to the same principles and goals as in the *Federal law for Financial Arrangements for Care (BGB1. No. 110/1993)*. In this way an almost uniform system for Care Provision in Austria will be achieved which will cover, apart from in a few cases, all people in need of Care independently of the cause of their handicap.

The system for Care Provision presents a combination of the Care and the Welfare systems. The finance for Care Provision will come not from contributions but rather from general tax revenue and payments corresponding to the set needs for Care in individual cases and diagnoses will be allocated according to a 7 level payment plan. Need for Care will be determined by the classification regulations under the *Law for Financial Arrangements for Care* contained in the *Catalogue of Measures for Care and Aid Provision*.

According to a survey in 1996 (Study 'Analysis of Care Provision Systems') by university professor Dr. Christoph Badelt, payments for care were received by 260,725 people under the Federal Law for Financial Arrangements for Care and by around 40,000 people under the Provincial Laws for Financial Arrangements for Care (as of 1.8.96).

Of the total of around 300,000 recipients of money for Care, 9.9% received money for Care for Level 1, 51.98% money for Care for Level 2, 19.78% money for Care for Level 3, 8.89% money for Care for Level 4, 6.96% money for Care for Level 5, 1.56% money for Care for Level 6 and 0.93% money for Care for Level 7.

The role of the Federal Government, the Provinces, Local Authorities and Users.

Essentially the main group of Austrian social security carriers, insurance brokers as a unit and other decision-making organisations (like the Federal Social Welfare Offices) will be charged with the implementation of the *Law for Financial Arrangements for Care*. As per the conditions contained in the Provincial Law for Financial Arrangements for Care, the implementation of the Provincial Law for Financial Arrangements for Care will be charged to Local Authorities, local administration authorities and offices of Provincial Government.

The Austrian Social Welfare Court will gradually be granted power as a special means of ensuring the greatest possible protection of the legal rights of those in need of Care. This will mean that fundamentally in matters regarding financial arrangements for Care, complaints against decision makers will not be dealt with by an administrative authority but possibly by the Provincial Court for Matters of Employment and Social Welfare.

The principle of giving the greatest possible capability for self-determination and need-oriented calculations will be upheld by means of granting payment directly to those in need of Care themselves, allowing them to decide for themselves which and how many Care payments they – or whoever – will claim for.

Extension of Care Provision

With Care Provision, an almost uniform system has been created in Austria that should ensure that the financial needs relating to additional expenditure for Care of all those in need of Care are met. Nevertheless, there were and are just as before a few groups not covered by this system. Until the amendment of the *Federal Law for Financial Arrangements for Care (BGB1. No. 111/1998)* those concerned were emeritus professors. Those belonging to the free professions (lawyers, doctors, pharmacists etc) in possession of a Retirement or Maintenance Pension or legal locum insurance (court) can be included by means of the personal scope of the *Federal Law for Financial Arrangements for Care*, as prescribed by the Federal Minister for Employment, Health and Social Welfare, as long as the relevant court is prepared to cover the monetary expenditure for the contributions for Care Provision.

Basically it can be said that those in need of Care have a claim on money for Care according to the Federal Law for Financial Arrangements for Care when in possession of one of the named basic benefits (Invalids Pension, Incapacity Benefit, Orphans Pension). The following people especially have a claim on the relevant Provincial Law for Financial Arrangements for Care: working handicapped people, recipients of Social Welfare, Provincial or Local Authority employees in possession of a Retirement or Maintenance Pension from the respective regional authority and relations of the insured person.

Perspectives

A series of changes were made to the regulations of the Law for Financial Arrangements for Care in relation to the current amendment of the *Law for Financial Arrangements for Care* on the basis of evaluations of the experiences drawn until now from the carrying out of said, as well as on the basis of judicature in force from the highest levels of the Supreme Court for Social Welfare Matters. In particular, the existing 7 level Classification Plan was rewritten and so brought about an improvement especially for those people in extreme need of Care. The revision of the conditions for periods of incapacity meant that, for instance, children in need of Care who spend time in

hospital or mentally handicapped people who require live-in Carers receive the money for Care for the duration of this aforementioned Care – a clear improvement in quality. The needs of mentally or psychologically handicapped people are also under consideration for discussion in detail in 1999, as is the extremely problematic area of assessing the needs for Care of children and young adults and examining and regulating same in more concrete terms.

2.2 DENMARK

Anders Møller Jensen

Empowerment of users of social services through direct payment has not to this date had a very high priority in Denmark. Here, the legislation and the public debate have been focused on other ways to stimulate the influence of the users in social services, which to a very high extent are planned and delivered by the local and regional authorities. These approaches emphasise the participation of users (and sometimes relatives) in the assessment and decision making about the services provided to the individual and forming of representative bodies for more general influence on the services provided.

But in the last 10–15 years a practice has developed around the rules for cash benefits in the former *Act of Social Assistance (Article 48.4)* where very physically disabled persons could, under certain circumstances, be granted benefits to such an extent, that they themselves could employ a team of helpers.

There have also been experiments in some local authorities (kommuner) where e.g. older people, who were assessed for a certain amount of practical help, have had the opportunity to choose their carers from approved private service companies as an alternative to services provided by the local authority.

Client empowerment in the new Danish legislation

The new *Social Service Act 1998*, authorises different the kinds of Direct Payments that can be made to the users of social services.

The duty of the local authorities to provide practical help, personal care and assistance in order to maintain physical and mental abilities from former legislation has been continued by the *Social Service Act* on 1 July 1998.

Programme No. 1: Cash payment to persons with handicaps

Article 76, section 2: If a person under the age of 67 with significant physical and mental handicaps needs personal care (personal hygiene, dressing and undressing, help to eat etc) for more than 20 hours a week, the user may choose to receive a direct payment.

This provision is targeted at a small group of persons who need extensive care but do not fulfil the demands of home help scheme according to *Article 77* (see below).

Programme No. 2: The extended help system handicapped people in special circumstances

With reference to the *Social Service Act, Article 77*, the local authority covers the costs of employing carers for care, monitoring and accompaniment of persons with a significant and permanent physical or mental handicap, that necessitates a special kind of support. There is no limit of age.

A grant like this implies that the client is able to manage their own arrangements, i.e. hire the necessary assistance and be responsible for the daily work planning.

The regulation presupposes that there is a need that not covered by the 'normal' programmes on personal care, practical help, cash payment rule, and accompaniment e.g. and that the client wants to live an active life outside the home and need help for that.

A case story of one of the most radical arrangements under *Article 77* in the *Social Service Act* would be a young man with a muscular dystrophy who is 100% disabled and permanently linked to his wheel chair. He lives alone and has interests in participating in activities in the community.

After assessment from the local authority he will be empowered to engage his own team of helpers who can assist him 24 hours a day. He will himself be the employer and will have the responsibility for paying out salaries and the bookkeeping. Every month the local authority will transfer the necessary amount of money to his bank account.

The expenses for this arrangement can easily amount to 1 million Kroner a year and are financed according to the general rules of financing specialised social services, that is 50% from the local authority (kommunen) of the citizen (who has assessed the arrangement) and 50% from the regional authority (amtet) (that is runs the accommodation which may be the alternative for the user to a self empowerment arrangement). The total number of users under *Article 77* is estimated to be around 200.

The future

In the new legislation on social services, great emphasis has been put on the respect of the individual in many instances. This is a clear trend in Denmark as in many other countries and we might therefore expect more Direct Payments and other self-empowerment schemes in the future. Denmark will probably place more emphasis on other kinds of empowerment, than Direct Payments, i.e. kinds of empowerment which provide legal rights to assist, influence on those who provide, easier ways to claim etc.

Direct Payments can be a very effective form of client empowerment in the right circumstances, e.g. where there is a competitive social services sector. In Denmark there is a long tradition of the local authorities as the sole providers of most kinds of social services, and there is no current debate about changing this. Small scale private companies in recent years have tried to penetrate the Danish social and health services market, but with little success until now. Extending direct payment will among other things therefore depend on a future change in the way social services are provided in Denmark.

Direct payment has however to some extent also been introduced for people who have been assessed to receive cars and other aids due to a handicap. If they are not satisfied with the kind of aids offered them by the local authority, they can have the value of the offered item on a voucher and buy the wanted aids in the market (normally at a higher price).

2.3 FINLAND

Pirjo Virkkala

Informal Care Allowance

The informal care allowance is based on the Social Welfare Act and the Decree on Support for Informal Care 318/1993 (Sosiaalihuoltolaki, Asetus omaishoidon tuesta 318/1993). The support for informal care under Section 27a of the Social Welfare Act refers to a care allowance to be **paid to ensure care or other caring** of an elderly, disabled or sick person in his or her home, and to services, such as these are defined in the care and service plan for the person to be cared for. In addition to the allowance paid – to cover costs for care – support for informal care also includes other services provided by the social and health care services. The extent and the way of providing services are defined individually in the care and service plan.

The allowance to be paid to the carer rises gradually with increased nursing needs and demanding care. The decision to grant an informal care allowance is made by the manager of home help services.

The local authorities have the right to decide on implementation of support for informal care, according to the general obligation stipulated in the *Social Welfare Act*, in the municipality. The municipality decides on the payments to be made within the fund reserved.

In 1997, the minimum amount of the informal care allowance was 1137 Finnish Mark and the maximum was 7000 FIM per month. In 1996, the total sum of payments in Finland amounted 333 million FIM.

In 1996, there were 19,347 persons in Finland to be cared for with the support for informal care. An example would be an elderly person, aged 85 years, with dementia, living with a relative who is her personal assistant. She has 7 hours home help per month and has been assessed by the home help supervisor to receive 3000 FIM monthly which is paid into the caregiver's bank account.

Personal assistants for severely disabled persons

A severely disabled person may be compensated for the expenses of employing a personal assistant if he needs *the assistance of another person* to a considerable extent at home in matters *related to daily life* or outside home in the management of his affairs, in studies, leisure-time activities, work, or social participation in general. The statutory payments and compensations payable by the employer as well as other necessary and reasonable costs incurred in having an assistant shall also be considered as expenses. The disabled person shall, where necessary, be guided and assisted in matters related to the employment of an assistant.

The scheme operates under the *Services and Assistance for the Disabled Act 380/1987 (Vammaispalvelulaki)*. If allowances paid under other primary legislation (e.g. informal care allowance) are enough to satisfy the applicant's needs, compensation is not granted under the *Services and Assistance for the Disabled Act*.

The scheme is nation-wide and mandatory in connection with service accommodation, otherwise with discretion of local authority.

Payment made by the municipality to a severely disabled person is made from funds reserved in advance, and as a lump sum. The severely disabled person shall decide how the payment is spent to meet their personal assistance needs.

A severe disability is a prerequisite for payment. Further, the disability must cause special

difficulties to the person's moving around or otherwise coping with daily life. The decision on payment is made by a social worker. The decision requires a doctor's statement on how permanent the handicap or illness is.

Should the disabled person receive financial support for employing a personal assistant under some other primary legislation, this is taken into account when deciding on the amount and extent of services, or when deciding on reclaim of payment made.

The severely disabled person hires his personal assistant himself. The severely disabled person, or in some exceptional cases (for example if the person is mentally retarded) his guardian, is the employer of the personal assistant. An example for this service is a 40 year old paraplegic, living alone. She has 40 hours personal assistance per week and has been assessed by a social worker to receive 6500 FIM monthly which is paid into the personal assistant's bank account. For this money she can have for instance 4 part time assistants

The personal assistant is always chosen by the disabled person himself.

Payment for expenses of employing a personal assistant always requires that the severely disabled person himself (or his legal representative) is able to act as employer.

In 1996, the number of clients in Finland was approximately 2100.

2.4 FRANCE

Mireille Guyomarc'h, Rina Dupriet

Compensatory Allocation for Third Person and Specific Dependency Service

The French personal assistance system 'comparison of home-help procedures'

History

France has recognised, since the passing of the Law of 30 June 1975, the legitimacy of third person assistance for handicapped adults incapable of carrying out one or more actions essential for life. Designed for under-60s, the third party compensatory payment (ACTP) is aimed at providing this. It leaves the user completely free to determine how the monthly sum paid to him by the Department is to be used. As the user has only to declare expenditure exceeding 80% of full employment costs, he can do what he wishes with his payment: give it to his family, keep it for himself, invest it, pay someone without declaring it, and so on. Generally speaking, nothing guarantees that the payment will relate to a specific service. It is only with a restriction rate equal to or over 80% that he must supply proof that he is employing someone, or that a member of his family has had to give up paid work to help him.

It is this generosity, which might be described as excessive freedom, that has brought about developments in legislation and triggered the introduction of the Specific Dependency Service (PSD).

In fact, before PSD was introduced, dependent elderly people were treated as handicapped, their dependency being likened to a handicap; and as such, they received the third party compensatory payment. According to the departments, 60% to 80% of payments were made to retired people. In 1997, about 190,000 elderly and handicapped people were in receipt of ACTP.

The members of the general councils saw their expenses increasing, but could not be sure that elderly people were being helped. In view of the age of the applicants, it was not certain that their spouses could help them, and their children did not always live sufficiently close to guarantee daily help.

From the point of view of unemployment, the members also wanted to develop local jobs. An experiment involving the use of a new home help system was carried out in twelve volunteer areas, and allowed the levels of interest in the prospect of all the partners' working together locally to be assessed, in order to organise a better reimbursement of medical costs.

It was against this background that on 24 January 1997, Law No 9760, establishing the Specific Dependency Service (PSD), was voted in.

PSD is aimed at elderly people aged 60 and over, who fulfil the conditions of dependency and whose available resources are below a certain ceiling. The help may be given by one or more employees directly recruited as personal assistants, either through an agency service or through a body providing personal assistance services. A family member (except for a spouse) may also supply the assistance, but this person must be paid.

PSD should, in the near future, cover between 300,000 and 400,000 elderly dependent people with limited resources.

There are therefore two systems in France providing the same personal assistance service, depending

on age: compensatory third person payment (ACTP), and Specific Dependency Service (PSD).

Dependency criteria and assessment of needs

Like ACTP, PSD is a response to a request for help for a dependent person, made by a third person and aimed at meeting essential daily needs. The application for PSD is recommended by a medico-social team, at least one member of which visits the person concerned. The person is assessed by the team using a national schedule known as the AGGIR schedule (which takes account of independence, age, ISO Group and resources). The schedule is classified as follows:

- ISO Group-Resources (GIR I) relates to elderly people confined to a bed or wheelchair, whose mental capacity is seriously affected and who require the continual presence of a helper. Many in this group are terminally ill.
- GIR II relates to two groups of elderly people: those confined to a bed or wheelchair, whose mental capacity is not completely impaired and who require supervision for most daily activities, and those whose mental functions are impaired but have retained their ability to get about.
- GIR III relates to elderly people who have retained their mental functions and some degree of mobility, but who require help several times a day in order to maintain physical independence.

The medico-social team will draw up a care plan for the applicant within 40 days of the date on which the application file is lodged; the applicant must send this plan duly signed within 8 days, or request another care plan. PSD must be paid not later than 2 months after the application.

Assessment of resources and calculation of payments

PSD is combined with the applicant's resources and, where necessary, with those of his/her spouse or partner. The resources ceilings are fixed at Fr72,000 per year for a single person and Fr120,000 for a couple, or in other words Fr6,000 and Fr10,000 per month. The total paid for the service equals the sum total payable for the service less any balance of resources that exceeds the ceiling. When assessing resources, account is taken of income and the capital value of non-income-producing assets.

As PSD is a social aid payment, it is recoverable from any elderly person's inheritance that exceeds Fr300,000.

PSD may be paid in kind or in cash (cheque payable to the applicant's account) and may only be used for covering expenses previously defined in the care plan. It differs in this respect from ACTP, which allows the payment to be allocated much more freely to whatever the person deems necessary. It is financed entirely by the Department and is co-ordinated together with care financed by the Assurance Maladie (health insurance).

Allocating and monitoring the personal aid

A client may use PSD to employ one or more persons working for the local authority or for a non-governmental or commercial organisation, or even independent persons such as neighbours. He/ she may also employ members of his family (except for his/her spouse or partner) as personal assistants.

PSD may be used to cover expenses other than these payments, but they must be strictly defined (meals on wheels, remote alarm, temporary accommodation, minor alterations) in accordance with what is agreed in the care plan.

At least one member of the medico-social team shall monitor the assistance given at the PSD recipient's home; this shall include in particular a check at least once a year on its effectiveness and suitability for the person's needs, and the quality of service given.

If it turns out that the service given poses a risk to the health, safety or moral or physical well-being of the PSD recipient, the President of the Council may request the recipient to enlist another service provider; failing that, he may suspend the provision of the service.

Review

A review showing the actual distribution of PSD was drawn up on 30 June 1998 after 9 months of operation. 30,000 people per quarter submitted an application for PSD, that is, 90,000 people by the time of the schedule. 60% related to PSD at home, 40% to PSD in an institution. The rate of acceptance for '*at home*' files is 65%.

The take-up for PSD has been slower than anticipated: 58,000 people at home and in institutions. The total of recipients of the former ACTP aged over 60 who will enter the PSD system in the next 4 years, that is about 120,000 people, should be added to that number. PSD applications are rarely rejected on grounds of resource levels, which appears to make sense (Fr6,000 per month represents 170% of the minimum pension). On the other hand, it appears that a significant number of people have fought shy of requesting this personal assistance service for fear that their children will not enjoy the full total of their inheritance.

Most PSD applications rejected have so been because of dependence rates. 56% of applications rejected relate to people classed as GIR-4, that is, people within the scope of dependence. However, these people are not completely barred from receiving aid because they are directed towards home help financed by their pension fund or by social aid for persons of minimum old age. Contrary to the criticism levelled by detractors of the PSD system, elderly GIR-4 people living at home are not left out of the system, and generally speaking, their help is well co-ordinated.

On the other hand, they do pay for some of the home help provided.

PSD's strong points:

- It is, first and foremost, a co-ordinated and personalised care plan that requires local bodies to work together.
- The length of time for processing the file is very short (2 months). The person agrees to the solutions offered.
- There is a right to choose the person to provide the assistance, provided that person is not working illegally.
- The amount paid is significant for a personal assistant total (about Fr3,200 per month).
- PSD at home is generally accepted by people, and it is unfortunate that the genuine problems encountered with trying to set up the system in institutions has undermined the overall image of the service.

Potential

For 1999, the priority area is undoubtedly that of personal assistant qualifications: paid helpers; family helpers.

The law makes provision for training, but as its financing has not been specified, it will be difficult to implement.

With regard to co-ordinating the people involved, this will be done according to each individual

person's specific needs. On the other hand, work still needs to be done to co-ordinate more effectively the policies of the various bodies, departments, social action centres (which oversee many different services), associations and funds.

The hourly cost price financed by the PSD differs, depending on whether a direct-paid employee is involved (in which case the employer will not be required to pay social security contributions), price Fr50 per hour, or a home personal assistance agency, is provided by a CCAS (local municipality) or voluntary organisations (Fr80 per hour).

This creates very unfair competition, which risks causing the '*death*' of personal assistance services managed by CCAS and voluntary organisations, at a time when these groups have experienced and well-trained workers.

Retired people are not happy that the Specific Dependency Service is a social aid service. They would have preferred it to be a risk, such as health insurance, covered by a contribution. In the current context of reduction of charges on salaries, however, who could finance this dependency risk? Retired people do not seem prepared to make contributions for this service.

In the immediate future, it would be necessary simply to alter the deduction from inheritance, which is frightening many elderly people. Raising it to Fr500,000 or Fr600,000 would allow the inheritance of a house to remain a viable proposition, bearing in mind that ownership of property is an important issue for French people.

In conclusion, PSD combined with the care plan could, with some alterations, turn out to be an effective means of providing home personal assistance which better respects individual service users and their families.

2.5 GERMANY

Dr Helmut Hartmann

Care Insurance became law on 1 January 1995 after years of discussion. By the 1970s important organisations, like the Kuratorium Deutsche Altershilfe – KDA – (Foundation for Supporting Elderly People, had urged that the existing social insurance covering old age, accident, unemployment and illness be recognised as covering those 'in need of care'. Up to 1995 the need for care was the financial responsibility of the patients themselves or their relatives and in so far as it was possible from income support (according to the Federal law on social assistance – Bundessozialhilfegesetz, i.e. BSHG of 1961).

The role of the local authorities and the federal state and the role of the welfare associations and the consumers

Care providers (private, public or state) are funded by 3 possible sources:

- Clients themselves either out of their own pocket or out of a lump sum provided by the care insurance (based on an assessment of needs, including 3 categories; see below)
- Care insurance payments based on an assessment of needs (see below)
- Social assistance (BSHG) payments if the client is not eligible to care insurance payments

The care provider can only get the service paid for when the service specified can be demonstrated as 'needed', that is after an assessment of the patient's care needs by the medical service of the health insurance. This assessment includes the definition of the degree of need according to 3 categories and the definition of a set of individual service elements (out of a standardised list of 12 'service complexes'). Providers of care have to produce an extensive Care Document.

This bureaucracy in home care is costly and the waste has been publicly criticised by a welfare association 'Der Paritätische' in July 1998.

Care Insurance makes payment for:

- Personal care
- Nutrition
- Mobility
- Home services

Within these sectors a defined list of assistance is authorised (Article 14 Abs 4 SGB x 1) for a minimum period of at least 6 months. Under certain conditions basic medical treatment (Behandlungspflege) can be regarded as necessary in terms of the Care Insurance law – in particular, if the treatment cannot be separated from care activities.

The assessment of need defines the category (in brackets the percentage of clients using non-institutional care belonging to the respective category by the end of June 1997).

- Category I : care needed for at least 90 minutes per day (45.6%)
- Category II : care needed for at least 180 minutes per day (42.1%)
- Category III : care needed for at least 300 minutes per day (12.3%)

Based on the category the client can opt for two possibilities:

- Category I : up to 750 DM per month for service by a licensed care provider or 400 DM cash for free use
- Category II : up to 1,800 DM (care provider) or 800 DM (cash)
- Category III : up to 2,800 DM (care provider) or 1,300 DM (cash)

In exceptional cases (high degree of need) the amount of payment can be increased to 3,750 DM (only care provider). In the second quarter of 1997 about 75% of the using of home care opted for 'cash payment'.

From the government's point of view Care Insurance is a complete success. In total 1.6 million people (400,000 in homes) are looked after with an expenditure of 27 billion DM. At present, the care allowance has an estimated financial surplus of 8-10 billion DM.

Welfare associations have however criticised the fact that not every people in need of care can get a service from Care Insurance. All those who have less than 90 minutes of care are excluded. In addition there has been criticism of the strong pressure of care allowances on the price of care adding to the high levels of bureaucracy and waste already to which we have already referred.

With Care Insurance a market was created so that all services whether commercial, not for profit, public, state, etc. operated within the same obligations and with the same prices. The priority of welfare organisations (there are 6 acknowledged welfare organisations: Caritas, Red Cross, Diakonie, Der Paritätische, Workers Welfare, Jewish Welfare Organisation) which is still part of other social laws (i.e. Article 10 BSHG) have no longer been taken into account with regards to Care Insurance. This leads to the problem of personnel costs, for although the welfare associations pay their employees as the public services the independent sector has no wage agreements. Some people criticise the fact that the wage costs in Germany are higher due to their Care Insurance contributions. Others say that those who benefit from the care insurance are mainly from the middle class with above average income and assets and not the poor

Extension of the care insurance

Originally the plan was to include everyone in need not only disabled people in the new system of care insurance but costs worked against this plan. Everybody who is legally health insured (90% of the population in Germany) has to pay a maximum contribution of 1.7% from their gross income. Care insurance has in total more than 28 billion DM at its disposal. Daily care for everyone would then be limited to 90 minutes minimum and the handicapped people would be excluded – with the exception of an inclusive amount of 500 DM.

Because of the current surplus of 8-10 billion DM for the care insurance, some people suggested reducing the contribution rate (and therefore wage costs). The government expects in the next few years important increases in costs which could return the current financial surplus to balance.

Prospects

In the near future, the basic system of the care insurance will probably not change. The financial means are sufficient and the inclusion of other of people in this new branch of the social security has been generally acknowledged as positive.

There are discussions about changing the high levels of waste and bureaucracy within the care services.

Finally there is concern that the process rehabilitation is affected by the financial incentives for all

in the care insurance relationship, whether clients, relatives or providers, to declare a reduction in need and therefore of payment.

Case histories

Case 1:

A young man after a car accident is completely dependent on care linked to a wheelchair. He is living alone in his apartment. The medical service of the Care Insurance made an assessment with the result of 'Category I' because he needs 2 hours care daily. The man opted for 'cash payment' and is receiving 400 DM per month. The man wants to employ his own carer. Since he has no other income or assets he received additional payment from social assistance under 'handicapped assistance' so that he is able to employ his carer.

Case 2:

A woman 80 years old needs personal care and is beginning to show symptoms of dementia. She is living alone, her relatives are living in another city. Since this woman receives a pension, she is covered by Care Insurance. The first step of this woman has been to contact the medical service of Care Insurance: the assessment put her in Category I (at least 90 minutes care per day). She opted for receiving service by a care provider; she is entitled to use the service up to 750 DM per month. The service provider agreed with the care insurance agency a price – in practice this means, that 90 minutes per day are covered – not more. Because the woman needs more care, due to her dementia, help by voluntary workers has been organised.

Cost of the service

The price per hour home care is depending on the region (Bundesland) for which an agreement between care insurance and service providers has been made. The price per hour is difficult to calculate because the 'price' is related to 'points' defined for each of the 12 elements of service – payments are not related to time but to service elements. There are estimates that one hour home care would cost 45-50 DM.

Choice

In cities and urban areas various providers offer their service (e.g. in Hamburg more than 400 service providers). In some remote rural areas it could happen that only one or two providers are operating.

2.6 NETHERLANDS

Frits Van Brussel

Introduction

In the Netherlands the equivalent of Direct Payments is called 'Persoonsgebonden budget (PGB)', which means that each person has his own budget to be spent by him/her personally. In 1996 the system of Direct Payments was introduced into the nursing and care sector and for mentally handicapped people

For elderly people and physically handicapped people there are limited possibilities for Direct Payments. These possibilities are part of a law, which authorises municipalities to experiment with PGS's. An example is the *Provisions for Handicapped Act (Wet Voorzieningen Gehandicapten, WVG)*.

Direct Payments are rare in the total care sector. The PGB share in nursing and care services is still only 4% and for mentally handicapped people this share does not even exceed the 2% level of the financial resources within the law.

A mixed system

As is the case in other countries, the Dutch social security and care system is a mixture of state-controlled and (semi) private provisions. Central government makes the laws and monitors the regulations. Either semi-private organisations or local authorities are responsible for the implementation process. For this reason it is difficult to speak of one uniform system in the Dutch situation.

The semi-private sub-system

In the Netherlands the care sector is mainly run by private organisations and semi state-controlled institutions. The Dutch take out care insurance as needs which are difficult to insure are subject to social insurances, such as admittance to a nursing home and the care for handicapped and elderly people.

The governmental sub-system

Central government puts the implementation of parts of the care system in the hands of the local authorities. This concerns care in cases where the social insurance system fails or where there is a specific need for care. Examples are the implementation by local authorities of transport and adapted houses for handicapped and elderly people according to the Provisions for Handicapped Act. In the framework of this Act, local authorities are empowered to implement parts of the PGB system. A number of municipalities are experimenting with the system at this moment.

In order to have a link between the two separated subsystems, it was decided in 1997 to cluster the eligibility assessment for both the governmental and semi-private sector into regional organisations. Local authorities are obliged to set-up and preserve local eligibility assessment bodies. Thus local authorities are influencing the admittance to the care system and the decisions as to stimulate PGB initiatives.

Service in action

A. PGB for nursing/care and for mentally handicapped

Starting 1996, Direct Payments are applied in the fields of nursing/care and mentally handicapped.

The advantage of a PGB is that the service user as budget holder can choose the care provider, the number of working hours and the kind of care provided. The independence/self determination of the budget holder is therefore much greater than before.

To have a PGB entails also disadvantages:

- The service user must recruit one or more care providers and has to tackle employment legislation which can be very complicated.
- Payments to the care providers are handled by de Sociale Verzekeringsbank (SVB) which is a Bank for social insurance.
- The budget holder has to reach a written agreement with the care provider in order for the SVB to pay the care provider.

There are different agreements:

1. An agreement with a care providing organisation called a service contract.
2. An agreement with one or more individual care providers. The budget holder is then an employer.

There are different types of working contracts:

1. Usual work contract.
2. A call up work contract (this agreement can be used for asking help without specifying when it has to be provided).
3. A replacement agreement in case of the care provider goes on holiday or is off sick.

There are three possibilities:

1. An agreement with someone who works a maximum of 2 days per week (max. 9.5 hours per day or max. 19 hours per week). You need an employment contract but don't need to pay income tax and social insurance.
2. An agreement with someone who works more than 2 days per week. Then you are acting as a full employer.
3. An agreement with an individual care provider who is self-employed. This is called the free-lance agreement. The budget holder is in this case commissioning the care provider.

Who is entitled to a PGB?

People with physical handicap and chronic diseases who live at home and need long term care (longer than 3 months) are entitled to the PGB. This can comprise nursing and personal care called ADL (= general everyday life) and HDL (= every day housework).

How to get a PGB

Applicants need to sign on with a regional bureau, no matter how they are insured. The PGB is based on the *Exceptional Medical Expenses Act (Algemene Wet Bijzondere Ziektekosten, AWBZ)*. Once you have applied, you are placed on a waiting list (it can last more than one year before it is your turn). After acceptance of your application, the client is assessed by someone from the care office to find out what kind of care she/he needs.

Together they set up a care programme which sets out the care and nursing needs. This programme is then sent to the care office. The applicants will then be notified that they are entitled to a PGB and how much they will receive to purchase their care. An agreement stating the

rights and duties of each party is also sent. The amount of money allotted and the starting date of the arrangement are mentioned in this agreement. By signing the latter you are member of the association of Budget holders which is named in the agreement.

Care providers

Care providing organisations can be a home care organisation, a private home care agency, a private nursing agency, a mediation agency. Individual care providers can be a friend, a neighbour, a self-employed nurse, in fact anyone who can do the work required. It is possible and indeed quite common for a service user who has a budget for nursing, social care and housework to decide to use an organisation for social care, use a friend (employment contract) for household duties and a self-employed nurse (a freelance contract) for nursing.

Finance

Total financial resources amount to Dfl. 220 million in 1998 for these types of PGB's. In the coming years budget for the care sector will increase by 10% yearly. Budget holders will be able to receive an annual lump sum of Dfl. 2,400.—. Only a minority of the budget holders (5%) will need a budget that is lower than this amount. With the aim of decreasing bureaucracy, proposals are being submitted in order to increase the lump sum into Dfl. 6,500.— and even into Dfl. 10,000.—.

Service users can also choose for an individual budget, based upon achieved performance. For professional care, care providers have several standards:

Once a client decides to be no longer dependant upon professional assistance and prefers to choose for a PGB, the same standard figures will be applied. However, before calculating the budget, the costs in-kind are reviewed, followed by a 20% deduction. So, if a client prefers a PGB, only 80% of the (former) care in-kind will be paid as a PGB.

B. PGB for transportation and adapting houses for disabled and elderly people

The *Provisions for Handicapped Act* became effective in 1994. Local authorities are responsible for the implementation process of this Act, whereas the municipal departments of social service are frequently performing the actual implementation. The *Provisions for Handicapped Act* enables the handicapped and elderly people to have an adjusted wheelchair, to use adapted public transport, to adapt a house according to the disability needs.

Normally these are offered as in-kind provisions but a number of municipalities decided to allow a PGB for transportation purposes. The budget holder (i.e. the service user) receives a certain annual amount of money (no more than Dfl. 2,500.— on an annual basis) to arrange transportation from his house.

The municipalities of Zoetermeer (approx. 100,000 inhabitants) and Utrecht (approx. 250,000 inhabitants) started a pilot. The service user is allocated a tailor-made budget, allowing him to buy, control and retain the provision. The Utrecht pilot started with 100 participants.

Pilot review

The pilot will cover a 2 years' period. At the end of the pilot period there will be a final review of the usefulness of a PGB. If this is the case, the PGB will be extended.

2.7 SWEDEN

Lars-Göran Jansson

New rights in Sweden for persons with functional impairments

In Sweden the quality of life for people with severe disabilities should always be considered in relationship to that of able-bodied people.

After the Second World War, the economic circumstances existed for extensive social reforms and this was a time when there was most criticism of public care and its focus on large, closed institutions. The ideal of being able to live by yourself, which had been discussed for a long time within elderly care, now also developed supporters among the handicap organisations. Not least important was the founding of user and parent organisations who lobbied politicians and civil servants. This led to new legislation in 1967, for persons with learning difficulties and in 1985 another law (*Omsorgslagen*), gave handicapped persons improved legal status.

The two pieces of legislation of importance for people with disabilities are the *Social Services Act (Socialtjänstlagen)*, and the *Health and Medical Services Act (Hälso- och Sjukvårdslagen)*, which set out the responsibility that county councils have for health and medical care.

However these acts did not go far enough to ensure that living conditions for the handicapped were comparable to those of other people.

The *Support and Service for Persons with Certain Functional Impairments Act. LSS (Lag om stöd och service för vissa funktionshindrade)* came into force on 1st January 1994. The new law concerns rights. It is about being able to do everything that an able-bodied person normally does. To have, for example, help to go to the toilet from somebody one has chosen oneself and who is on hand, instead of the endless waiting for staff who are busy elsewhere. The law is also about the availability of a personal assistant, someone who can act as an escort wherever necessary, for a visit to the cinema, for example. It deals with support to families with handicapped children so that they have time and energy to enjoy a normal family life aside from the extra work that looking after a handicapped child entails. It deals too with the right to suitable housing and the provision of services to enable one to live away from home, as others do, when one grows up.

Roles and responsibilities

Relatives have always played an important caring role. The reform improves the options for relatives to be paid to care. There are e.g. short-term stay and relief service. LSS also gives a right for the relatives to get help from personal assistants, or be assistants themselves. LSS also states the right to an individual plan which co-ordinates the activities from different actors. The position of disability organisations has been affected because of that the legislation now states that both municipalities and counties must co-operate with them. The role of cooperatives established and run by disabled people is important as they provide appropriate advice and support and were the main route for the development of independent living in Sweden.

The local authorities are responsible for 9 of the 10 rights stated in the law (not '*advice and personal support*' = the county) and for the co-ordination of activities for the other actors.

The counties are responsible for, rehabilitation and handicap equipment. Also responsible for '*advice and personal support*', but this activity can be transferred to the municipality.

The National Board of Health and Social Services has the nation-wide responsibility, but in practice it is delegated to Länsstyrelsen, the governments regional organisation. A new authority, Handikappombudsmannen, has been founded as a result of the disability reform. The task of this authority is to take initiatives to promote handicap questions. The ombudsman can however not refer issues to court. Appeals against decisions must be referred by the handicapped person themselves. The court can overrule the decision made by the local authority.

The LSS-law applies to those who will benefit from these rights are persons with severe disabilities, namely, persons who are mentally handicapped or autistic, persons who have impaired mental ability as a result of brain damage in adulthood, persons with other permanent and severe physical or mental disabilities if they have considerable difficulties in their daily lives and need constant care and attention

This disability reform covers the whole of Sweden and although prior to the reform it was estimated that about 100,000 people (about 1% of the Swedish population) were going to be covered by the 10 activities of LSS, of whom 40,000 were people with intellectual impairments, in practice last year only 43,000 people used LSS-activities, of them 22,000 for advice and personal support and 12,000 personal assistance. In total the reform has been less expensive overall than expected although the cost per client has been more expensive than expected. (On average 70 hours help per week for those with severe disability using personal assistance, compared to the estimated 40 hours).

One interpretation of the less than expected take up could be that the need for 'new' groups has been exaggerated. If so, the reason for the discrepancy would be that persons with intellectual impairments are satisfied with the measures already provided mainly under the *Social Services Act* and the *Health and Medical Services Act*.

Case history

Case: Handicapped young man

Let us presume that this man needs help with personal hygiene, dressing shopping/cooking/ eating/travel/ and communication

In this situation he will have a 'personal assistant' (personlig assistant) personal If the need for help exceeds 20 hours per week, he applies to the social insurance office, who will decide how to help.

The young man in our example has been assessed as having serious, permanent disability, considerable difficulties in his daily life and a need for help and care. To get help according to LSS (Act Concerning Support and Services for Persons with Certain Functional Impairments) he must meet all the above criteria i.e. serious and/or permanent disability which requires considerable assistance.

Assessed as needing personal assistance for 25 hours per week. He can now choose an assistant – employed by the local authority, but our man still can chose who this person is. Otherwise he could have chosen a relative, such as his mother, as carer. Alternatively he can employ a personal assistant himself which is why most people not do so. If he is assessed to need help more than 20 hours per week, a decision will be made by the insurance office, but it is social services that will be responsible for providing the service. Under 20 hours a week social services both decides and provides the help.

Alternatively he could join a co-operative that provide personal assistants. In this case is the co-operative the employer (but the handicapped man is a part owner of the co-operative) who together with the district nurse, carry out an assessment.

The employment training centre (Arbetsmarknadsinsitutet) investigates if our man shall be offered training, to prepare him for some kind of new job. He is allowed disability allowance and for a period also temporary disability pension for a period. If he later on can get no job, he can be eligible for disability pension. He does not have to pay for any service. Under all circumstances this man knows that he will get money for housing and his daily living.

The future

The experiences of LSS by disabled clients has been very positive, with the exception of people with mental illness. They have asked for personal assistance in a smaller extent, and the assessing authorities are not used to this group of handicapped.

The situation for personal assistants has however raised some issues for whilst it has generally worked well, some assistants have found occasionally themselves in difficult situations with their client as employer, where for example, an employer with a drink problem has requested they buy him alcohol. There is no single role for the assistants, and the work can be lonely. There is also a risk that the possibility of employing relatives can create 'home-daughters', the mother who takes care of her child all her life, which at the same time means that she can have no life of her own.

There has been discussion in Sweden as to whether LSS also should cover people over 65 years. It is not very logical that you after many years of LSS a person on reaching their 65th year should suddenly receive assistance, based on another legislation. The major question is whether those already over 65 years. who apply for LSS could become clients of LSS?

2.8 UNITED KINGDOM

James Murphy

The NHS and Community Care Act in 1993 gave local authorities the key responsibility for identifying and assessing need for care and purchasing and monitoring the delivery of that care. In addition to this care management role, local authorities were required to undertake wider joint planning and consultation, including with carers and service users. These reforms also required new contracting arrangements, complaints procedures and inspection and regulation functions.

This *Community Care (Direct Payments) Act* came into force on 1st April 1997 and gives local authorities the power, though not the duty, to make Direct Payments between 18 and 65 years of age. This is instead of directly providing people with the community care services they have been assessed as needing under the 1990 legislation. Direct Payments may be substituted for any community care service, except permanent residential care and payments are made only via local authority social services departments.

Eligibility to access Direct Payments is established by:

- being willing and able to manage your own care;
- being over 18 and under 65 years of age;
- payments not to exceed the maximum cost of residential care;
- payments cannot be made to employ close relatives; and
- certain exclusions, including people with severe mental health difficulties and those under Home Office restrictions that are ex-offenders.

Central and local government roles

Independent Living in the UK is supported through Central Government by way of the Independent Living Fund.

Local authorities in the UK are placed to establish clear consultation mechanisms with service users, including disabled people. For the most part, where local authorities have responded enthusiastically to developing direct payment schemes, this has been based upon close consultation with disabled people and concerted pressure being exerted by disabled people.

One model which has been successful in the UK prior to legislation has been for schemes to be administered and controlled by organisations of disabled people. Such schemes included a range of independent living services such as peer support, training information, advice, and other infrastructure services such as payroll, emergency support and sometimes a register of personal assistants. Now that we have the new legislation a new model is being explored. This early example of direct payments gives the service users greater influence over the local authorities implementation of the legislation. In January 1996 Manchester City Council launched a 3 year independent living development programme based on the general principles of:

- empowering service users to manage their own assistants
- involving service users in the design and development of the project
- full consultation with service users and their organisations.

The Manchester scheme pre-dated the direct payments legislation, which came into effect in

April 1997, but was able to incorporate the implementation of the new Act locally. To date there are 44 disabled people accessing direct payments with a further 25 waiting to join the scheme. The scheme also provides support and administration for two other local authorities.

For the future

The Direct Payments system in the UK is a new departure and is subject to review by government at the time of writing.

Consideration of the extension of access to Direct Payments to older people is part of the review. Inevitably the question of cost arises. The present UK system is discretionary and limited in its application. Expensive support packages for younger disabled people are possible because of the relatively few recipients of Direct Payments. If higher volumes of users access Direct Payments there will inevitably be consideration of upper limits and stricter criteria for access possibly within a nationally prescribed framework as in France and Germany.

Early experience in the UK suggests that the overall cost of support packages for younger disabled people increases with Direct Payments, although the cost to Local Authorities may decrease. This is because the complex systems of benefits in the UK allows access to additional centralised funding services within the Direct Payments regime. Whilst the total increase in costs may be justified in individual cases by the greater quality of life experienced by the Direct Payments user, the overall impact on the public purse of widespread extension of Direct Payment could vary greatly in the absence of a national framework.

Case history

Here is the view of the first Direct Payments user in Manchester:

'Direct payments are a different way for social services to fulfil its community care responsibilities. Therefore the assessment for services, through to service package agreement the care manager and myself completed was the same process whether or not I choose the direct payments option The same eligibility and priority criteria was used. The purpose of direct payments is to provide disabled people with control of the community care services they have been assessed as needing and are eligible to receive.

The ILF assessment was fairly straightforward and concentrated on supporting the cost of the care I needed in the mornings. Obviously, there was no doubt about my need for the care, it was just a question of going through the system and hoping the sum available would be adequate. In truth the ILF offer was somewhat short of expectations and was slightly below the line of adequacy when holiday payments were included. It became obvious that the package would stand or fall on the position taken by the Health Authority. If they were amenable to supporting part of the cost of my package then I was in with a chance of success, if they felt unable to offer their support I would be in difficulty.

In essence the Health Authority fully supported the principle of Direct Payments and were more than willing to examine ways of assisting. The obvious route was to look at the Continuing Care Criteria to see if there was any elements of that which applied to me. Thankfully there was. Again, I had to have more assessments; one health, one physiotherapy and an evidential letter of support from my doctor. These served to suggest a requirement for physiotherapy on a continuing basis and the need for 'social and psychological' welfare measures, in other words being able to get out and about.

This represented the final piece of the funding jigsaw.

In reality it would be true to suggest I didn't really appreciate the level of responsibility I was taking on. Now I have been in the position of employer for over twelve months and steered my way through writing job descriptions, writing and placing adverts and interviewing prospective candidates I can honestly say there is more involved than I ever imagined. Having said that, I believe all the elements associated with Direct Payments will eventually become a matter of routine and I will appreciate the freedom more when that point is reached. I began by establishing my care in the same pattern it had been provided by traditional services and I have now introduced a small number of variations which fit my circumstances better. Obviously this process will continue but I do have one or two concerns about the future.

From the outset it has been stressed to us (Direct Payments Recipients) that we should be good employers. Unfortunately it appears that we may be prevented from being such by limitations of funding. For example, a less than inflation increase to the payments from Social Services and the Health Authority and the total absence of an increase from the ILF could bring disaster. At present I am able to pay a reasonable hourly rate but this will be eroded over the next two or three years if the current trend of increases is allowed to continue. I foresee better rates of pay being available in other positions before very long and this is likely to mean I will lose staff. Holiday pay is another issue. I have eight sometimes nine staff on my payroll, yet I only receive three weeks holiday pay and one weeks sickness pay. This is obviously woefully adequate with the number of staff I have. I am left in the position of only being able to employ people on a casual contract basis, with no holiday pay and only statutory sickness pay available. Considering the terms of service given and expected from good employers we are hardly able to live up to the mantle of 'good employers' being deprived of the tools as we are.

Most people would probably say that I am the type of person unlikely to leave the situation as it stands at present. They expect me to carry a reasonable argument forward and be persistent in the pursuit of an acceptable solution. This will definitely be the case. Other people on Direct Payments Schemes throughout the country must be experiencing the same problems and I anticipate these will have to be addressed at a national level eventually. Before that can happen, someone has to carry the cause locally.

2.9 PILOT PROJECTS

Belgium

Vlaams Independent Living Centrum Brugge

There is currently no direct payment system in Belgium. It is at the experimental stage. The association *Independent Living Vlaanderen* – ILV, has been fighting for 10 years to introduce a so called *Persoonlijk Assistentie Budget* – PAB (Personal Assistance Budget).

In April 1996 ILV created the *Vlaams Independent Living Centrum* – VILC. The mission of this centre was to give full support (information, training in dealing with care providers, with employee-employer relationship, counselling, administrative help) to the handicapped people so that they can run their own life and their own care. It helped the 15 selected candidates through the experiment.

The Flemish government adopted a resolution to carry out a one year experiment starting in July 1997 and ending in June 1998.

This experiment included 15 handicapped people who have been selected at random. The *Flemisch Funding Institute for Social Integration of People with Handicap* was allocating the budget for reimbursement. This institute determined the amount of assistance hours to be reimbursed, needed by each person. The minimum of assistance time was 7 hours a week and could not exceed 38 hours a week. 25% at least of the amount of the care time to be reimbursed has to happen at the house of the service user. The assistance is reimbursed at maximum 1.2 million francs per person, per year.

The payment of the PAB is a reimbursement of the costs made by the handicapped person. These assistance costs have to be proven. The institute determines who the care provider should be and set up their working contract with the handicapped person.

The care provider excludes any relatives up to and including third removed.

Care assistance entails assistance of a handicapped person to accomplish the following duties: mobility, preparing food, personal hygiene, dressing, general household and social contact.

The persons who get a PAB have to give up any assistance (even partially) from institutions or a care provider paid by the local authority.

The ILV has published an evaluation report including the experiences of the participants to the experiment.

Even if the participants had a lot of problems initially (dealing with recruitment, working contracts, paying taxes, finding the right care provider, providing proof of costs incurred) the leading conclusion is that this system improved their quality of assistance (more mobility, more independence, more reliability) and definitely improved their general well-being and quality of life.

Italy

Raffaello Belli

As regards Direct Payments in Italy there are three main public sources.

'Indennita' di accompagnamento'. The eligibility depends upon your need for a personal assistant or that you are unable to perform one or more daily tasks. Eligibility also depends upon local medical boards and how the law is correctly enforced (sometimes you may cash *'indennita' di accompagnamento'* only if you have very severe disabilities, sometimes less severe disabilities are enough). When you are entitled to *'indennita' di accompagnamento'* it is a legal right, it is paid by the state and it is about 675,000 lira per month.

Municipalities may provide money for personal assistance as charity with eligibility and amount decided locally. This is not a legal right and the average amount is probably between 270,000 and 1,080,000 lira a month (mostly near 270,000).

According to the national law of 21 May 1998, n. 162, regional governments may provide Direct Payments for independent living. This is a new law which states that it is a legal right, but the law is written so that in fact it is not mandatory at the moment.

Tuscany is probably unique in that the regional law specifically obliges those local authorities responsible for people with disabilities to promote independent living.

Through European Union financing, a centre for independent living has been established and a 4 day training programme for personal assistants has been organised.

Local authorities are responsible for Direct Payments in Tuscany. There is no specific threshold for eligibility save that the service user must be assessed as having a severe disability. Payment is made on both a national basis (without financial assessment) and on a local level where assets are assessed.

The eligibility and the amount of money depends upon municipalities. In Florence this is 1 million Lire a month, but also includes the discretionary charitable allowance quoted above in this report. There is no restriction as to the choice of personal assistant whether self employed or from an agency.

Overall there is a long way to go in Italy to advance the principles of independent living but it is considered likely that Direct Payments will become more extensive in the future.

EUROPEAN DIRECT PAYMENTS LEGISLATION

Bundesfliegeldgesetz [BGB1. Nr. 110], 1993, Austria

(Federal Law on Direct Payment [BGB1. Nr. 110]) 1993, Austria

Lov om social service, 1.7.98, Denmark

(Social Services Act), 1.7.98, Denmark

hjælpeordning [art. 77], Denmark

(Personal Assistance [art. 77]), Denmark

kontant tilskud til personlig hjælp og pleje [art. 66], Denmark

(Funding for Personal Assistance and Nursing Care [art. 66]), Denmark

Sosialihuoltolaki, Asetus omaishoidon tuesta 318/1993, Finland

(Social Welfare Act and Decree on Support for Informal Care), 1993, Finland

Vaamaispalvelulaki 380, 1987, Finland

(Services and Assistance for the Disabled Act 380), 1987, Finland

La loi du 24 janvier 1997 – No 97.60 instituant une prestation d'autonomie pour les personnes âgées dépendantes. (PSD a Domicile), France

(Special Benefit for Dependent Persons at Home [elderly]), 1997, France

L'allocation compensatrice pour tierce personne (ACTP), 1975, France

(Direct Payment for personal assistance [disabled]), 1975, France

Pflegeversicherungsgesetz Sozialgesetzbuch x 1, 1995, Germany

(Care Insurance Act – Social Law x 1), 1995, Germany

Algemene Wet Bijzondere Ziektekosten, Netherlands

(Exceptional Medical Expenses Act), Netherlands

Wet Voorzieningen Gehandicapten, Netherlands

(Provisions Act for Disabled and Elderly People), Netherlands

Lag om stöd och service till vissa funktionshindrade, Sect. 9:2, 1994, Sweden

(Support and Service Act for persons with functional impairments, Sect. 9:2), 1994, Sweden

Community Care (Direct Payments Act) 1996, United Kingdom

Persoonlijk Assistentie Budget (PAB), Belgium

(Personal Assistance Budget) – experimental at present, Belgium

Legge-quattro per l'assistenza, l'integrazione sociale e i diritti delle persone handicappate [17.02.92], Italy

(Law on Social Assistance, Integration and Disabled People), 1992, Italy

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