

**The Implementation of Policies Supporting Independent Living for Disabled People in Europe:
Synthesis Report**

By

Ruth Townsley
with Linda Ward, David Abbott and Val Williams
Norah Fry Research Centre
University of Bristol

November 2009, amended January 2010

TABLE OF CONTENTS

EXECUTIVE SUMMARY.....	3
CHAPTER 1: BACKGROUND AND PURPOSE OF REPORT	5
CHAPTER 2: THE POLICY CONTEXT AND LEGAL FRAMEWORK.....	12
2.1 The extent to which states are including options for independent living within the mainstream of provision for social services, social security or long-term social care	12
2.2 The extent to which disabled people are acknowledged as having the potential for independence, choice and control in their lives in national policies and strategies.....	13
2.3 How has the system developed and where have new ideas come from?.....	14
2.4 Evidence of strategic commitment to independent living at different levels of implementation (i.e.: national/regional policy and local/practice levels)	15
CHAPTER 3: PROGRESS TOWARDS INDEPENDENT LIVING.....	18
3.1 Where are disabled people living?.....	18
3.2 Expenditure on institutional care versus support for people to live in the community, or to live independently	22
3.3 Institutional care – who is most at risk?	24
CHAPTER 4: SUPPORT FOR INDEPENDENT LIVING - PERSONAL ASSISTANCE	26
4.1 The organisation of human support (including personal assistance) to disabled people to enable them to live as independently as possible in their mainstream of the community	26
4.2 The organisation of personal assistance services	28
4.3 What kind of personal assistance is available?	28
4.4 Eligibility criteria and uptake of personal assistance services.....	30
4.5 Financial instruments for supporting personal assistance.....	32
4.6 Portability of personal assistance support for independent living	34
4.7 What support is available to family carers?	35
CHAPTER 5: ASSISTIVE EQUIPMENT AND ADAPTATIONS.....	37
5.1 Aids and adaptations available	37
5.2 Access to equipment and adaptations (assessment and eligibility)	37
5.3 Funding and service user contribution	38
5.4 Work adaptations	40
5.5 Portability	40
5.6 Choice and control over equipment and adaptations	41
CHAPTER 6: EVIDENCE OF OUTCOMES AND EFFECTIVENESS OF POLICIES ON INDEPENDENT LIVING	42
6.1 Research evidence relating to outcomes of independent living.....	42
6.2 Economic evidence - relating to costs and benefits of independent living, including any cost-benefit analysis if available.....	43
6.3 Role of disabled people in research and in agreeing outcomes and outcome measures	45
CHAPTER 7: CONCLUSIONS AND RECOMMENDATIONS	46



EXECUTIVE SUMMARY

Background and context

The area of interest for this ANED enquiry was the progress within European countries on policies supporting independent living for disabled people. The aims were:

- To review the national legal framework and implementation of policies in support of independent living for disabled people in each country
- To evaluate national policy development from a comparative perspective and to understand the state of the art in each country
- To share good practice
- To provide the Commission with useful evidence in support of future activities
- To provide recommendations to the Commission on priorities for future policy and research development.

A questionnaire was sent out to all the countries. The initial reports submitted in response to this were reviewed and clarification or further details requested where necessary. This report is based on the final, revised, reports of 25 countries. (Reports were not submitted by Cyprus, Hungary or Slovenia. The report from Luxembourg was not available in a final agreed version at the time of the analysis, but a brief summary of the situation there is included.)

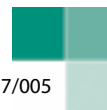
Independent living was identified as being of significant importance to disabled people in many of the country reports reviewed by ANED rapporteurs in the synthesis reports on both Employment and Social Protection and Inclusion last year. However, relatively little attention has been paid to support for independent living in European level policy initiatives, for example, in relation to the Commission's agenda to support the development and modernisation of social services of general interest in the European Union.

There are several definitions of independent living. In this report it focuses on a definition which means that disabled people should be able to decide where and how they live, with access to a range of services (including personal assistance) to support their life in the community.

Main findings

- **Policy context and legal framework:** The majority of states have policies with clear statements supporting independent living (but not all do). Some groups however may be excluded from legal frameworks which promote/safeguard independence i.e. people with intellectual disabilities. In some member states, there is continued reliance on institutional care/family carers. There is no one single model of independent living and the involvement of disabled people and user led organisations varies considerably across countries.
- **Evidence of commitment to independent living at various levels:** Few countries matched their stated strategic commitment to what was happening 'on the ground'. The main reasons for this seemed to be: limitations of local resources and/or regional interpretation of strategic frameworks; the lack of a policy lead; policy being under-developed; assessment procedures which focused on processes rather than meeting needs.

- Progress towards independent living:** There were wide differences in defining and interpreting key terms such as independent living and institutions. That said, it seemed that there were only three member states with no evidence of large scale institutions (but a concern that there was some regression). In countries where community options were more in place and reliance on institutions diminishing, there were still questions about the extent to which the community options had *practices* which were institutional. In countries where there was little progress, there remained a heavy emphasis on the role of family carers.
- Factors impeding progress towards community/independent living:** These included: a perceived prohibitive level of expense required to support independent living in the current economic climate; insufficient support/services in the community; concerns from carers (about e.g. isolation, bullying); lack of specific safeguards to prevent institutionalisation; and a view that in some instances, public opinion did not support deinstitutionalisation.
- Support for independent living: personal assistance:** In one country, self directed personal assistance was the norm. In about half of the others there was ‘twin-track’ support i.e. combination of services and self directed personal assistance. In the other half, there was also a ‘twin-track’ approach, but support not self directed. In 2 countries, there was an absence of support – service led or otherwise.
- Assistive equipment and adaptations:** Individual choice about equipment was often over-ridden by a medical assessment of ‘functional limitations’ and bureaucratic problems. Availability of funding for equipment and adaptations varies widely. There are separate systems for work-related/home based needs and a lack of portability between – sometimes within – countries. There were some centres of good practice.
- Evidence of outcomes and effectiveness:** There is very little research which has looked at outcomes relating to the policies around independent living (with Austria as a notable exception). Similarly, there has been little published research on cost/benefit issues and those that do look at *savings* rather than costs/benefits. There were no clear examples of the involvement of disabled people in the design of research about independent living.
- Conclusions:** Progress is hugely varied with arguably too few countries offering good community options or effective support for independent living (with a small number of exceptions). Progress still risks excluding some specific groups. One key question is whether there is a clear, shared vision of independent living – above and beyond the detail of how to make it happen? More work remains to be done to put disabled people at the heart of decision making about independent living at every level.
- Recommendations:** Greater use of European funding (e.g. European Structural Funds) to support the development of initiatives to foster independent living, including personal assistance schemes. Develop pilot strategies to increase the mobility of disabled people – within and between countries. Explore ways to monitor and check any trends back towards institutional living. Improve the collection of relevant data. Share good practice. Maximise the involvement of disabled people’s organisations in the planning, delivery and monitoring of policies and practice to support independent living.



CHAPTER 1: BACKGROUND AND PURPOSE OF REPORT

Making equal opportunities for disabled people a reality has been the objective of the European Commission's disability strategy since 2003. For this to happen disability issues need to be mainstreamed within all relevant EU policies; the EU Disability Action Plan 2003 - 10 provides the means to do this.¹

The Academic Network of European Disability experts (ANED) was established by the European Commission (EU) in 2008. Its purpose is to provide scientific support and advice for the Commission's Disability Policy Unit; in particular, to support the future development of the Disability Action Plan and practical implementation of the United Nations Convention on the Rights of Disabled People.² The European Community and its Member States jointly signed the Convention in 2007, thus confirming their view that disability was a 'broad human rights issue' (embracing civil, political, economic, social and environmental rights) and a matter of law.³

ANED's focus is on research and policy to support equal opportunities for all disabled people and their full participation in every aspect of life. The Network is co-ordinated by Human European Consultancy (Netherlands) and the Centre for Disability Studies at the University of Leeds (United Kingdom), with national experts in 29 countries and an additional pool of experts in specific fields. A key activity for the Network is to contribute to the evaluation and monitoring of policy and practice in European countries. Specific policy fields of interest to the Commission are selected for review by ANED country experts, and synthesised by an expert rapporteur.

The focus of this report

The area of interest for this ANED enquiry was the progress within European countries on policies supporting independent living⁴ for disabled people. The brief for the work was:

- To review the national legal framework and implementation of policies in support of independent living for disabled people in each country
- To evaluate national policy development from a comparative perspective and to understand the state of the art in each country
- To share good practice
- To provide the Commission with useful evidence in support of future activities
- To provide recommendations to the Commission on priorities for future policy and research development.

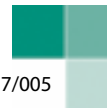
In order to get this information a questionnaire was sent out to all the countries. The initial reports submitted in response to this were reviewed and clarification or further details requested where necessary.

¹ The Disability Action Plan 2003-10 is developed in two year phases, with policy priorities that respond to the equality gaps faced by disabled people. The 2008-2009 DAP focuses on accessibility. The aim is to stimulate inclusive participation of people with disabilities and to work towards full enjoyment of fundamental rights. For further details see: <http://ec.europa.eu/social/main.jsp?catId=430&langId=en>

² <http://www.un.org/disabilities/default.asp?id=259>

³ European Commission, 2007, *The EU Disability Action Plan*, p3

⁴ A discussion of what is meant by 'independent living' follows later in this chapter



This report is based on the final, revised, reports of 25 countries, which understandably varied in their scope, length and ability to respond to the different questions posed.⁵ (Reports were not submitted by Cyprus, Hungary or Slovenia.

The report from Luxembourg was not available in a final agreed version at the time of the analysis, but a brief summary of the situation there is included in Chapter 7.)

The questionnaire asked for information on the measures that exist in each country to facilitate disabled people to have choice and control of their lives, on an equal basis with other citizens. For example:

- What is the **legal and policy framework** for providing support for independent living in different European countries?
- What progress has been made towards **community-based, independent, living** (from institutional alternatives)?
- What **types of support exist for independent living** for different groups of disabled people and their carers? How do people get access to it? Who benefits from the support that *is* available?
- What kinds of **personal assistance services** (controlled and directed by disabled people themselves) exist?
- What exists in terms of **assistive equipment and adaptations** to increase choice, control and independence in daily life?
- What evidence is there on the **outcomes and effectiveness** of national policies on independent living?
- What examples of **good practice** are there, in relation to disabled people's involvement in designing, managing or delivering support for disabled living?

The context for this report

There are a significant number of country-specific research reports on different aspects of independent living in different European states, but only a handful⁶ which take a cross-European comparative perspective, providing any Europe-wide evidence on progress in implementing national policies and practices in this key area.

Independent living was identified as being of significant importance to disabled people in many of the country reports reviewed by ANED rapporteurs in the synthesis reports on both Employment⁷ and Social Protection and Inclusion⁸ last year.

⁵ The country reports can be accessed at <http://www.disability-europe.net/en/themes/Independent%20living>

⁶ See <http://www.inclusion-europe.org/publications.htm>, for *Included in Society*,2004; *Deinstitutionalisation and Community Living*,2007; *The specific risks of discrimination against persons in situation of major dependence or with complex needs*,2008; EC Directorate for Employment, Social Affairs and Equal Opportunities (2009) *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care* <http://ec.europa.eu/social/BlobServlet?docId=3992&langId=en>

⁷<http://www.disability-europe.net/content/pdf/ANED%202008%20NSR%20disability%20synthesis%20report%20SPSI%20-%20311008.pdf>

⁸<http://www.disability-europe.net/content/pdf/ANED%20Task%207%20report%20Social%20Inclusion%20final%2020-05-09.pdf>

The latter report noted that: ‘Countries have taken a number of policy measures towards improving independent living of people with disabilities’.⁹ But it also highlighted the fact that even in the minority of countries identified as having direct payments schemes in place (i.e. cash payments paid directly to disabled people to allow them to choose and manage their own care) ‘the goal of enabling people with disabilities to choose the care arrangement that best suits their needs’ remained ‘far from accomplished’.¹⁰

By contrast, relatively little attention has been paid to support for independent living in European level policy initiatives, for example, in relation to the Commission’s agenda to support the development and modernisation of social services of general interest¹¹ in the European Union (although there is significant attention to these issues from European organisations such as the European Centre of Excellence for Personal Assistance and the European Coalition for Community Living and the European Day of People with Disabilities 2009 conference focused on creating the conditions for independent living).¹² Indeed, there is some scope for concern at the absence of any reference to personal assistance or direct payments (usually core elements of any definition of independent living) within the Commission’s First Biennial Report¹³. The discourse on disabled people there is couched largely in terms of ‘care’ and ‘dependency’.

Yet at the same time, country based policies are increasingly moving towards one of greater self-determination for disabled people. It is hoped that this review of developments to support independent living will contribute to redressing this imbalance.

What is ‘independent living’?

*Independent Living means to have the same range of options and the same degree of self-determination that non-disabled people take for granted.*¹⁴

Adolf Ratzka, Director of the Stockholm Independent Living Institute.

Many definitions of ‘independent living’ exist within the research, policy and disability people’s literature. Here we set out the definitions used by the UN and by the European Network on Independent Living¹⁵ respectively – the former because it provides the guiding framework for this report; the latter because it highlights key elements of the definition which are particularly important to disabled people and their organisations.

The UN Convention

Article 19 of the UN Convention on the Rights of Persons with Disabilities¹⁶, ‘Living independently and being included in the community’ states that State parties to the Convention:

⁹ Shima, I. & Rodrigues, R. (2009) *The implementation of EU social inclusion and social protection strategies in European countries with reference to equality for disabled people*, p.2

¹⁰ *Ibid*, p.25

¹¹ European Commission, 2008, *First biennial report on social services of general interest* http://ec.europa.eu/employment_social/spsi/ssgi_en.htm

¹² www.ecepa.org & www.community-living.info

¹³ http://ec.europa.eu/employment_social/spsi/docs/spsi_gpa/commnatsecdoctrav_en.pdf

¹⁴ Ratzka, A. *Independent Living with Personal Assistance*, Presentation to ENIL conference, Sept 2009

¹⁵ The European Network on Independent Living (ENIL) is a European wide network of disabled people. It represents a forum intended for all disabled people, independent living organisations and their non-disabled allies on the issues of independent living and the independent living movement.

¹⁶ <http://www.un.org/disabilities/default.asp?id=259>



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

To do this they are to ensure that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.'

In brief, then, independent living here means that disabled people should be able to decide where and how they live, with access to a range of services (including personal assistance) to support their life in the community. By 'personal assistance' we mean: 'to be able to customize services to your unique individual needs by either employing your assistants and deciding who works with what, how, when and where or by buying services choosing freely among many competing service providers.'¹⁷ Independent living does *not* mean that disabled people must do things for themselves, or live on their own.

Independent living has a number of different dimensions, in terms of both its *goals* and the *means* to be used to achieve these goals. Overall, the *goal* of independent living for disabled people is that they should have choice and control over the decisions, equipment and assistance that they need to go about their daily lives, so that they can participate in society on the same basis as other people. This ultimately involves access not only to personal support services but also to wider services like appropriate housing, transport, education, employment and training.

This report, however, focuses primarily on provisions for access to personal support for independent living for disabled people at home in the community. It does not look at the impact on independent living of the wider services and environment that impinge on disabled people's lives.

The European Network on Independent Living

Independent living is defined, particularly by organisations of disabled people, not only in terms of the *goals* to be achieved, but also by the *means* to be accessed to achieve those goals.

Thus, the European Network on Independent Living (ENIL) adopted the following definition of independent living in 1992, along with the different elements it must embrace:¹⁸

¹⁷ Adolf Ratzka, *Independent Living with Personal Assistance*, Presentation to ENIL conference, Sept 2009

¹⁸ ENIL meeting, Berlin, 7-10 October 1992



Definition of Independent Living

'Any organization, governmental or non-governmental including organizations for disabled persons, individuals and professionals who use the term 'Independent Living' in their work have to comply with the following principles:

1. Solidarity

- a. to work actively for the development of full equality and participation for persons with disabilities regardless of type or extent of disability, sex, age, residence, ethnic origin, sexuality or religion
- b. to work so that people with disabilities can have the resources to live independently
- c. to recognize Independent Living as a basic human right
- d. to share or exchange information, advice, support and training in appropriate form, e.g. tape, braille, large print, free of charge for persons with disabilities or, where there is a charge, to ensure that people with disabilities have the resources to pay for these services
- e. to cooperate with and support other organizations which belong to the international Independent Living network or who support the goals of the Independent Living movement.

2. Peer support

- a. to use peer support as the foremost educational tool for sharing information, experiences and insights in order to make people with disabilities conscious of the audio, visual and cultural, psychological, social, economic and political oppression and discrimination that they are exposed to
- b. to make persons with disabilities aware of their possibilities to reach full equality and participation
- c. to empower persons with disabilities by assisting them to acquire the skills to manage their social and physical environment with the goal of full equality and participation in their families and society.

3. Deinstitutionalization

- a. To oppose all types of institutions, stationary or mobile, especially designed for persons with disabilities. An institution is any public or private establishment, organization or service which creates special segregated solutions for persons with disabilities in education, work, housing, transportation, personal assistance and all other areas of life, which by its nature limits disabled persons' possibilities to make their own decisions about their lives or reduces their opportunities to participate in society on equal terms.
- b. In particular, establishments, organizations or services may not use the term 'Independent Living', if they promote or accept personal assistance services that require the user to live in special dwelling units or which deny or reduce the individual user's right to full choice and control over his or her life by forcing the user to live by the routine of others.



4. Democracy and self-determination

Organizations may use the term 'Independent Living' only, if all the following conditions are satisfied:

- a. if they are membership organizations based on democratic principles such as one person - one vote and
- b. if full membership with voting rights is reserved for persons with disabilities only and
- c. if the organization as a practice favours disabled persons for positions within the organization for both paid staff and volunteers including the head of staff and
- d. if the organization as a rule is represented in negotiations, meetings and the media by disabled persons.'

In reviewing the evidence contained in the country reports submitted for this project the aim was to look at the *progress* being made by individual countries in developing policy and practice to support independent living. Mansell et al (2007)¹⁹ have helpfully conceptualised progress away from institutionalisation and towards independent living as having three elements:

- Progress towards transforming and reforming institutional care – evidence of separation of buildings and support
- Progress towards community living - evidence of providing options and support in the community
- Progress towards independent living – evidence of support for people to live in their own homes and have choice and control through independent budgets.

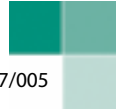
This report is concerned primarily with the last of these two.

The reports we received from the ANED experts in each country provided us with a wealth of often detailed information. In order to provide a helpful overview and synthesis of the trends and issues contained within the individual reports, we have inevitably been unable to do justice to all the material provided. Interested readers may wish to pursue specific issues further by looking at individual country reports.²⁰ Our report, then, focuses on the following areas fundamental to the attainment of independent living for disabled people living across Europe:

- The policy and legal framework in the different countries involved (Chapter 2)
- The progress that has been made nationally towards independent, community based living, from its institution based alternatives (Chapter 3)
- The availability of personal assistance to support independent living for disabled people living in different European states (Chapter 4)
- Access to assistive equipment and adaptations to support independent living for disabled people in different countries (Chapter 5)

¹⁹ Mansell, J., Knapp, M. Beadle-Brown, J. and Beecham, J. (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European study. Volume 1: Executive Summary*. Canterbury: Tizard Centre, University of Kent

²⁰ <http://www.disability-europe.net/en/themes/Independent%20living>

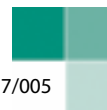


- A review of the evidence available on the outcomes of independent living and the effectiveness of different country policies to promote it (Chapter 6)

Examples of good practice in the involvement of disabled people and their organisations in the design, management and delivery of policies and services to support independent living

- a key criterion for independent living for disabled people's organisations, as we have noted
- are included in boxes throughout the report.

The Conclusions drawn from the evidence of the country reports are presented in Chapter 7, together with a list of Recommendations on what should be done to ensure access to independent living for more disabled people in Europe, whatever country they live in, and ultimately, it is to be hoped, mobility of support for disabled people within and between Member States.



CHAPTER 2: THE POLICY CONTEXT AND LEGAL FRAMEWORK

This chapter reviews the extent to which member states have adopted policies which promote/provide for independent living options. The chapter also considers how far disabled people are assumed to have the capacity for independent living. There are several ways in which progress towards independent living has come about – some of it more influenced by disabled people themselves – some of it not. Finally, the chapter describes evidence of strategic commitment to independent living at a number of different levels.

2.1 The extent to which states are including options for independent living within the mainstream of provision for social services, social security or long-term social care

The majority of member states appear to have developed mainstream policy where there are clear statements supporting options for independent living including direct payment schemes (Estonia, Netherlands, Iceland, Slovakia, Ireland, United Kingdom – see below, Spain and Norway). In addition, some countries have developed individual pieces of legislation which articulate specific aspects of support for independent living, such as the right to personal assistance (Finland, Sweden, Denmark, Poland, Italy, Spain) and to personal budgets (Germany, Netherlands, United Kingdom). Others, such as Portugal, are at an early stage of developing an independent living project that will include personal assistance.

The policy framework in the United Kingdom provides a range of support to allow the majority of disabled people choices to live in the community rather than in institutions. In terms of national strategy, *Improving the Life Chances of Disabled People* (PMSU 2005) provided a 20 year vision for the inclusion of disabled people by 2025. The 2008 Independent Living Strategy is then a key reference point (based on a major review in 2006). There is a five year plan, and the main aims include ensuring that all disabled people who need support in daily life achieve ‘greater choice and control over how support is provided’. The strategy emphasizes the values of autonomy, choice, freedom, dignity and control. Full details of the Strategy are available at:

<http://www.odi.gov.uk/working/independent-living/strategy.php>

As part of social care reforms, the government document *Putting People First* moved towards the ‘personalisation’ of support - including commitments towards greater individual choice and control (Department of Health 2007²¹; Leadbeater at al. 2008²²). Some of the key elements (of relevance to this report) include: a greater emphasis on self-assessment of need; person-centred planning and self-directed support; increasing the numbers of people using Direct Payments; and, ‘personal budgets for everyone eligible for publicly funded adult social care so that there is a clear, upfront allocation of funding to enable people to make informed choices about how best to meet their needs’. Further information:

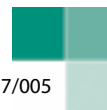
<http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/index.htm>

Some countries notably, France and Portugal recognise the importance of increasing accessibility to the built environment and community facilities as a mechanism to improve the quality of life of disabled people and facilitate independent living.

²¹ Department of Health (2007). *Putting People First: a shared vision and commitment to the transformation of adult social care*, London: Department of Health

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118

²² Leadbeater, C., Bartlett, J. and Gallagher, N. (2008). *Making it Personal*, London: DEMOS.



Accessibility is recognised as a fundamental right for ensuring independent living and participation of people with disabilities. (Portugal)

A rights-based, equality and anti-discrimination context frames support for the principles of independent living notably in Ireland, France, Belgium and the United Kingdom.

In Lithuania there are no laws directly related to independent living, but there are laws such as the 'Law on Equal Treatment' (2008), 'Law on social integration of the disabled' (2004) and 'Law on Social Services' (2006) that underpin ideas such as choice, equality and right to live independently in the community and the provision of services to enable this to happen. But the country report also notes that

Existing laws are incompatible with one another and they impact on equality, disability and incapacity.

For some countries, independent living does not appear to be specifically supported, as a concept or philosophy, at policy level (Czech Republic, Greece, Malta, Austria, Bulgaria, Latvia). Indeed for some of these countries (notably, Greece, and Czech Republic), there is no discourse of self-directed support or a clear statement regarding the dismantling of existing institutions. In other instances, Romania for example legislation that is possibly relevant to independent living does not provide any support for independent living .

2.2 The extent to which disabled people are acknowledged as having the potential for independence, choice and control in their lives in national policies and strategies

Most states have, to some extent, acknowledged that disabled people have the potential for self determination, as evidenced by policy statements and guidance materials. For about half of these (Sweden, Slovakia, Norway, United Kingdom, and Iceland), it appears that access to services and support for independent living is not restricted (at least in theory) to any particular impairment groups, although two authors (Iceland and Slovakia) point out that anecdotal evidence may not bear this out in practice.

However, even in countries where there is strong policy support for independence, choice and control (Germany, Netherlands and Denmark, Ireland, France, Belgium, Italy, Spain – see example below), some groups of disabled people (notably people with intellectual disabilities) are often subject to measures of legal/mental capacity which have the potential to exclude them from benefiting from support to live independently.

The opinions of disabled people (especially if they have severe cognitive or intellectual disabilities or cognitive and physical disabilities) are not taken into account when decisions are made about their entering or remaining in institutions. This decision rests with families, legal tutors and public administrators. Although people with dependence legally enjoy the same rights, freedoms and civil and political constitutional duties as other citizens, they may be deprived of them in cases of legal incapacitation, through a court order. Even without being ruled incapable, in practice, the vulnerability of their situation makes it difficult for people to exercise their rights (Libro Blanco, 2004 ²³). Lack of community alternatives, together with a lack of client-focus approaches help explain this situation. (Spain)

²³ IMSERSO (2004). Atención a las personas en situación de dependencia en España. Libro Blanco. Madrid: Autor.

In some countries (Malta, Greece, Romania, Bulgaria, Latvia, Lithuania) a continued reliance on institutional care, and/or relatives and extended family members as ‘carers’ of disabled people is not consistent with a commitment towards self-directed support and independent living. Effectively this means that disabled people are not perceived as independent actors, who have the capacity for choice and control over their own affairs. For disabled people in Poland this situation is compounded by a social and economic environment that is inaccessible to them:

Legislation in Poland does not particularly acknowledge disabled adults as having the potential for independence, choice and control in their lives. Generally speaking, people with disabilities have the same legal capacity as all other Polish citizens and, in theory, the same right to live an independent life.

Nonetheless, disability in Poland, especially severe disability, is connected with severe restrictions in independence. Lack of alternatives, poor accessibility and insufficient support create dependency for many disabled people, or at least restricts their right to choose. For instance, many people do not choose to live in an institution but do so because no other alternatives exist. (Poland)

2.3 How has the system developed and where have new ideas come from?

There is no one model of development when it comes to ideas relating to independent living. For some countries (Netherlands, Denmark, Latvia, Lithuania), the development of policy initiatives has largely been led by policy makers, professionals, academics (Spain, United Kingdom) and NGOs (for disabled people, as opposed to user led organisations (ULO)). For others (Norway, Slovakia, Finland, Belgium, France, Spain) this process has been informed by effective consultation with disabled people and the involvement of ULOs in the development of strategy, particularly in terms of personal assistance (e.g. STIL in Slovakia; Assistentti-info in Finland). For a small group of countries (Germany - see below, Sweden, Austria, France, Ireland, United Kingdom), the development of ideas (if not policy, in the case of Austria) has been led very much by disabled people through independent living initiatives and other ULOs.

In Germany, since the 1980s independent living has mainly been promoted by the disability rights movement. In recent years, the idea has been taken up by other disabled people’s organisations and by official politics. In 1990 an umbrella organisation for independent living called “Interessenvertretung Selbstbestimmt Leben in Deutschland” [www.isl-ev.de] was set up. Its members are individual activists of and Centres for Independent Living. Both the centres and the umbrella organisation are committed to the principle of the disability rights movement: “nothing about us without us”. In 1997 a national organisation for the promotion of personal assistance for disabled people called “Forum selbstbestimmter Assistenz behinderter Menschen e.V.” [www.forsea.de] was founded. This forum is a member of the disability rights movement and has since then been successfully lobbying for the approach of independent living and its integration into official policies.

In some countries where institutionalisation continues to be the norm in social care for disabled people, intense lobbying and advocacy by disabled people and their allies has resulted in the setting up of independent living projects which demonstrate the principles and viability of such schemes (Bulgaria).

In addition, in a social environment where the self-determination of disabled people is not generally well supported, groups of disabled people have organised themselves to provide support, advice, information or advocacy services for independent living (Poland). In Slovenia, three disabled people who had been at a boarding school began a 'grassroots' organisation called YHD, now registered as the *Association for the theory and culture of handicap, YHD*.

Currently, there are 90 personal assistants and 81 users of assistance living in their homes in different parts of Slovenia. YHD provides administrative framework and deals with bureaucracy and funding, pays out salaries, provides training, offers support in organising assistance, develops a theory and culture of disability, is actively lobbying for a Law on Personal Assistance and is actively involved in public and political debates on these issues.²⁴

However, for four countries (Czech Republic, Malta, Greece, Romania, Portugal and Iceland), the development of ideas relating to independent living is considered by authors of those country reports to not be well developed and it is acknowledged that more work needs to be done to resolve this. However, only one report (Iceland) shows evidence that this need is being addressed. Most country reports however do cite particular examples of collective action with independent living goals, such as in Romania:

IHTIS is an association, founded in 2004 by a group of young people with physical disabilities who have reason to say: 'This is what we make for ourselves in society which we live.' (<http://asociatia-ihis.ro/membrii/>). Their project 'Support our campaign '350.000 Euros = 350,000 People's Solidarity'. Donate 1 Euro for the first Center for Independent Life to be built in Romania' is one of the first initiatives of persons with disabilities for their independent life in Romania.

2.4 Evidence of strategic commitment to independent living at different levels of implementation (i.e.: national/regional policy and local/practice levels)

Very few countries appear to have matched their levels of strategic commitment to implementation at local and practice level. Six countries (Germany, Netherlands, Norway, Sweden, United Kingdom, Belgium) have strong and well-established policy commitments to independent living which appear, largely, to be matched by continued good practice in terms of implementation at local/practice level. Nevertheless, most of these country reports also raise some on-going public policy concerns:

- In Norway, possible moves towards larger forms of sheltered housing
- In the Netherlands and Germany, the focus is still very much on independent living support for disabled people with physical/sensory impairments and structures mitigate against those with higher support needs
- In Sweden there are concerns about the costs of independent living and a review is imminent)
- In Belgium, whilst some institutions remain, deinstitutionalisation has developed in each region of the country. This is alongside enlightened services providing personal assistance, and the use of personal budgets.

²⁴ Although we did not have a country report from Slovenia at the time of writing, this information was sent by colleagues in Slovenia after the draft of this report was submitted and it seemed helpful to include it here.

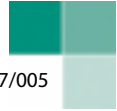
Equally, it appears that strategic commitment is not borne out in practice, or that full implementation of support for independent living for all disabled people is limited by local resources and regional interpretation of national policy (Slovakia, Iceland, Finland, Denmark, Ireland, Portugal, Spain, Italy):

- For example, in Slovakia, a strong policy commitment to independent living is not matched at practice level where an emphasis on ‘clearing’ waiting lists for residential care appears to be leading a move towards building new institutions.
- In Iceland, the authors of report state that commitments to independent living found in formal laws, policy statement and governmental declarations do not coincide with the practice and reality experienced by disabled people, who often live lonely and isolated lives, despite living in the community.
- In Finland, there is new legislation (as of 1/9/09) to support the development of personal assistance, yet the author states that locally progress is slow, and there is still resistance to deinstitutionalisation and the development of independent living by established provider organisations.
- In Ireland people with learning disabilities still live mainly in institutions and PA services are only available if individuals can get a place on a waiting list with a voluntary sector organisation. Whilst the Irish ‘Statement on Housing Policy 2007’, aims to *‘meet individual accommodation needs in a manner that facilitates and empowers personal choice and autonomy’*, regulations that outline standards for access – especially for new build houses, which have to be ‘visitable’ by disabled people – are only managing a compliance rate of 24%.
- In Portugal in spite of the government’s efforts to promote independent living and autonomy for disabled people *‘...society, including public services and institutions, still persists in presenting people with disabilities as citizens that need social, medical or family assistance and therefore it is very difficult for them to be independent and autonomous.’*
- Lack of regulation undermines the implementation of apparently progressive policies, for example in Spain: *‘Housing policy includes economic support for living in a house and eliminating barriers for those on low incomes, including disabled people. 3% public housing should go to disabled people and be accessible. No mechanisms to regulate this, however.’*

For these countries, the rhetoric does not match the reality. There is a vision, but no clear direction, leadership or mandate to put this into practice at local level.

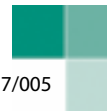
For other countries (Greece, Czech Republic, Estonia, Malta and Austria), the concept of independent living is not adequately described or supported at policy level, or there is a significant gap between national policy and ‘the real needs of the disabled people’ (Lithuania) leaving local and regional public bodies, NGOs and ULOs to implement their own developments, with widely varying results.

In the Czech Republic, a lack of policy lead, particularly in terms of deinstitutionalisation has effectively ‘frozen’ in time services for disabled people, which the author believes is responsible for demotivating NGOs to provide alternative support, thus limiting options for disabled people generally. A similar situation exists in Latvia where the level of institutionalisation of people with mental impairments is actually increasing (see *‘Programme on Development of Social Care and Social Rehabilitation Services for People with Mental Impairments 2009-2013 which provides for the development of traditionally accepted social care in institutions with the provision of bringing up the numbers of places.’*)



In Malta, a recent attempt by the NGO KNPD (National Commission Person with a Disability) in 2004 to introduce direct payments was not taken forward as policy, despite presenting an apparently persuasive case.

In Greece, Austria and Bulgaria, there is still an emphasis on assessment of access to support for community living on the basis of impairment, as opposed to need. This reliance on a medical model of disability restricts the development and implementation of independent living in practice, since even progressive local services and support structures (of which there are many in Austria) find their ability to provide support is 'blocked' by a system which is inconsistent with a rights-led approach.



CHAPTER 3: PROGRESS TOWARDS INDEPENDENT LIVING

Article 19 of the UN CRPD (2008) states that, in recognising the equal rights of disabled people to live in the community, with choices equal to others, Parties to the Convention should ensure that disabled people:

- Can choose where they live and with whom
- Are not obliged to live in a particular living arrangement.

With this statement in mind, we examined the country reports for evidence relating to progress made towards deinstitutionalisation, and for details about where, and in what circumstances, disabled people are living.

3.1 Where are disabled people living?

There is a very mixed picture concerning the living arrangements of disabled people in the 25 EUMSs covered by this report.

We asked the country experts to explain what progress has been made from institutional to independent community living in their countries. In other words, what progress has been made towards choices for disabled people to be able to live in their own homes in the community. Specifically, we asked:

- To what extent does the provision of support to disabled people still rely on segregated residential institutions (rather than people living in their own homes in the community)?
- How many people, from which groups of people, are living in institutions compared to those living in the community (please tell us if this important data is unavailable)?
- What processes or safeguards exist to ensure that people do not enter or remain in institutions against their choice (e.g. under what circumstances, or for what reasons, are people still denied the right to live in the community)?

First of all, it is important to highlight that many country report authors found it very difficult to collect and present meaningful evidence relating to this topic. For some, data were simply not available in any form (i.e.: there were no statistics relating to numbers of disabled people living in institutions or in the community). For others, data available were incomplete, or difficult to interpret since they were aggregated with data relating to other groups of people using residential care, such as older people. In many countries, it appears that the data available are not stratified by impairment so it is impossible to know which impairment groups are represented and to what extent.

Two other problems concerning interpretation of the data provided by country experts should also be raised here. Firstly, very few country authors were able to provide any past data (alongside current data), as points of comparison by which to measure progress towards community living. Secondly, there were numerous differing interpretations of what counts as an institution. One such definition is provided by the DECLOC report²⁵ which defines an institution as a place for more than 30 people. This definition is itself open to interpretation in various ways.

²⁵ http://www.kent.ac.uk/tizard/research/DECL_network/Project_reports.html

For example, does it include sheltered housing facilities where people live in groups of up to 50 self contained units, but share some communal resources/facilities, including in some cases support from professionals on-site? Some authors would say yes, others no.

Of course it is arguable that an institution is not just about numbers of people and an alternative definition from the European Coalition for Community Living²⁶ is:

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

Despite these concerns relating to the availability and viability of data provided by country experts, some generalisations can be made with a degree of accuracy.

There are three countries where there is no evidence of large-scale institutional living (Denmark, Norway, Sweden). In these countries disabled people live in group homes, (in Sweden these are limited to less than 6 people), in sheltered housing, with their families (who may also provide support) or independently in their own homes (with self-directed support through personal assistance if needed).

In Norway, generic services are the basis for support for disabled people. These are provided by local authorities (municipalities) and benefits (which provide economic basis for independent living) are provided by the state. Local Authorities are also responsible for housing for people that need practical support to live independently (e.g. those who cannot buy or rent without help). This includes group homes for people with intellectual disabilities. Residential care is typically provided in people's own homes (owned or rented) or a group home. There is also a sheltered housing system (ormsorgsboliger) run by local authorities, whereby disabled people (and others who use support services) can buy or rent apartments from the local authority, with some services provided on-site.

However in Norway, moves to try to provide community based housing options for a very small group of people with multiple impairments (less than 200) have been impossible to implement. And in Denmark, there are concerns about current practice in terms of community support and the degree to which this is becoming more institutionalised. The Danish Centre for Equal Opportunity (2008) reports on concerns by disabled people's organisations that development is moving away from support for independent living to more of a focus on building larger residential units containing from 30 to 50 separate apartments. In April 2009, the Danish government minister responsible for disability issues acknowledged this concern and suggested that Denmark should 'take inspiration from the Swedish model' whereby community-based residences are designed to accommodate a maximum of six individual units, or apartments, and are situated in ordinary buildings. It remains to be seen whether this will be borne out in practice.

In eight countries (Estonia, Iceland, Finland, Malta, France, United Kingdom, Ireland, Portugal), large scale institutions still exist, but reliance on these is diminishing and housing options appear to be mainly based within the community (in group housing, sheltered housing, family homes or less frequently, independent living).

²⁶ <http://www.community-living.info/>

Many of the authors of these reports raised concerns that some of these seemingly community-based options (where provided in a group setting) are often still rooted in institutional practices. It is also unclear, from many country reports, what proportion of disabled people who are said to be 'living at home' (for example this accounts for 97% of the disabled population in France and 95% in Portugal) are actually accessing self-directed support in order to live independently.

It appears that there is still a reliance on family members to provide care and support, rather than a system which promotes and supports independent living. For example, in Ireland, a very small proportion of disabled people use institutional residential services (3%). However, only 9% of the remaining disabled population are living independently, compared with the vast majority of people who live with support from family members (87%)

In three countries, progress appears to be static (Czech Republic, Spain, Lithuania), with no significant changes or improvements noted by the authors and with residential care still prevalent. In Spain, it appears that there are a number of options for supporting community living but that these are not promoted hence awareness of their existence and take-up amongst disabled people is low. In Lithuania and the Czech Republic, the number of disabled people living in residential institutions has remained unchanged since 2000. The Lithuania report author states that the network of community services for disabled people is underdeveloped due to the persistence of an ethos of reliance on family members for support:

The disabled person living at home should get these services...In reality, the supply of these services is limited or doesn't exist... In our opinion, the most important reasons why we have such a situation is because care and support for disabled persons is considered to be the responsibility of the family or relatives. (Lithuania)

Indeed, this 'culture of dependency' (Ratzka, 2007²⁷) whereby disabled people are perceived as the 'responsibility' of their parents or other relatives appears to be persistently pervasive in many Eastern European countries and a reason for lack of progress in developing alternatives to institutional care. In four countries (Poland, Latvia, Bulgaria, Romania), despite policy supporting deinstitutionalisation, it appears that a lack of any real options for community-based living arrangements have left many disabled people in a position where they are forced to 'choose' residential care, rather than live with no support, or with families who do not have the resources (time or money) to support them in the absence of other options.

There are no processes safeguarding people to continue living in the community. The lack of supporting services, lack of personal financial resources and lack of support from family members or relatives quite often leads people to choose traditionally accepted care services in institutions. (Latvia)

If a person with disabilities needs comprehensive support to lead an independent life, and the family's care comes to an end due to various reasons, there are not a lot of possibilities to live independently for such a person...In practice, in many cases the residential institution is the only alternative. (Poland)

²⁷ Ratzka, A. (2007) Independent Living for people with disabilities: from patient to citizen and customer. www.independentliving.org

Several authors make reference to their country's difficult financial situation, with the corollary that developing alternatives to institutional care is perceived as 'unrealistic' or 'idealistic' in the current economic climate.

Worryingly, for three countries (Germany, Netherlands and Slovakia), despite positive policy exhortations and many positive developments in terms of implementing independent living, progress towards deinstitutionalisation appears to be slightly retrograde: authors report that reliance on institutional care (in terms of numbers of people registered as living in institutions, and in terms of applications to institutions) has increased over the past two to three years.

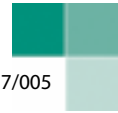
There is no empirical evidence available to explain this trend, although the author of the Netherlands report felt that insufficient community support and (potentially ungrounded) fears by carers may be responsible for the growth in residential placements:

It does appear that intramural placements are increasing, albeit slowly, possibly in reaction to the difficulties sometimes encountered in community living, including isolation and fear of bullying (a fear perhaps held more by parents and professional caregivers). (OSI Monitoring Report 2005, Rights of People with Intellectual Disabilities, quoted in Netherlands report).

In Germany, the country author noted that there had been a rise of 10% in numbers of institutions (from between 1999 and 2003) and that the rise of numbers of places available had increased to the same extent over this period. Neither the author of the Germany or the Slovakia report had access to evidence to explain this retrograde trend, but it is puzzling given the otherwise positive stance towards independent living in policy and practice more generally in these two countries.

The following four countries were unable to provide data, or gave data that was not usable or impossible to interpret for the reasons noted at the beginning of this section: Austria, Greece, Belgium, Italy. Nonetheless, some of these authors felt able to draw conclusions about trends and issues regarding the living arrangements of disabled people in their countries. For example, the Austrian country expert made several points that underline a lack of commitment towards full-scale deinstitutionalisation and even towards the ethos of community living in Austria (let alone Independent Living):

- There are no safeguards or processes to ensure that people do not enter or remain in institutions.
- All over Austria, large institutions still exist, and are being financed and developed and politically supported by provincial governments. Several examples are given, the largest housing 600 children, adults and elder people with disabilities in Styria. Even in the 3 provinces with strong Centres for Independent Living, major investments are still being made to support large institutions (from 44 people up to 250 people in one place)
- Public opinion is such that it is still considered 'normal' for disabled people to live together in large groups, even in the community, where group homes can be for 10-40 people at a time.
- Some disabled people are forced to live in care homes for elderly people as there are no personal support services available locally, or their own homes are not accessible.



3.2 Expenditure on institutional care versus support for people to live in the community, or to live independently

We asked country experts to provide details of expenditure on institutional support and on support for people living independently and/or in the community. In particular we were interested to know if there was any evidence of comparison of the overall expenditure, or the average cost per person. We also wanted to know if any major investments are still being made to develop residential institutions rather than moving away from them (e.g. construction of new institutions, or development of old ones).

Again this was an area fraught with difficulties and open to many nuances of interpretation by the authors.

A large proportion of country experts (ten out of 25) were not able to access sufficient or adequate data for this purpose. However, some general trends may be noted from the data available.

Trends in expenditure on residential institutions

For three countries, there is currently no official investment in institutions for disabled people (Denmark, Norway, Sweden), although concern was raised by the Norway author about the recent financing of larger groups of units in sheltered housing schemes (these appear to be growing from groups of five to six to groups of ten plus).

For three countries (Iceland, Greece, Ireland) expenditure on existing institutions appears to be static in that no significant changes were noted. However, in Ireland, the country expert notes that up until recently, there were tax incentives of up to 40% offered to those who invested in construction of institutions such as private hospitals and registered care homes. Although these incentives were abolished in April 2009, the many facilities built during the lifetime of the tax breaks are still operational. As the country author explains:

Although the incentives have been abolished, the infrastructure put in place during their existence will continue to be utilised and people will continue to be placed in such facilities until some definitive statement of a commitment to independent or community living is made by the Government. (Ireland)

Nine countries (Austria, Netherlands, Slovakia, Poland, Germany, Spain, Romania, France, Bulgaria) appear to show new, or increased levels of expenditure on institutional care, despite some of these having no point of comparison to a past date. This includes the building or development of new institutions. For example, in Romania in 2006, two new residential institutions were set up for more than 200 people, and plans for the period 2007-2011 include on-going investment in new institutions. In France, the number of residential institutions for adults aged 20 to 60 increased by 20% between 2001 and 2006 (from 3,015 to 3,720). Similarly, the number of places available increased by 19% from 99,080 in 2001 to 118,200 in 2006. As the author of the France report put it:

French disability policy does not intend to switch radically to an independent living policy and deinstitutionalisation is not on the agenda. (France)

In some other countries, for instance Spain (with the development of State Reference Centres), investment is being made in developing new form of residential institution aimed at older disabled people, particularly people with dementia.

Some countries (notably Poland and Slovakia) appear to be allocating significant funds towards ‘updating’ or ‘extending’ existing residential institutions. The author of the Slovakia report explained that the rationale was to develop the accessibility of existing institutions whilst establishing ‘new style’ institutions in order to clear waiting lists for residential care (there are 16,000 people on such lists). Similarly, in Poland since 2000, large public funds have been allocated towards enabling existing institutions (social welfare homes) to reach new standards for accessibility and care, and local authorities’ expenditure on social welfare homes has increased every year (CSO 2006, 2008)²⁸.

Both the Poland and Slovakia country experts suggest that the nature of such obvious public investment acts as a disincentive towards the implementation of real deinstitutionalisation, refutes the vision of independent living for disabled people, families and the general public, and demotivates alternative providers/enablers such as NGOs and Centres for Independent Living.

Only one country (United Kingdom) provided evidence which showed a slight decrease in institutional expenditure (for all groups, not just disabled people) in England between 2006-7 and 2007-8, when adjusted for inflation. However, as the authors point out, expenditure on residential service provision still accounts for 41% of the total gross spending on personal social services in England, so investment remains substantial.

Ten countries were unable to provide data, or gave data that were not interpretable for the purposes of this report (Estonia, Finland, Czech Republic, Malta, Portugal, Latvia, Italy, Lithuania, Belgium).

Trends in expenditure on community-based support and independent living

Unfortunately it proved impossible to draw any conclusions about current trends in expenditure on community-based support and independent living, for the following reasons:

- Data provided by country experts in answer to this question related to availability of options (i.e.: number of places available), use of options (i.e.: numbers of disabled people taking up each option) as well as to expenditure on each option. Sometimes these data were aggregated or combined.
- Data relating to community-based living arrangements and independent living were often combined/confused under one heading such as ‘people living at home’ (France), accessing ‘home-care’ (Latvia), living in ‘residences’ (Denmark), or living in ‘autonomous residences’ (Portugal).

²⁸ Central Statistical Office (CSO). (2006). Podstawowe dane z zakresu ochrony zdrowia w 2005 r. (Basic data on health service in 2005). Warsaw: Author, <http://www.stat.gov.pl> ; CSO. (2008). Podstawowe dane z zakresu ochrony zdrowia w 2007 r. (Basic data on health service in 2007). Warsaw: Author; <http://www.stat.gov.pl>.

- Data relating to independent living were also difficult to interpret, since a variety of terms were used which may, or may not, mean that disabled people are accessing self-directed support via personal assistance and personal budgets – ‘support for independent living’ (Estonia), ‘support to people at home’ (France), ‘people living alone’ (Ireland), ‘people organising their own social services and receiving social care benefits’ (Lithuania), ‘people receiving direct payments including care allowance’ (Slovakia).
- Data about expenditure, availability and uptake in each situation were very often not comparable (for example, it related to different age groups, different impairment groups, or to limited geographical areas).

There was a tiny minority of exceptions to this, where meaningful comparative data were available, which are set out in the table below. However as will be apparent, even this material is unclear, or incomplete in many respects:

3.3 Institutional care – who is most at risk?

The aim of this section was to provide evidence relating to a range of equality dimensions, such as any differences in treatment/access for disabled women, people with different kinds of impairments, people from different ethnic groups and older people.

Overall, it has not been possible to give the degree of detail that was hoped for, since this level of data was mostly not available in the reports, and even when queried with country authors it was very often not obtainable since data at a more basic level was unavailable as a starting point.

However, where data were available the following groups of disabled people appear to lose out the most:

- People with intellectual disabilities (and in some countries, also people with mental health support needs) appear to be over represented in figures relating to institutional care and there is some evidence to suggest that people are being placed in institutions against their will (Slovakia, Finland, Estonia, Germany, Netherlands, Ireland, Italy, Romania).

... (the) largest group in institutions are people with ID (65%). The ‘disproportionality’ principle also works against them. If it is considered cheaper to put people in institutional care, then they have no legal right to resist that. Officially disabled people have the right to opt for different types of institutional and home care. (Bundesministerium für Familie, 2006, p. 227)²⁹ But there have been cases which resulted in institutionalization, although the concerned person wanted to live in the community.

Especially people with severe disabilities and in need of 24 hours personal assistance increasingly face this conflict of priorities; authorities tend to be rather restrictive and take decisions that are likely to lead to lower costs. (Germany)

²⁹ Bundesministerium für Familie. (2006). Erster Bericht des Bundesministeriums für Familie, Senioren, Frauen und Jugend über die Situation der Heime und die Betreuung der Bewohnerinnen und Bewohner. Retrieved 08.07.08, from <http://www.bmfsfj.de/bmfsfj/generator/Publikationen/heimbericht/01-Redaktion/PDF-Anlagen/gesamtdokument.property=pdf,bereich=heimbericht,sprache=de,rwb=true.pdf>

Virtually all people with ID and chronic psychiatric conditions live in institutions, or in 'semi-mural dwellings' (homes in ordinary communities, owned and supported by care organisations). Therefore the progress towards independent living is entirely to do with people with physical or sensory impairments. (Netherlands)

- People with significant, multiple physical/sensory/cognitive impairments get reduced access to community options (Iceland, Germany, Slovakia, Finland, France, Norway)
- Age also appears to be a factor in unequal treatment for some groups of disabled people. There is some evidence that placement in residential institutions increases with age, particularly for older people with learning disabilities (Ireland, Italy). This may go some way to explain why, in some countries, where data were available on gender (e.g. Portugal), it shows evidence of more women than men living in institutions (since it is well established that there are more women over the age of 60 than men).
- However, in some countries (e.g. United Kingdom), younger disabled people appear to face a higher degree of potential institutionalisation. The authors of the United Kingdom report highlighted concerns about the placement of large numbers of disabled children and young people in residential 'educational' placements.

United Kingdom research has shown that these placements are very often made in response to a lack of appropriate, local, community-based support, and hence are evidence of unequal treatment of disabled people

It is worth highlighting that in one country (Greece), people with physical/sensory impairments have significantly less access to community living options than other groups.

Supported housing/ sheltered flats for independent living in the community have not been developed for people with physical disability (in contrast with progress in mental health and intellectual disability). De-institutionalization in this respect has only involved a few small-scale pilot projects, implemented by large-scale institutions for their own residents. (Greece)

However, even for other impairment groups, many community options in Greece still appear to reflect institutionalised thinking/practice and the assertion by the Greek government that 'progress towards deinstitutionalisation' has been made has been refuted by one leading user-led organisation:

Between 2003 and 2005, 130 community units were created in the form of hostels, protected flats, day centres and mobile units to support people with mental health as well as people with intellectual or learning disability... However in November 2008, the National Committee of Ex-Users and Survivors of Psychiatry issued a Press Announcement denouncing these findings, a measure that attracted wide controversy at the time, due to the funding insecurity of the operational program for mental health reform. They maintained that there had been no real reform of models of service provision and that the logic of psychiatric institutions continues to dominate in community-based units. (Greece)

Detailed data on the situation of different impairment groups was not available from these countries: Austria, Czech Republic, Malta, Belgium, Bulgaria, Denmark, Estonia, Spain, Lithuania, Latvia, Poland.



CHAPTER 4: SUPPORT FOR INDEPENDENT LIVING - PERSONAL ASSISTANCE

This chapter describes the nature and extent of support available to enable disabled people to live in their own homes in the mainstream of the community, with a particular focus on forms of personal assistance to support independent living.

4.1 The organisation of human support (including personal assistance) to disabled people to enable them to live as independently as possible in their mainstream of the community

We asked country experts to provide brief details of the delivery options that exist to support disabled people living in the community. Due to some of the limitations of the data provided, we have included information relating to people who are accessing community-based living arrangements (such as living with support from family, living in group homes and other forms of community-based residence, etc) and those who are living independently (with personal assistance). The key factor here is about the existence of forms of human support to enable disabled people to go about their daily lives, as independently as possible, regardless of where they are residing. We have had to slightly re-frame this area of analysis to reflect the data that the ANED experts provided from the perspectives of their own countries.

Just one country (Sweden) is supporting self-directed personal assistance, with (predominantly) use of mainstream services as the main delivery option for disabled people. We might suggest that Sweden is offering its disabled citizens full choice and control over the support they need to live independently, with (almost) equal access to the same mainstream services as other non-disabled citizens.

Twelve countries (Slovakia, Finland, Netherlands, Denmark, Austria, Germany, Ireland, United Kingdom, Spain, Belgium, Norway, France) are currently providing 'twin-track' support, where options for self-directed personal assistance for independent living co-exist alongside more traditional service-led and directed options. Here we might suggest that these eleven countries are offering their disabled citizens partial choice and control over the support they need to live independently, with some degree (albeit limited in some places) of equal access to the same mainstream services as other non-disabled citizens.

Nine countries (Poland, Estonia, Italy, Bulgaria, Romania, Latvia, Lithuania, Portugal, Iceland) are also offering co-existing support as above, but where the personal assistance element is **not** self-directed (i.e.: disabled people can access some sort of personal assistance via a variety of means, but have no control over its planning or implementation in terms of recruiting staff, planning activities, managing the staff and the budget, etc). In many of these countries, the concept of personal assistance is at a very early stage of development (e.g. Poland, Lithuania, Latvia), is not widespread (e.g. Bulgaria, Italy), or is significantly limited in its scope (e.g. Portugal, Iceland, Bulgaria). In the case of these countries, we might suggest that they offer their disabled citizens very little choice and control over the support they need to live independently.

- In Portugal, personal assistance is only available in the work-place, and the personal assistant is chosen by the employer.

- In Iceland, a form of personal assistance as 'home-help' is available to disabled (and non-disabled) people living in community-based residences or their own homes. But the country experts do not feel that this counts as personal assistance to support independent living in the philosophical/activist sense.

We have, however, included Iceland in this group as it appears that the service offered is very much on a par with similar services offered by many of the countries cited above who have described this as 'personal assistance'.

(Of course it could be argued that since none of these countries are supporting self-directed personal assistance, that strictly speaking, the Iceland authors are correct in their stance on this issue.)

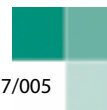
- In Bulgaria, there is an attempt to introduce a personal assistance scheme in Sofia (called the independent living, or assistant for independent living scheme). But the country expert explains that this scheme is poorly developed and managed and has not sufficiently communicated its aims to disabled people eligible to apply. An outcome of this, according to the country report author, is that the majority of people using the independent living scheme have 'chosen' family members to act as personal assistants, a situation which is described as follows:

This makes it very much a luxurious family support, increasing family income, with no impact on disabled people to gain independence and have opportunities to participate.
(Bulgaria)

One country (Czech Republic) is only providing service-led support for people to live in the community, or independently (in isolated cases). Here we could say that these disabled citizens have no choice and control over the support they need to live independently. In the Czech Republic, disabled people can apply for a direct payment to purchase services to support independent living, but in reality people have no choice over how to spend their budget since they can only choose from what is currently available from local service providers. And in some places this might only be their local institution.

In two countries (Greece, Malta) it appears that there is virtually no support whatsoever, service-led or otherwise, to enable people to live independently, either in their own homes or in other community-based residential provision (including with families). The Greece author explains that Greece's range of traditional support for community living is still being developed and that currently, these community-based services do not provide support with daily living at home for disabled people. There is a 'Help at Home' program (since 2006) aimed at older non-disabled people, which some disabled people access. But this is apparently so restrictive that it is incompatible with supporting any real notion of independent living in any meaningful sense. In this country, it appears that disabled people have no access to, or choice and control over, support to enable them to live independently. Nor does it appear that they have any form of equal access to mainstream services accessed by other non-disabled citizens.

In Malta, a state run agency called Agenzija Support is responsible for developing and running group homes and supported living for disabled people in different locations across the country and within this there is some availability of support from 'assistants'. However in reality, this provision is so undeveloped to date that most disabled people find it difficult to access.



4.2 The organisation of personal assistance services

We asked country experts to tell us about how personal assistance services are organised, specifically whether these are controlled and managed by disabled people themselves, either through Centres for Independent Living or other forms of user-led organisations (ULO).

As the previous section showed, there are 22 countries where some element of personal assistance for independent living appears to be available (even if this is not self-directed or is offered alongside more traditional service-led options).

Of these, eleven countries (Germany, United Kingdom, Sweden, Spain, Austria, Ireland, Belgium, Norway, Finland, Italy, Lithuania, France) talked about the involvement of user-led organisations and Centres for Independent Living in some elements of the support, organisation and implementation of personal assistance, both at a strategic level and to individual disabled people using and managing personal assistance.

In some countries, the input of ULOs and Centres for Independent Living was not universal, and was limited to certain geographical areas, to tiny 'pockets of good practice', or to support to particular impairment groups. In one country (Lithuania), the country expert explained that there is only one organisation providing personal assistance to 14 disabled people and that as this is new and the only one so far in Lithuania, it is currently operating illegally, "because of the incompatibility of national law" (Lithuania).

In the remaining ten countries (Romania, Bulgaria, Denmark, Latvia, Estonia, Poland, Netherlands, Slovakia, Iceland, Portugal) the evidence in the report appears to indicate that disabled people can only access personal assistance via state-run agencies, NGOs, or local authorities.

4.3 What kind of personal assistance is available?

We asked country experts to describe the nature of personal assistance support available to people in their own homes, at work, and in education and training. In the 22 countries where some form of personal assistance is available, it appears that for the vast majority, this is focussed predominantly on support at home, and in some cases support to access social and recreational activities.

Support at home would include support with tasks such as: house-keeping (laundry, cleaning, paying bills, correspondence, etc); food planning, shopping, preparation and cooking; personal care (washing, dressing, etc). Only two country reports (Iceland, Belgium) mentioned that personal assistance to disabled people might include support with caring for children, so it is unclear whether this is an area of need that is supported more widely or not.

Some country experts also mentioned that personal assistance sometimes includes an information, advice and advocacy component, but details on this were scarce.

Personal assistance for health care and medical needs was only mentioned by two countries, both in terms of the fact that this is an area where there is some confusion and debate over the role that personal assistance might play.

Generally, all kinds of personal needs are covered, but medical tasks can only be provided by personal assistants if the user can direct them. (Austria)

Twelve countries specifically mentioned that personal assistance could be access for support with employment. Similarly seven countries said that personal assistance was available to disabled people to support education and training. Nine reports made no mention at all of whether personal assistance was available for disabled people at work or in education and training. However, it is unclear whether this means it is unavailable in other places, or that country authors just omitted to include specific details. The two most detailed responses on this area came from Austria and the United Kingdom.

In the United Kingdom two separate schemes, Access to Work and Disabled Students Allowance, fund the provision of personal assistance to disabled people in employment and in education and training. The Austrian country author helpfully described the sort of support that personal assistance can cover in relation to employment (although there was no mention of support for education and training):

Activities of personal assistants at the workplace can be among others: accompanying on the way between home and the place of work, vocational training as well as for being away on the business; Supporting manual activities for doing a job or during a vocational training, e.g. filing or copying; Assistance for personal hygiene during the time on the job or the vocational training as well as other forms of assistance due to a disability, e.g. putting on or taking off a jacket, assistance for having lunch. (Austria)

In many reports, it does appear that personal assistance covers ‘activities outside the home’ and can be used very flexibly, but without more specific details it is difficult to judge to what extent disabled people may access personal assistance for employment or education/training purposes. It is worth, however, quoting some of the descriptions of personal assistance that most approximate to good support for independent living:

The concept of personal assistance is that it should be personal support that gives the individual greater opportunity to live an independent life. Personal assistance means personally designed assistance provided in different situations by a limited number of people.

It means that users have control over how services are organised and can custom-design their services according to their individual needs and also decides who is employed as personal assistant, when and how aid should be given... Personal assistance services are provided wherever they are needed, including the workplace. (Sweden)

From September 2009, this will be a subjective right for all disabled people, including people with intellectual disability. It would introduce rights to assistance for domestic, social, educational and employment purposes, including a right to 30 hours per month to support recreation and social interaction. When the level of need is agreed, it is the responsibility of the disabled person to recruit and employ an appropriate person(s) to provide assistance. They have complete control over the recruitment, day-to-day employment, hours of work, etc (personal confidentiality is also a key principle in this arrangement). Alternatively, the person’s guardian or carer may act as the employer of the personal assistant. Under the new law family members may not be employed as assistants except in exceptional circumstances. (Finland)



Since the concept of personal assistance was originally developed from activists of the disability rights movement, it involves the philosophy that disabled people must be in control of these services (ISL 2001). The so called “employer model” implies that only services which follow the following principles are called personal assistance services:

- Disabled people control and manage staffing (“Personalkompetenz”): They close contracts with their assistants and decide about the working conditions including the salary. Disabled people are free either to function as employers or use the service of a personal assistance agency
- Disabled people control the ways in which personal assistance is carried out. They instruct their assistants and decide which services are carried out and which not (“Anleitungskompetenz”)
- Disabled people are in control of the services’ budget and its management (“Finanzkompetenz”)
- Disabled people are free to decide about the organisation and practice of personal assistance according to their needs and wishes (“Organisationskompetenz”)
- Disabled people are the ones who decide in which room or at which place assistance is carried out (“Raumkompetenz”): Personal assistance can take place in private homes, in the public, at the workplace, at a holiday resort, paying visits to friends etc. (Germany)

4.4 Eligibility criteria and uptake of personal assistance services

We asked country experts to tell us who can receive personal assistance and to give details of any eligibility criteria. We also wanted to know how many people, from which demographic groups, are actually accessing personal assistance services. For many country experts, this was a difficult area to cover, since information in their own countries was not always available.

Eligibility criteria

In terms of details on eligibility for personal assistance, eight (of 22) reports did not cover this topic, or did not provide clear enough information from which we could draw conclusions.

Of the thirteen reports, where detailed information was available, seven countries (Finland, Netherlands, Austria, Bulgaria, Spain, Estonia, France) appear to have systems based on a medical model of assessment, where access to personal assistance is assessed in terms of the nature of a person’s impairment and their overall likely need for support in terms of hours per week, or per month. In this case, several country experts noted that personal assistance thus tends to be weighted towards people with physical/sensory impairments, as opposed to people with learning disabilities or mental health support needs, since the nature of the formers’ impairments may be more likely to meet assessment criteria which emphasis ‘substantial physical care needs’, as opposed to the social support needs more commonly highlighted by the latter two groups. In some countries, eligibility is more a matter of where a person lives, since different geographical locations may have different services available, or there may only be one or two personal assistance ‘schemes’ in the whole country. Clearly, both these situations lead to significant inequality in access.

Seven countries (United Kingdom, Denmark, Norway, Slovakia, Germany, Ireland, Sweden) indicated that any disabled person (and some cases other non-disabled people like carers and older people) can apply for personal assistance services under their eligibility criteria.

However, even in these countries, inequality in access is an issue to be tackled. In Slovakia, there are no explicit exclusion criteria but anecdotal evidence from the country author suggests that social workers not encouraging people with learning disabilities and their families to apply due to assumptions about their capacity to manage the system. In Norway, Belgium and the United Kingdom, the right to services is rationed, and people's access to personal assistance will depend on how much, and what type, of services have been deemed 'available' in their locality. In Belgium, this is fairly mechanistic, in that a set number of personal budgets for personal assistance are agreed each year in certain localities.

In the United Kingdom, eligibility to direct payment and individual budgets (to pay for personal assistance) is based on individual assessment, but this is underpinned by set thresholds for eligibility, which can change in response to what level of resource is available.

Local authorities also have a duty to set thresholds for eligibility: to determine the level at which they can afford to meet needs. They do not have to meet needs which are below the threshold ('unmet need') but generally they do have to meet those that are above the threshold. The threshold may be moved according to the level of resources, and people who have been eligible may become ineligible if resources become tighter, as has been the case in the United Kingdom in recent years. Therefore there are no absolute categories for eligibility to services. (United Kingdom)

The issue of 'capacity to manage the system' was also highlighted by some country reports in terms of the impact that this has on eligibility to personal assistance.

If no support is available to organise personal assistance (from either user-led organisations or others) then in some countries people with learning disabilities and some people with mental health support needs are 'automatically' excluded from the process. And even where such support does exist, generalised assumptions about capacity appear to be all too often made based on assumptions about impairment, rather than on a thorough assessment of the support a person might need to manage personal assistance.

Actual uptake of personal assistance services

In terms uptake of personal assistance, this was an area where much detail was lacking in the country reports, mainly due to a lack of available data in experts' home countries. The material that is available is best set out in the following table. However, it is worth pointing out that comparisons between countries are difficult to make without reference to more general statistics relating to the total population of disabled people, which, for reasons explained in the previous chapter, were also mostly not available.

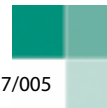
Table 2 Number of disabled people using personal assistance services, by country

Ref	Country	Number of disabled people using personal assistance services	Date of statistic	Data not available in country, not usable in current form, or not given
AT	Austria			X
BE	Belgium			X
BG	Bulgaria			X

CY	Cyprus			No report
CZ	Czech Rep			No PA
DE	Germany			X
DK	Denmark	2,152	2007	
EE	Estonia	370	2007	
EL	Greece			No PA
ES	Spain			X
FI	Finland	5,500	2009	
FR	France	16% of all disabled men 25% of all disabled women	2002	
HU	Hungary			No report
IE	Ireland	7,701	2008	
IS	Iceland			X
IT	Italy	19,722 (in Sardinia only)	2009	
LT	Lithuania	14	2009	
LU	Luxembourg			Final report not available at time of this analysis
LV	Latvia			X
MT	Malta			
NO	Norway	3,714	2008	
NL	Netherlands			X
PL	Poland			X
PT	Portugal			X
RO	Romania			X
SE	Sweden	15,293	2008	
SI	Slovenia			No report
SK	Slovakia	6,099	2008	
UK	Utd Kingdom	England 93,000 Wales 1,540 Scotland 2,605 (Recorded as uptake of direct payments) England (Personal assistance at work) 34,800	England 2009 Wales 2008 Scotland 2008 2003/4	

4.5 Financial instruments for supporting personal assistance

We asked country experts to provide details about how personal assistance is financed. Four reports (Poland, Latvia, Spain, Lithuania) did not provide sufficiently clear information to enable us to assess the system in their country, however, for some of these this is perhaps understandable since personal assistance and funding for it appears to be at a very early stage of development. The remaining country reports showed evidence of three main approaches to financing personal assistance, as set out below.



Personal assistance is funded via a personal budget or a direct cash payment

Nine countries appear to be using a system whereby personal assistance is funded via a personal budget³⁰ or a direct cash payment³¹ to the disabled person themselves, or the organisation managing the support (Germany, Belgium, Netherlands, United Kingdom, Denmark, Slovakia, Sweden, Finland, France).

Within this group, practice varies greatly by country, as one might expect.

For example, five countries (Sweden, France, United Kingdom, Germany, Denmark) support the use of direct payments or personal budgets for disabled people to employ family members as personal assistants, if they wish. Whilst in two countries (Slovakia, Finland) this is only permitted in exceptional circumstances.

There are also huge differences in terms of variations in the limits that are applied to the resources allocated.

In Finland, the funding may only be used to cover the wages of personal assistants, not any other associated costs or expenses, and may be provided by the municipality direct to the employer or to the personal assistant. In Slovakia, there is an upper limit of 7,300 hours of personal assistance per person per year.

In the United Kingdom and Germany there are no limits in theory, however, in practice it is clear that funding and amounts of personal assistance that people are entitled to, are linked to the resource that is available from state agencies or local authorities and their thresholds for setting eligibility criteria.

In all of the countries in this group, disabled people are entitled to self-direct either the funding system and/or the organisation of the personal assistance it pays for, if they wish, and are also eligible to tailored support to do so. In all but two countries (Denmark, Slovakia), this is peer-support, that is, support which is provided by Centres for Independent Living or ULOs.

In Germany, the NGO Lebenshilfe offers counselling for disabled people and their families on how to operate a personal budget. This service is accessible to people with learning disabilities. In addition, budget counsellors are being trained by other organisations and may work either as employees of a ULO, or operate on a freelance basis and be costed into an individual's personal budget.

Personal assistance is allocated as a service

For seven countries, disabled people receive personal assistance as a service, in terms of an allocation of hours, rather than as a budget, or a cash payment (Portugal, Italy, Norway, Estonia, Romania, Ireland, Bulgaria).

³⁰ By this we mean a clear, up-front allocation of money that a disabled person can use to design and purchase support to meet their personal assistance needs.

³¹ Direct payments are cash payments paid directly to the disabled person, for them (or an organisation/person supporting them) to buy in their own support, rather than have it delivered by a local authority or state agency. A direct payment may form part of a personal budget.

For example, in Norway, disabled people are not allocated money or a budget, but a number of hours that they have control over in terms of when, where and how the hours are used.

Details on how things operate are less clear for this group of countries. Generally data was not available to clarify whether or not disabled people can employ family members as personal assistants under this system (with the exception of Romania and Bulgaria where this is possible).

In terms of the limits that are applied to the resources allocated, again data were mostly not available, although in Estonia there appear to be no limits on the level of resource that may be provided (up to 24 hours per day, 7 days per week), whilst on the other hand, in Portugal, personal assistance is only available for disabled employees.

In just three countries in this group (Italy, Ireland, Norway), disabled people are entitled to self-direct aspects of the organisation of their personal assistance, if they wish, and are also eligible to tailored peer-support from Centres for Independent Living or ULOs to do so.

Personal assistance is funded by individuals' benefits

In two countries, disabled people are expected to use their benefits to fund personal assistance if they want/need it (Iceland, Austria).

In Austria, 'long term care benefit' is the main source of finance for personal assistance and can be taken as a direct payment. Theoretically it can be used to buy in support, but in reality the universality of this approach is hampered by a lack of personal assistance schemes and services in many areas of Austria. Moreover, the author points out that the amount of the benefit is often too low to purchase sufficient personal assistance for effective independent living.

In Iceland, disabled people may apply for 'home support services and social support'. The authors of the Iceland report do not categorise these services as being personal assistance, however, for the purposes of fair inclusion and comparison with other countries represented in this synthesis, we have chosen to include Iceland's system under the aforementioned heading.

Disabled people are expected to pay some or all of the costs of this support, using their benefits or other financial means, depending on their financial circumstances.

4.6 Portability of personal assistance support for independent living

To what extent can disabled people have mobility as personal assistance users within their own countries, and between countries? Can people move from one part of the country to another and still receive the same type and level of help and support? Theoretically, direct payments should allow funding to follow the disabled person, rather the service provider. Does this happen in practice?

It was clear from the reports that this is a major issue for countries that are developing personal assistance services. Even in countries such as the United Kingdom and France, where legislation is in place to make the provision of health and social care nationally equivalent, there are still references to 'patchy' provision (France) and the difficulties with locally administered arrangements (United Kingdom).

In Spain, provision is also not portable between regions and the data provided shows a clear relationship between legislation and the provision of personal assistance within the country, with the Basque region which has such legislation having 77.09% of the beneficiaries and Andalucia, which does not, having only 5.51%. In addition, reports from 12 other countries (Norway, Finland, Germany, Netherlands, Sweden, Denmark, Ireland, Latvia, Lithuania, Italy, Czech Republic and Belgium) noted or implied that benefits and arrangements were not portable between different states or regions of the countries. The report authors of the United Kingdom and Finland mentioned that there were possible improvements to come, with Finland mentioning a 'checking and evaluation point' coming in the autumn of 2010 and the United Kingdom government is undertaking a consultation, 'Shaping the Future of Care Together', which includes proposals for the increased portability of assessments, although not of the services that might result from them.

In terms of aids and assistive equipment, only Norway specifically stated that this was a national service and that there were therefore no restrictions on moving to another part of the country. In contrast to this, in Sweden for example, it was stated that the provision for assistive devices was very different in different parts of the country, with some areas it being a free service, whereas in other regions there could be high charges. In countries such as Lithuania where there are 10 counties and 60 municipalities, the complexity is enormous, resulting in severe restrictions on disabled people:

Disabled people who want to receive aids and adaptations have to apply to the municipality of their place of residence bringing medical papers; a copy of an identity card; proof of address and a disabled identity card. Because of these requirements, disabled people can not move from one part of the country to another, because it restricts their opportunities to get and repair technical assistance items. (Lithuania)

The only countries that have arrangements for the portability of support for independent living were Slovakia and Austria. In Slovakia, direct payments are provided continually to disabled people who move from one district to another. The limitation to this is when a person moves to another country, and even then the support is maintained for a maximum of two months, after this the support is ended. In Austria, for people getting personal assistance support from Centres for Independent Living in the Tyrol or Vienna, as long as their permanent address remains in the Tyrol or Vienna, disabled people can stay in other parts of Austria or other European countries and take their support with them. It is not clear for how long this arrangement is valid, and has obvious restrictions in that the permanent address has to remain the same. An interesting distinction within Austria is that the Centres for Independent Living in Tyrol and Vienna are staffed by disabled people, whereas in Upper Austria, where these portability arrangements do not exist, the staff are mostly not disabled.

There were 8 reports in which this issue was not mentioned, or there was no information: Iceland, Estonia, Malta, Greece, Romania, Bulgaria, Poland, Portugal.

4.7 What support is available to family carers?

In many countries, family carers play an extensive, sometimes exclusive, role in supporting disabled relatives with independent living. What support is available to them in their role?

Full information about the support that is available to family members was rarely explicit within the reports, with none being given in regard to professionals.



Whether we can assume that this was because little or no support is available to family members in some countries and none available to professionals, it is hard to say. The report from Greece explicitly states that there is no support to family members or informal carers.

The most commonly cited form of support for family members was financial. Nine reports (Germany, Netherlands, Sweden, Slovakia, United Kingdom, Denmark, Bulgaria, France, Spain,) stated that family members could be paid directly for caring for their relative. Each country that has this form of support has different regulations. For example, in Slovakia the care has to be for a minimum of 8 hours and Sweden there are no limits and it can be used alongside other forms of support. In Bulgaria, it is more restrictive in that a personal assistant has to be an unemployed family member from a low income family. In France, the disabled person can choose whom they employ, but they are able to employ a family member if they wish. Both the United Kingdom and France reports raised the issue of a possible conflict of interest when employing family members as personal assistants.

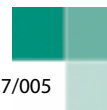
Benefits paid to family members was the other financial issue that was commonly cited (Slovakia, Norway, Finland, Germany, Netherlands, Austria, Ireland, Poland, Denmark, United Kingdom). These benefits could be in the form of direct care allowances or benefits (Slovakia, Norway, United Kingdom, Netherlands, Ireland, Poland, Portugal) or payment of pension contributions (Germany, Austria).

In the case of Austria, it was suggested that these benefits were provided to ensure that family members, particularly women, stay at home to care for their disabled relative.

Another form of support that families could benefit from was 'respite care' (short breaks). This was available in ten countries (Slovakia, Iceland, Czech Republic, Netherlands, Malta, Austria, France, Spain, Portugal and United Kingdom). Figures for the amount of respite that were provided were only given in Sweden where the allowance was 30 days per year, plus eight hours of home care services monthly and in Iceland where families could have 48 hours per month. In Austria 'family hospice leave' is available to families who care for terminally ill family members. There is insufficient evidence to determine who provides the respite care, but in some cases it is stated that it is provided by NGOs.

A variety of support services are cited in the reports, but some are vague in nature such as in the Latvian report where 'assistance or consultation about problems' is mentioned or in the Lithuanian report where there is conflicting evidence. It is stated at one point that this sort of support is not developed and does not exist but later talks about 'help and support' for families in the assessment process. The Danish report states that 'help' must be given to families but it is unclear what form this should take.

Home care services were mentioned in the reports from Slovakia, Czech Republic, Poland and Portugal. Information, advice and support were available in Spain, Belgium, Portugal and the United Kingdom. Training for family members was mentioned in the Spanish report and in Italy family members were involved in providing training. Childcare is provided for severely disabled children in Estonia and day care for older people in Portugal. There was little information given around the assessment process, except in the United Kingdom report it was noted that disabled people and their family members have a right to request an assessment under the Chronically Sick and Disabled Persons Act (1970) and Disabled Persons (Services, Consultation and Representation) Act 1986.



CHAPTER 5: ASSISTIVE EQUIPMENT AND ADAPTATIONS

In order to benefit from independent living, disabled people may often need particular forms of assistive equipment related to their impairment, they may need adapted transport, and also adaptations to their home. These are all vital if people are to be supported to stay in their own homes, rather than to live in state facilities. This chapter reports on the data from country reports about the availability of such aids and adaptations, and also the assessment procedures, eligibility and access to such equipment. All these matters are to do with the control and choice disabled people may exert over their own lives.

5.1 Aids and adaptations available

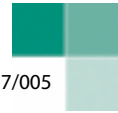
The right of disabled people to access equipment and adaptations is often enshrined in legislation that is distinct from that governing the right to personal assistance and other supports. Several country reports named particular legal instruments, which were social security or national insurance schemes (e.g. the Act of Social Security in Norway; Health and Medical Services Act in Sweden). This distinct legal framework is linked with other discontinuities in accessing equipment and adaptations.

In general, country experts' reports distinguished between technical aids which related to specific impairments (e.g. hearing aids, prosthesis, a wheelchair) and adaptations to the home, or equipment used in the home. The latter could include modifications to a bathroom, or installation of ramps. Not all country reports were complete; however, six country reports mentioned only impairment-related 'technical aids' (Belgium, Bulgaria, Estonia, France, Greece and Latvia). In some cases, country reports were explicit and said that it was *only* such functional aids that were funded. This was so for instance in Greece and Estonia.

By contrast, five other country reports only mentioned adaptations to the home or to transport (Austria, Czech Republic, Denmark, Romania and Finland) and in one of these countries at least (Romania) it was stated that it was only possible to obtain funding for accessibility of the built environment, and not access to equipment. Only a small number of reports contained details of both functional aids and home adaptations (Iceland, Malta, Netherlands and United Kingdom). However, it is very hard to know if this distinction is clear, since it may well be that the country expert reports chose to focus on one or the other domain. What can be surmised is that in general there is a distinction between a) functional, impairment related aids, and b) adaptations to the built environment. Application systems appear to be different for each of these domains, including in the United Kingdom, where impairment related aids are available as part of the National Health Service (NHS) and improvements to the home such as handrails, or home equipment such as hoists, are funded by social services.

5.2 Access to equipment and adaptations (assessment and eligibility)

In most countries in Europe, an individual disabled person who needs particular equipment has to make an application to obtain what he or she needs. In order to be successful, that application has almost always to be backed up by an assessment of their own individual need, or functional limitation. In most cases where this was specified, country reports explicitly mentioned medical assessments (Denmark, Greece, Finland, Ireland, Italy, Lithuania, Latvia, Norway, Poland, Portugal, United Kingdom). It would appear that any choice over equipment such as a wheelchair, a hearing aid, or even a personal adaptation, is overridden by a medical assessment of the functional limitation of the individual.



Some country reports specified that these assessments were indeed very much based on the medical model of disability, and for instance in Greece, the impairment assessment has to match strictly the conditions of the social security body, in order for the individual to be successful in his or her application for equipment. Some country reports (e.g. Sweden, Netherlands, United Kingdom) referred to the use of multidisciplinary teams and assessments which included input from social workers and occupational therapists, for example.

Many country reports mentioned centres, where equipment and aids could be accessed. In many cases, such centres included access to information and advice, and so were generally flagged up as good practice. In Belgium, for instance, there are 'knowledge and support' centres (KOC), which include give access to a databank of information about equipment available. In the United Kingdom, there are independent living centres, which perform similar functions.

Where social services were involved in the access arrangements, matters often become even more complicated. In Austria, for instance, the system was described as 'very chaotic', with several authorities involved. Even though social workers support individuals to apply for equipment, these workers are not independent of the sources of funding. In Lithuania, the system for application was described as 'inflexible', with applicants having to prove place of residence, and gather together medical papers and identity card, and in some other countries the system appeared to be akin to a medical lottery, with disabled people applying to funds such as the 'national insurance medical house' in Romania. Even where there appear to be better funding overall, the actual systems of application are often described as 'bureaucratic' (Norway), and are based largely on medical diagnosis, rather than on need (Greece).

In Norway, a new scheme is being piloted to avoid some of the bureaucracy involved in applying for equipment or aids. This is the 'user pass' (brukerpass), in which a person who already has access to the type of equipment in question can use the brukerpass to gain access to replacement, repairs, etc.

In practice it means that people do not need to contact the local rehabilitation system, but can go directly to the HMS and also the supplier of the equipment. (Norway)

This system has been shown to reduce the cost of administration, and also to reduce time lags in supply.

5.3 Funding and service user contribution

The exact funding available for equipment and adaptations was often not clearly stated in country reports, partly no doubt because many countries provide these services as actual physical items, rather than as grants to individuals. Even where a degree of choice is offered to service users, budget limitations are often mentioned. For instance, in Denmark, there is a special rule that hearing aids should cost no more than 728 euros, and a maximum price is set in many countries on home adaptations, vehicle purchase or adaptation and so on. In the Madrid area of Spain, for instance, the maximum grant for a vehicle is 4,000 euros, and in Ireland there is a maximum grant of 30,000 euros to cover 95% of the costs of housing adaptations, where the maximum yearly income is less than 30,000 euros. Similarly there is a maximum grant of 6,000 euros in Ireland for mobility aids.



It is impossible from the current data to provide evidence on the range of costs of equipment or adaptations across Europe.

This is partly because of the patchy information in reports, but also no doubt because budgetary limits are not always openly known. However, it would be clear from these reports that the availability of funding for equipment is extremely variable in different countries. The Lithuanian report, for example, states that:

This system restricts disabled people's possibilities to live independently and with dignity. The incomes of disabled people are low, requirements for technical assistance items are high and inflexible, and disabled people are constrained in their activities and choices.
(Lithuania)

There is clearly a concern with budgeting, and this principle overrides free choice; in order to curb expenditure, many country reports mentioned that lists of possible or recommended equipment were adhered to. This means in practice that people choosing to opt for something outside the prescribed list will have to pay the extra cost out of their own pocket. In France, for instance, if the price of an aid exceeds the social security limit, then it can be topped up Disability Compensation Benefit, but only for three years. This is also true in Norway, where equipment is borrowed, and there is a restricted list of 'approved products'. In order to obtain equipment outside this range, disabled people have to make a particular case or can 'top up' the price to choose something they particularly want.

Some country reports specifically mentioned that equipment and aids are given to individual disabled people on a loan basis, which has the advantage that they do not have to pay for their own equipment. This is the case in the United Kingdom. If equipment is provided free of charge under the NHS, it belongs to the area that supplied it. The disadvantage is then that disabled people have to re-apply to access new equipment if they move to another area.

Aids and adaptations are not normally supplied to individuals free of charge. This may happen in some countries for specific types of equipment, but nine country reports specifically mentioned means testing (Germany, Estonia, Greece, Finland, Ireland, Iceland, Poland, Slovakia, United Kingdom). In the United Kingdom, for instance, equipment that is supplied by social services for the home will be supplied by the state, but will have to be partly paid for by the individual, according to his or her ability to pay. This is the same for any social service. Other country reports occasionally mentioned quite idiosyncratic rules for supplying aids or equipment; for instance, in Iceland, service users are expected to contribute according to a means test. However, some may also have to share equipment with others, and none of these schemes are open to those living in residential accommodation (where the organisation is expected to supply the aids or equipment needed). In Greece, all eligible individuals pay 25% of the price of any aid, except if they are paraplegic or tetraplegic. There are also very specific limits to the cost covered for equipment in Greece, according to type. Thus, a manual wheelchair has an upper limit of 629 euros, a child's wheelchair 1,743 euros, and so on.

In practice, then, disabled people are often responsible for paying excesses for equipment which they need in order to be able to live independently. This will include wheelchairs, walking aids, sensory aids and adaptive equipment in the home. They may either pay in order to exercise choice, or they may have to pay as part of a means-tested grant.



5.4 Work adaptations

When a disabled person moves from home to the workplace, some of the equipment or aids they require will move with them. However, there may also be other needs that are specific to the workplace.

For instance, a person who needs a particular type of lightweight wheelchair at home may need a more sturdy one at work, or one which gives better access to other furniture in the workplace. There may also be specific needs for adaptations to computers, and a range of other work-related needs.

In nearly all of the nine reports that mention work-related needs, the systems for accessing equipment appear to be quite separate from the systems for accessing home-based equipment or aids. This appears to be so in Austria, Germany, Denmark, France, Ireland, Iceland, Italy and the United Kingdom. Norway is the only country that specifically mentions that the right to assistive equipment is the same, whether that relates to home, everyday life, work or school life.

In many countries, the system for accessing work-related aids is not only different, but is legislated for quite differently. Vocational rehabilitation schemes are mentioned in Austria and Germany, for instance, and are administered by the employment authorities. This is also the case in the United Kingdom, where Access to Work is a scheme set up under the Department for Work and Pensions, rather than the Department of Health. Some country reports mention that it is in fact easier to obtain funding for adaptations in the workplace, and in Austria, for instance, work accidents are covered by a compulsory insurance scheme.

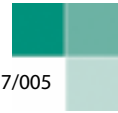
In Iceland, the task of providing equipment for work or education falls to the local Regional Office for the Affairs of Disabled people. However, those who are entitled to this assistance within Iceland are entitled to the same assistance in other member states. Thus there is an agreement within the EU, which allows individuals to cross national boundaries in search of employment.

Adaptations that are needed at work are often not the property of the individual employee, but are instead assigned to the employer. Therefore, this would provide a disincentive for a disabled employee to move jobs, since they may have to re-apply for certain adaptations, computer devices, and so on.

5.5 Portability

Where disabled people own their own equipment, such as wheelchairs, aids or even home adaptations, it is far easier for them to move to other areas of the country – or indeed abroad. This is specifically so, for instance, in Greece and Spain.

Not all country reports discussed this issue, but of those that did, it was more often the case that portability of equipment was limited. This appears to be largely because equipment and adaptive aids are supplied under regional or municipal administrative procedures. If the local area holds the grant, then individuals have to apply for assessment to that locality only. Since different localities may have differing criteria for eligibility, as well as different overall resources, a disabled individual may therefore have to re-apply for the basic necessities of his or her life, if they move to a new area.



This is specifically so in the United Kingdom, Lithuania and Belgium. However, it may well be true for most of the other countries, where regional systems of supply and assessment are mentioned.

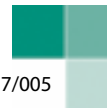
5.6 Choice and control over equipment and adaptations

To sum up, the choice and control of individual disabled people appear to be particularly restricted when it comes to equipment and adaptations that are needed for everyday life. Restrictions are imposed by a combination of different factors:

- a) There are often separate systems of application and assessment, regarding equipment and aids, housing adaptations, and general social care. All of these can be supplied under separate administrative procedures.
- b) There is a general push to control budgets available for equipment and adaptations. While the overall budget is far less than for general social care, nevertheless it is regulated in quite rigid ways in many countries across Europe. This can include the setting of fixed upper price limits for particular types of equipment, and also the use of prescribed lists of approved products.
- c) Application and assessment for functional aids may be a different process from that needed for adaptations to the home.
- d) Equipment and aids are generally supplied by local areas or municipalities, and therefore, it becomes hard for a disabled person to move from one area to another. If they do, they often have to re-apply for equipment.
- e) AT is pre-selected by authorities and there is no possibility of getting AT across member states.
- f) Workplace requirements are often dealt with separately to home-based adaptations, in regard to legislation and procedures for application.

Compared with personal assistance schemes and the general aspirations for independent living, aids and equipment seem to lag behind. The principle of choice, for instance, seems to be absent from the lists of equipment and grants supplied by many countries. If an individual disabled person requires a support service, then the principle of independent living would mean they should be informed about the alternatives, should be able to assess their own needs, and should be in control of choosing and possibly organising their own support services. However, none of these principles appear to apply to equipment and adaptations, in most countries in Europe. This discrepancy is explicitly mentioned in some reports, and it is worth perhaps ending on a comment from the Swedish report, which outlines a logical solution:

It is also worth mentioning that technical and human personal assistance exist in separate systems. You are allowed to choose and employ your assistants, but you cannot choose your wheelchair or hearing aid depending on your individual preferences. At the moment a disabled person have no right to claim any specific assistive aid or substantial influence over your assistive aids, as is the case with personal assistance. In some places in the country trials have been initiated to allow for a greater influence over the assistive aids by the user. The goal would be a similar solution with cash payments both for technical and human personal assistance. (Sweden)



CHAPTER 6: EVIDENCE OF OUTCOMES AND EFFECTIVENESS OF POLICIES ON INDEPENDENT LIVING

6.1 Research evidence relating to outcomes of independent living

There is very little evidence of research that has specifically set out to measure the outcomes of independent living, with one notable exception (Austria, see below). Several reports mention shortcomings in regard to research evidence. The Slovakian report authors acknowledge the lack of ‘systematic’ research in this area, as does the report from Spain which states that current research in this area consists of a focus only on specific aspects of good practice and literature reviews. The Portuguese report also mentions a lack of studies that evaluate the impact of policies and the French report states that ‘national indicators and qualitative assessments are still missing to show evidence that these improvements are in progress’.

Country authors have given some minor examples of research findings relating to independent living, which are mostly by-products of research about other areas. For example, a survey conducted by Repkova (2004)³² in Slovakia during 1999, to examine disabled people’s perceptions of independence, found that feelings of independence were experienced most highly by direct payments recipients, as opposed to people being supported by relatives, or by care professionals. In Finland, recent research into independent living has shown that disabled people consider their quality of life to be increasing, as is their interest in managing their own support (Eriksson 2008)³³. Other minor examples are given in the Estonian report of research relating to the employment of Personal Assistants and in the Belgian report which cites a workshop presentation on deinstitutionalisation (Jos Huys 2008)³⁴.

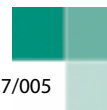
In Bulgaria, an example of an NGO conducting research in this area is given (Bulgarian Centre for Non-for-Profit Law)³⁵. A report on the regulation of community-based social services was published in 2008 that revealed numerous shortcomings of the system from the ‘start up needs assessment’ stage to the role of the service user in the service delivery process.

³² Repkova, K. (2004). *Selbstbestimmung der Menschen mit Behinderung*. Wien: Literas-Universitätverlag.

³³ Eriksson, S. (2008). Erot, erilaisuus ja elinolot – vammaisten arkielämä ja itsemäärääminen. Kehitysvammaliiton tutkimuksia 3/2008.

³⁴ Jos Huys (2008). De-institutionalization in Belgium. Presented at the workshop on “de-institutionalization and life in freedom”, at the “25 Years Independent Living in Sweden” international conference, Stockholm, Sweden, November 28-29, 2008.

³⁵Bulgarian Centre for Non-for-Profit Law (2008) *Quality of the Social Services in Bulgaria?* http://www.bcnl.org/doc_en.php?DID=484



The United Kingdom report cites a relatively extensive amount of research data relating to equipment, with reports by Williams et al (2009)³⁶, the Health and Social Care Information Centre (2009)³⁷ and Ipsos-Mori / Department of Health (2008)³⁸ being cited as well as results from Equality 2025 focus groups. In addition, an independent review of eligibility criteria for public funding of social care needs was mentioned that raises concerns about the level of support available and lack of clarity around assessment criteria (CSCI 2008)³⁹.

More significantly, there has been some recent evaluative work conducted in Austria relating to personal assistance services in Upper Austria (Bacher et al. 2008)⁴⁰ and in to the provision of personal assistance and personal budgets in Vienna (Mayrhofer & Sutterlüty 2008)⁴¹. Both studies found that that personal assistance significantly improved the quality of life of disabled men and disabled women involved in the research, and the authors recommended that it should therefore be continued and further developed. In the Norwegian report a publication by Tøssebro and Lundebry (2002)⁴² is cited which gives an overview of results of evaluations of community living that have been carried out since deinstitutionalisation. Results suggest that there have been improvements in housing standards in terms of material and social conditions, more self-determination on everyday issues and increased contact with family members.

There are 16 countries where there is either no research available, or no details given: Czech Republic, Germany, Denmark, Greece, Iceland, Netherlands, Malta, Sweden, Romania, Ireland, Poland, France, Latvia, Portugal, Lithuania, Italy.

6.2 Economic evidence - relating to costs and benefits of independent living, including any cost-benefit analysis if available

There appears to be very little published research on costs and benefits of independent living. The analysis has highlighted studies conducted by researchers in the Netherlands, Germany, France, Spain, Italy and Sweden, but these relate solely to fiscal costs/savings, rather than assessing broader benefits, including downstream costs and benefits. Clearly this is an area where there is huge scope for more significant research to be undertaken within and across member states. In the United Kingdom, although not mentioned in the report, a significant piece of research has been carried out in this area (Hurstfield et al. (2007) 'The costs and benefits of independent living')⁴³.

³⁶ Williams, B., Copestake, P., Eversley, J. and Stafford, B. (2009). *Experiences and Expectations of Disabled People: A research report for the Office for Disability Issues*, London: ODI, <http://www.odi.gov.uk/docs/res/eedp/eedp-full-report.pdf>

³⁷ Health and Social Care Information Centre (2009). *Referrals, Assessments and Packages of Care for Adults, England* <http://www.ic.nhs.uk/webfiles/publications>

³⁸ Ipsos MORI (2007). *Public Bodies' Response to the Disability Equality Duty: an audit of compliance with the requirement to publish a Disability Equality Scheme*, http://www.odi.gov.uk/docs/res/compliance-report/ded_report_2007combined.pdf

³⁹ CSCI (2008). *Cutting the cake fairly: CSCI review of eligibility criteria for social care* http://www.cqc.org.uk/db/documents/FACS_2008_03.pdf

⁴⁰ Bacher, Johann; Pfaffenberger, Monika; Pöschko, Heidemarie (2008). *Persönliche Assistenz in Oberösterreich*. Endbericht. (detailed summary in English) Internet: http://www.persoelliche-assistenz.net/forschung/fb_index.htm

⁴¹ Mayrhofer, Hemma; Sutterlüty, Marlies (2008). *Modellprojekt Persönliche Assistenz (PA) Wien*. Endbericht der Begleitforschung. Vienna: Kompetenzzentrum für Soziale Arbeit. Internet: http://behinderung.fsw.at/export/sites/fsw/behinderung/downloads/PAB_Endbericht_20080331.pdf

⁴² Tøssebro, J. & H. Lundebry (2002). *Statlig reform og kommunal hverdag*. Report, NTNU, Department of Social Work and Health Science, Trondheim

⁴³ Hurstfield, J., Parashar, U. & Schofield, K. (2007) *The costs and benefits of independent living*. ODI: London

In addition, work by Heywood et al (2005)⁴⁴ in the United Kingdom on the costs and benefits of equipment and adaptations, concludes that the impact of this type of support can be dramatic.

Of the studies where costs have been mentioned, the research in Germany concludes that allotted budgets do not cover the costs of personal assistance, especially for those with higher needs (Bundesvereinigung Lebenshilfe für Menschen mit geistiger Behinderung e.V., 2008)⁴⁵ and that because of a 'best value' approach, some people have been forced into institutional care.

In the Netherlands, researchers have estimated that the cost of financing personal budgets has risen from 1.1 billion EUR in 2006, to 1.5 billion in 2007 (Gezondheidsorg balans, 2008)⁴⁶. The data from Sweden shows an increase in overall spending on housing adaptations but the cost per grant has slightly decreased. Alongside evidence that the cost of personal assistance is less than that of local government's home help services, it would suggest that this form of support has some benefits in terms of cost in Sweden.

In general, the figures that are given broadly suggest that the cost of independent living is less than that for institutional care although there is no consistency between the countries in the collection of data or a sense of comparing 'like for like'. The French report states that there is no global data comparing expenditure on residential institutions to that spent on supporting people at home, or average cost per person, but does give figures to show a much higher spend overall on residential services than support services (in 2007, 10.3 billion EUR as opposed to 818 million EUR). The authors hope that comparative data will become available in the near future, although they recognise that it is not a priority for research at the present time.

The Spanish report gives some useful figures relating to the costs of residential support 'in a dependency situation' (17,553.96 EUR per person, per year), residential centres for disabled people 'not in a dependency situation' (12,095.03 EUR per person, per year) and supported living (7,829.72 EUR per person, per year). They also provide figures for the cost of a personal assistant working 40 hours per week of 1,000 EUR, bearing in mind that people with high dependency require an average of two personal assistants. They conclude that the figures show that, as in Germany, there are insufficient funds provided for professional assistance. The Belgian report states that the personal assistance budget in the Flemish region can vary between 8,543.24 EUR and 39,866.45 EUR per year.

According to two studies in Sweden, the introduction of support for Independent Living through personal assistance has saved taxpayers at least 29 million SEK since 1994. This is because in an open market, personal assistance costs less overall than home help services provided by public agencies (Ratzka, 2007⁴⁷; Socialstyrelsen 2008⁴⁸).

⁴⁴ Heywood, F., Gangoli, G., Langan, J., Marsh, A., Moyers, S., Smith R., Sutton, E., Hodges, M. and Hamilton, J. (2005). *Reviewing the Disabled Facilities Grant Programme* London: Office of Deputy Prime Minister & Higher Education Statistics Agency <http://www.hesa.ac.uk/>

⁴⁵ Bundesvereinigung Lebenshilfe für Menschen mit geistiger Behinderung e.V. (2008). *Das Persönliche Budget. Ein Erfolgsmodell oder doch nur ein Strohfeuer?* Marburg.

⁴⁶ RIVM *Gezondheidszorg balans 2008*, http://www.rivm.nl/vtv/object_document/o7740n34421.html

⁴⁷ Ratzka, A. (2007). *Independent Living for people with disabilities: from patient to citizen and customer*. <http://www.independentliving.org/docs7/ratzka20071022.html>.

⁴⁸ Socialstyrelsen (2008) *Personlig assistans enligt LASS ur ett samhällsekonomiskt perspektiv Rapport från Socialstyrelsen (Assistance under LASS from a socio-economic perspective)*



In addition, the Italian report briefly mentions that the cost of living independently is 1/3 of the cost of institutional living.

Finally, unpublished research by a MA student in Iceland found that support for DP in private homes is cheaper than support in group homes. When considering these figures, it should be borne in mind that the higher costs in institutions may be due to the likelihood of the more intensive support needs of these residents.

There are 17 countries where there is no research available, or no details given: Slovakia, Norway, Czech Republic, Estonia, Malta, Austria, Germany, Romania, Ireland, Bulgaria, Poland, Latvia, Portugal, Greece, Lithuania, Denmark, Finland.

6.3 Role of disabled people in research and in agreeing outcomes and outcome measures

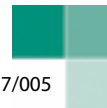
There are no clear examples in country reports of the involvement of disabled people in research relating to independent living. Considering the overall lack of research in this area, this is not a particularly surprising finding. There were several instances in the reports where it was hard to determine how far disabled people had been involved in research, with involvement being implied but not explicitly stated.

For example, in Spain, RETEVI (a network on Independent Living composed of experts from various universities from Madrid, Spain, as well as representatives of the associative movement, and the Forum on Independent Living) carries out research, which would imply that disabled people are involved in this process, but this was not made clear. Similarly, in Sweden it was strongly implied that disabled people, through the Independent Living Movement, were involved throughout all stages of provision and in Bulgaria research carried out by a Centre for independent living, Sophia, included a Disability Rights Monitor project and an Annual Disability Rights Report which suggests that disabled people were involved.

The German report mentions a consultation model that involves the German Disability Council, an association of over forty disabled people's organizations at the federal level which advocate independent living. It is widely consulted by those involved in 'official disability politics'.

There were 14 countries where no mention was made of the role of disabled people in research or agreeing outcomes or outcome measures: Netherlands, Norway, Sweden, Denmark, Romania, Ireland, Poland, France, Latvia, Portugal, Lithuania, Italy, Belgium, United Kingdom.

http://www.socialstyrelsen.se/NR/ronlyres/E188FA5F-4E0E-4449-8562-9FD8DCE0C7D0/10796/200813127_Rev1.pdf



CHAPTER 7: CONCLUSIONS AND RECOMMENDATIONS

The aim of this chapter is to provide an overview of where countries are in relation to the provision of support for independent living to their disabled citizens, and what might be done to foster progress in this area. To address the former question, we have used the information supplied in the individual national reports to locate countries on different positions of the de-institutionalisation continuum referred to in Chapter 1. The continuum, developed by Mansell et al ⁴⁹, conceptualises progress from deinstitutionalisation towards independent living in terms of how far national policies rely on segregated or institutional provision of support for disabled people, and the extent to which community options or support for independent living are available:

1. Progress towards transforming and reforming institutional care – evidence of separation of buildings and support
2. Progress towards community living - evidence of providing options and support in the community
3. Progress towards independent living – evidence of support for people to live in their own homes and have choice and control through independent budgets.

For the purposes of this report, given its focus on independent living, items 2 and 3 are the key criteria. We have loosely categorised countries, on the basis of the information they supplied to us, into five broad-brush groupings (which clearly overlap to some extent):

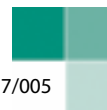
- Those yet to embark on deinstitutionalisation to any significant extent (i.e. they have yet to reach Stage 2 above)
- Those which have made some, limited, progress towards community living (i.e. they are not fully at Stage 2)
- Those showing mixed evidence on options for community living (but they have reached Stage 2)
- Those showing clear evidence of community support and some progress towards independent living (i.e. between Stage 2 and Stage 3)
- Those where policy and practice focuses on independent living (i.e. at Stage 3)

Countries yet to embark on deinstitutionalisation to any significant extent

In the **Czech Republic**, national policies do not appear to be explicit or directive enough to bring about change and effective deinstitutionalisation. There is no evidence of the involvement of the disabled people's movement in policy making or service provision, nor of the existence of personal assistance or other support for independent living. Many disabled people are still living in institutions. This situation appears to be a function of funding issues, together with some policy, and public, apathy. In **Bulgaria**, the 2008 *Deinstitutionalisation through Provision of Community Services to Risk Groups* programme funded by the EU PHARE mechanism⁵⁰ has yet to make any quantitative difference to the number of people living in institutional settings. The authors are largely critical of the few support options for community living that exist and there is no clear evidence of choice or control for disabled people.

⁴⁹ Mansell, J., Knapp, M. Beadle-Brown, J. and Beecham, J. (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European study. Volume 1: Executive Summary*. Canterbury: Tizard Centre, University of Kent

⁵⁰ EU pre-accession tool supporting preparation of candidate countries to full membership



Countries which have made some, limited, progress towards community living

In **Malta** most disabled people receive assistance from family members. Although there has been movement from a system based on needs, to one based on rights, institutional provision still predominates.

Steps towards supporting disabled people to live in their own homes have yet to be taken to any great extent. There is no move to close down existing institution and support for community living is not well developed. In **Romania** there are a significant number of disabled people within large residential institutions, in particular for people with intellectual disabilities.

Community services are still at an early stage of development. Essential services do not exist, especially for those people who become disabled at an adult age. In **Poland**, there are few opportunities for disabled people to live independently. Some NGO's try and address these gaps, but there are no significant proposals for policies or strategies to support people to live in the community rather than in institutions. In **Latvia**, progress towards independent community living has been very slow, in large part due to its financial crisis. The country is in the early stages of developing 'halfway houses' and group homes, but there are no specific strategies or policies around independent living in place. In **Portugal**, although there is an awareness of the need for autonomy and independent living, there is still a long way to go in securing this for disabled people. NGOs are said to have 'made a huge effort to promote independent living and integration in local communities'. However, obstacles remain in relation to physical access – to buildings and public spaces – and the lack of relevant evaluative research and data. In **Greece**, there has been some progress in developing options for community living, like supported housing and sheltered flats, for people with mental health problems or an intellectual disability; there has been little progress in this respect for people with physical impairments. Some community support exists, but it is very undeveloped. In **Lithuania**, families still act as the primary source of support for disabled people, while most resources are put into institutional care. There are laws that should make independent living possible, but they are incompatible with each other and this causes huge difficulties. On the positive side, disabled people are involved in some active NGOs which are the main instigators of change. Finally, in **Estonia**, there is a personal assistance scheme but this is state run. There is very little obvious involvement of disabled people in general, and community support is not well developed. There is virtually no support for family carers, the expectation being that they will support disabled people at home.

Countries showing mixed evidence on options for community living

In **Slovakia**, two new policies have set out entitlements to direct payments and personal assistance. There are also measures from social services to support community based care and recent guidance aims to focus support at community/home level. But, there is still a reliance on institutional care and insufficient safeguards for people with intellectual disabilities not to be placed in residential units. There is also some evidence of retrograde developments in moves to building more institutions and investment in upgrading existing ones. Although **Iceland** has only three small institutions, community living is still institutionalised to a great extent and the concept of independent living is not fully developed or even understood despite policy exhortations. **Finland** is in quite an anomalous situation, as it still has institutions for people with intellectual disabilities on the one hand, yet has legislated for personal assistance on the other. The question here is whether there is a lack of strategic lead on independent living as a philosophy.

Religious and charitable organisations have played a leading role in service provision in **Ireland**, and there are still a large proportion of disabled people who live in institutions or residential provision. Although some of the rhetoric of independent living is starting to appear in policy, there is a recognition that this is not matched by practice. In **France** there are still large numbers of people in institutions, but significant legislation is in place to improve quality of life for disabled people.

Major policy changes in **Spain** have occurred in recent years. These provide choices for disabled people to live independently in their own homes and in the community. However, only some groups of disabled people (still few in number) are playing a role in promoting independent living. Services with a more inclusive approach, such as personal assistance services, are insufficient in terms of the financial support available. In **Luxembourg**, there has been continued movement away from large, segregated institutions to smaller residential homes (8-12 people). The most recent trend has been to offer opportunities to people to rent or buy their own apartments.

Although residential institutions are still being supported through government agreements, they are small in size (mainly less than 30 places). But the relative proportions of disabled people in more individual, independent housing and more institutional residential care are 15% to 85%. There are no personal assistance services controlled and directed by disabled people in Luxembourg or Centres for Independent Living.

Countries in progress between Stages 2 and 3 (evidence of community living options, with some progress to independent living)

In the **Netherlands**, the idea of independent living seems only to apply to people with physical or sensory impairments. For these people, there seems to be a very medicalised access system (i.e. they have to have a professional assessment, and have very little power over their own assessment); however, once they are assessed as eligible, they can get a personal budget and decide how to spend it for themselves. There are a vast range of services and service providers, but people with intellectual disabilities and mental health needs mostly live in institutionalised settings. These may be houses in ordinary communities, but they are often owned and organised by service providers. On the positive side it appears that people in these homes may be able to choose to have a personal budget and choose their own support workers. There is a mixed message from **Italy**, where there is great variation between different regions, with some attempts to put the principles of independent living into action. Personal assistance seems to be accepted as an idea for disabled people with physical impairments, but not those with intellectual disabilities or with mental health needs. Where personal assistance exists it tends to be provided by associations and by municipalities, with very varied progress towards the involvement of disabled people and user control. In **Austria**, there is a well-established group of three Centres for Independent Living that are developing good local practice in supporting and implementing personal assistance. However, Federal and Provincial laws, and the paradigm of the medical model of disability, do not fully support these developments.

Countries where policy and practice focuses on independent living (Stage 3)

Norway has achieved almost all of the markers towards independent living outlined above. There are no institutions for disabled people.

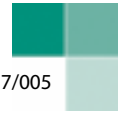
There is a well established system of support in the community, based on access to generic social services for anyone who needs them. Mostly disabled people live in their own homes with support. However, personal assistance is provided by on an hours based rather than a cash/personal budget based system.

Whilst in theory the disabled person has control over the use of these hours, in practice the municipality often decides how support and services are provided. In **Germany**, the principles of independent living and user control seem to be quite high-profile, and disabled people themselves (and their organisations) have had an impact in campaigning for independent living and changing laws. The evidence is in the number of Centres for Independent Living (now one per state), and the new right to a personal budget (2008). The articulation of the principles of user-control (e.g. what makes a personal assistance service) is faultless. However, it is very unclear how many people benefit from these provisions, and there is some worrying evidence that institutions may be on the increase. This is particularly so for people with more severe impairments, for whom the PA system does not seem to work so well.

Sweden stands out in its progress towards enabling disabled people to be fully included in the communities of their choice and its independent living movement is internationally renowned. There are no institutions in **Denmark** and the vast majority of all disabled people live independently in the community, supported via individual budgets. Legislation supports the right to live in the community, a right which can only be denied if people are deemed dangerous to themselves or to others. Only a small proportion of disabled people live in 'residences', though this number may be increasing as fewer independent options appear to be available, particularly for people with intellectual disabilities. Residences, in the form of sheltered housing schemes, appear also to be growing larger and more 'institutional' in form. This is a worrying trend.

In **Belgium**, new systems of providing budgets to individuals with disabilities are being developed. Clear procedures exist with regard to the provision of assistive devices, which are procured through close collaboration between multi-disciplinary teams and disabled people. The recent emergence of individual budgets will allow people more choice than the 'package' system that is more common with the existing personal assistance budget, when it is available. Finally, in the **United Kingdom** there has been significant movement towards policy support for independent living in recent years. The policy framework in the United Kingdom provides a range of support to allow the majority of disabled people choices to live in the community, although there are concerns about the denial of choices to some.

There is a national strategy on independent living that emphasises 'choice and control' and there are moves towards legislation on the 'right to control' over how support should be delivered to disabled people in general. There have been specific policy initiatives aimed at securing more choice and control for people with intellectual disabilities also. Recent policy development has been much influenced by the 'personalisation' of social services within a mixed economy of social care. There is evidence of a fairly rapid expansion in direct payments and individual budgets but this is not always supported by appropriate and adequately funded self-assessment and peer support arrangements and the delivery of services by disabled people's organisations remains limited, though formal government policy is to encourage this.



Final remarks

Countries who responded to the questionnaire described a very wide range of approaches to the issue of independent living. Some, as we have shown, are arguably not even at ‘first base’ in terms of progress towards deinstitutionalisation. Others have been much more successful in delivering policy and practice to support the human rights of disabled people to live in a place of their choice, with choice and control over the individualised support they require. Clearly, there are still far too few countries are in this group.

A clear issue in most country reports is the particular risks faced by specific groups of disabled people of being excluded from independent living options in practice, by virtue of restrictive laws and policies, and because of unhelpful public attitudes. People with intellectual disabilities, high levels of support needs and mental health support needs are particularly at risk here.

This report highlights the fact that independent living has a number of different components – direct payment schemes, personal assistance, options for community based support, and – critically for disabled people’s organisations, the involvement of disabled people and their organisations in the planning, delivery and monitoring of services to support independent living. We would suggest that, in addition, all countries would benefit from affirming an explicit commitment to independent living as an objective, and to setting out the steps necessary to translate this vision into practice. The principles of independent living which have been powerfully articulated by disabled people themselves (see, for example, Chapter 1) need to be at the heart of the detail. This might hopefully mitigate against a worrying trend of mixed messages in relation to continued, or new, investment in institutional care.

Reforming or remodelling institutions or institutional practices in community settings is clearly a retrograde step in any movement towards independent living for disabled people.

Definitions of personal assistance, and how it is delivered on the ground, vary enormously between different countries. Greater involvement of disabled people’s organisations is critical here, given the evidence of the low involvement of disabled people’s organisations in some countries, including some in which Centres for Independent Living exist, but which do not appear to play a role in managing personal assistance or direct payment schemes.

Of key importance, given the European commitment to enabling the free movement of workers and their families between Member States, is the significant lack of progress on transferability or portability of support for independent living between countries as the current obstacles to this constitute a significant barrier to equality for disabled workers. It will clearly be a challenge to unpick how all the different aspects of independent living – benefits, direct payments, equipment and adaptations, personal assistance – can be made transferable but the issue must be addressed as a matter of urgency if the promise of freedom of movement in Europe is to apply equally to disabled people.

Country reports highlight the importance of good data collection: robust data or statistics on the availability and take-up of support for independent living, is, with some exceptions, very poor at the moment, as is comparative data on relative investments in institutional versus community based support. Arguably, there is more research needed about the costs and benefits of specific approaches/models of support which underpin independent living.

What do we know (and what do we still need to find out) about creating the optimum conditions for independent living for disabled people to achieve real choice and control over their daily lives?

In all these areas, the sharing of information and good practice is critical, within and between countries - about what can be done, what works in practice and which approaches best support the translation of the principles of independent living into practice - especially where disabled people are at the forefront of developing these.

Why does this matter? The European Disability Forum (EDF) perfectly expresses the human rights imperative which drives the need for independent living options which disabled people and their organisations have sought for so long:

EDF firmly believes that each individual has the right to live in dignity and to be respected for the person he or she is. This implies – among other things – having the same rights and obligations as other citizens. Disabled people with diminished autonomy should have full recognition of their humanity and their right to impartial advocacy and support to ensure their access to all rights and freedoms. This is the basis for the realization of full citizenship and full inclusion in society.

Recommendations

1. **Greater use of European funding (e.g. European Structural Funds) to support the development of initiatives to foster independent living, including personal assistance schemes**

Although European funding has been used to fund pilot disability projects in the past, there is considerable scope for this to be used to promote independent living (and definitely not to support institutional care).

2. **Develop pilot strategies to increase the mobility of disabled people – within and between countries**

We have seen that there are significant barriers to mobility for disabled people within and between countries because of the lack of transferability of services and supports for independent living. This needs to be addressed as priority. There are clearly major challenges posed by this in terms of the principles of subsidiarity. But there is an urgent need to explore strategies to tackle this breach of disabled people's equality with other European workers. Options that could be explored are bilateral agreements between countries to reduce/remove barriers to freedom of mobility, as has been done in relation to other measures of social protection.

3. **Explore ways to monitor and check any trends back towards institutional living**

Some countries provided indications in their reports of a trend back towards the provision of services in institutional settings, rather than in the direction of independent living. Finding effective ways of limiting such trends will be important if progress along the continuum towards independent living for disabled people in Europe is to be made and sustained.



4. Improve the collection of relevant data

This report has highlighted the areas of data and research in which there are significant gaps. It would be easier to make improvements and progress towards independent living if we knew, for example, how much money was spent in a country on institutional provision as opposed to community based services or how much money was spent on measures to support independent living. We also need to include disabled people in setting the research agenda on independent living, to ensure the collection of meaningful data from a social model perspective. We recommend highlighting examples of countries that have managed to collect such data so that others might follow their example.

5. Sharing good practice

There is a need for exchange of views and knowledge about good practice in 'how' to make the transition from institutions to independent living - i.e. states need advice on good practice in how the process of de-institutionalisation, closure and transition, can be managed effectively and successfully (especially in countries with less experience of doing this). An exchange process could involve governments, service providers and Disabled People's organisations.

Countries can clearly learn from each others' examples of good practice; this is what the Open Method of Communication is all about. We have seen that sharing good practice is important both between and within countries. It is also valuable in relation to the options for independent living open to disabled people with different impairments e.g. the extent to which people with physical impairments and those with intellectual disabilities confront similar or different barriers to accessing their human rights around independent living and the differences in options and opportunities available to them.

6. Maximising the involvement of disabled people's organisations in the planning, delivery and monitoring of policies and practice to support independent living

The disabled people's movement is, and has always been, at the forefront of thinking about, campaigning for, and in some countries delivering, support for independent living. Their role in the provision of services such as information, advocacy and brokerage for direct payments, personal assistance, personal budgets, flexible support and Centres for Independent Living is key to the sustained success of independent living.

For this to happen, disabled people's organisations need ongoing support, including funding (where appropriate and without compromising independence) to carry this work forward and to promote best practice, based on the shared, lived experience of disabled people themselves.