

Independent living: making choice and control a reality

**An ESN report on how social services in Europe
are promoting choice and control
alongside people with disabilities**

The European Social Network (ESN) brings together people who design, manage and deliver public social services, together with those in regulatory and research organisations. We support the development of effective social policy and social care practice through the exchange of knowledge and experience.

Foreword

“ I welcome this report and ESN’s commitment to independent living. It is good to see that all countries in this ESN report have ratified the UN Convention on the Rights of People with Disabilities and have legislation contributing to independent living, through personal assistance and personal budgets.

However, it is alarming to see that the same countries are witnessing cuts in services for disabled people due to the financial crisis. Independent living for disabled people is a right under the UN Convention and services to support this should be provided. People with disabilities should not be affected disproportionately by cuts in comparison with other citizens.

Without access to services here in Sweden, I would not enjoy the full life I lead, including being able to work. I meet many people who are less fortunate. They live in institutions and want out. They have not been given a choice on where to live and with whom - many have been abandoned by family. They are not allowed to go out in the evenings; they need to check in as if they were in prison. They do not decide what they will eat or what they will do. This situation is a breach of their rights under the UN Convention.

The ratification of the Convention is just the first step - the next is implementation – that’s why we need to work with social services to design approaches that embody independent living and will make choice and control a reality for all.

The European Network on Independent Living thanks ESN for this report and the chance to participate in the ESN Spring Seminar 2013 and looks forward to further work together. ”

Jamie Bolling
ENIL Executive Director





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1. Introduction

Living independently and having choice and control over the decisions we make about how we live our lives is something almost all of us take for granted. It is important that the 80 million¹ people with disabilities in Europe today are able to exercise choice and control over their daily lives as well. People with disabilities are people with abilities, ambitions and plans.

ESN members, managers of public social services, are responsible for services for people with disabilities at local level across Europe. To varying degrees depending on legislation and funding, these services support independent living.

ESN's 2013 Spring Seminar "Choice and control for service users" (18-19 April, Helsinki, Finland) dealt with this key issue focusing on people with disabilities and long-term health conditions (up to the age of 65). ESN members' experiences show that the active involvement of people with disabilities in choosing their own services and making decisions about their care enhances their quality of life and also improves services. The UN Convention

on the Rights of People with Disabilities (UNCPRD) and the European Disability Strategy 2010-2020 seek to advance the rights of people with disabilities and to remove barriers to independent living and social inclusion in society.

This report follows on from ESN's very first published report "Towards a Peoples' Europe" (1998) on direct payments in Europe. It begins with a brief outline of the definitions of key concepts relevant to the independent living agenda. The report goes on to outline how national policy in six countries promotes independent living and the extent to which it encapsulates choice and control.

The countries are *Austria, Estonia, Romania, Sweden, Spain* and the *United Kingdom*. Particular attention is paid to personal budget and personal assistance schemes that exist in these countries. Finally, the report presents the views of ESN members on challenges and opportunities in advancing this agenda and the international and European policy context.

¹ European Commission Communication: European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe. <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52010DC0636:en:NOT>

2. Key concepts

'Independent living' and 'choice and control' are the two key concepts in this report – and they are closely related. **Independent living** concerns the ability of people with disabilities to make choices and decisions about their lives and to enjoy the same degree of self-determination as non-disabled people. **Choice and control** refers to the ability of people with disabilities to make decisions about their lives and care, notably being able to decide where, with whom and how they want to live.

There are arguably two contrasting models of care for people with disabilities. The traditional welfare model is based on **long-stay residential institutions**, where care is combined with housing, food provision and even a social life. **Person-centred community-based care** is a model which supports people with disabilities to manage their own lives: housing, care, food and a social life. We believe that independent living can be best realised and that choice and control can best be enjoyed by service users in a model of community care.

Providing service users with funds is an important step towards independent living. There are various models: **direct payments** are cash payments given to service users to buy their own services after a needs assessment has taken place. **Personal budgets** are a sum of money allocated by public authorities from different funding streams from which service users can purchase their own services. The distinction lies in the fact that 'personal budgets' are financed by different public budgets. **Personal assistance schemes** allow someone to employ a personal assistant or have a personal assistant arranged by

an intermediary. Personal assistance may be one of the main expenses funded by a direct payment or personal budget.

Self-advocacy movements involve service users organising themselves to improve their own lives and help public services to enable them to improve their lives: they have been central to the move towards independent living.

Why does independent living matter?

For service users, the concept of independent living ensures that they are able to play an active role in managing their own care. It strengthens the right for people with disabilities to the same chances in life as everybody else and promotes the right to make life decisions without undue influence or control by others. The testimony of a young self-advocate with an intellectual disability at ESN's Spring Seminar 2013 underlined how much independent living matters.

For social services, the independent living approach should mean that they are helping individuals, their families to support themselves, rather than become dependent on services. International principles of social work favour an approach where care promotes users' independence and participation. They encourage social workers to relate to each person as an individual with their own particular needs and preferences². Therefore, social services increasingly have to ensure that they are empower people with disabilities, seeing them as capable people with their own ambitions and plans, rather than as victims dependent on protection.

UN Convention on the Rights of People with Disabilities Article 19 - Living independently and being included in the community

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

² International Federation of Social Workers, Statement of Ethical Principles, updated 3 March 2012. <http://ifsw.org/policies/statement-of-ethical-principles/>

Self- advocacy: Why it is important that we know our rights and make informed choices
Martins Rullis, Self-advocate and service user, Self-Advocacy Movement, Latvia
Speech given at ESN Spring Seminar, 18 April 2013, Helsinki Finland

“ My name is Martin Rullis. I am 33 years old. I live in Riga. My life story is also a story about the changes in the lives of Latvian people with intellectual disabilities in the past 20 years. When I was small, there were no alternative services for Latvian people with intellectual disabilities. For a short time I attended a special kindergarten. Then I started to go to school. I also have experience with home education. After attending the special school, I began attending a day care centre. It was one of the first in Latvia. For me it was very important to participate in society. I did not want to sit at home alone. The staff at the day care centre were organising lot of projects to implement new services in Latvia.

In 2000 they established the Supported Employment program. One of the most important things for my life was that I want to get a job. I started to use the supported employment service. I was very interested in computers. A job coach helped me to get the status of unemployed person. And I had the opportunity to attend computer courses organized for unemployed disabled people. After the courses, I got the job. For seven years I have been working in an international telecommunications company. At first, I received a lot of help from my job coach. She talked to my colleagues about my problems and my strengths. Now my colleagues help me with any problem I have. They know when I need help and how to help me.

These last 7 years I have attended a day care centre to participate in a music group and meetings of fellow self-advocates. In 2004, our day centre created the first self-advocacy group in Latvia. I had a strong motivation to participate in this group. When I started to work together with other people, I saw that their lives and choices are different than for people with intellectual disabilities. To make decisions for ourselves, we need to have the knowledge. We learned many new things. We learned about our rights. We learned to make our first decisions, to express our thoughts. It was exciting. We soon realized that such groups should be formed elsewhere in Latvia. Therefore, we organised 2 projects, and we trained 10 groups from Latvian day centres and 6 groups from institutions. Today we have 17 active groups across the different Latvian regions. We are learning new things and then we teach our friends. We organize seminars and conferences. We talk with important people. We talk with society. This knowledge is very useful to me in my daily life. Often I have to make decisions at work. At first it was very difficult and I worried about it. Now I have more experience and making decisions no longer seems so difficult. Also, work colleagues understand now that I need time to decide and that I may need information in language which is easy to understand.

Latvia has two groups of people with intellectual disability: Those who live in families and those who live in institutions. In Latvia there are 15000 people with intellectual disabilities. About 6000 of them live in institutions. Currently the number of people with intellectual disabilities who live in institutions is decreasing. Some of them have started to live outside the institution. Two years ago, we joined a very important project. The UN Convention on the Rights of Disabled People was translated into easy-to-read versions in Latvian and Russian. This document is important for us. Before it, all decisions about our lives were made by our family or social workers, or even employees of the institutions. Now we are trying to engage in the building of our lives. It's hard, but we learn a lot. We want to be responsible for our own lives. For us it is very important to get support from other people.

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Our families need to understand that we are able to make decisions. It is very important to change people's thinking about people with intellectual disabilities in particular, employees who work in institutions. In institutions it is almost impossible to make independent decisions. So we can make the right decisions, but we need to learn and to receive the right information. Our self-advocacy groups

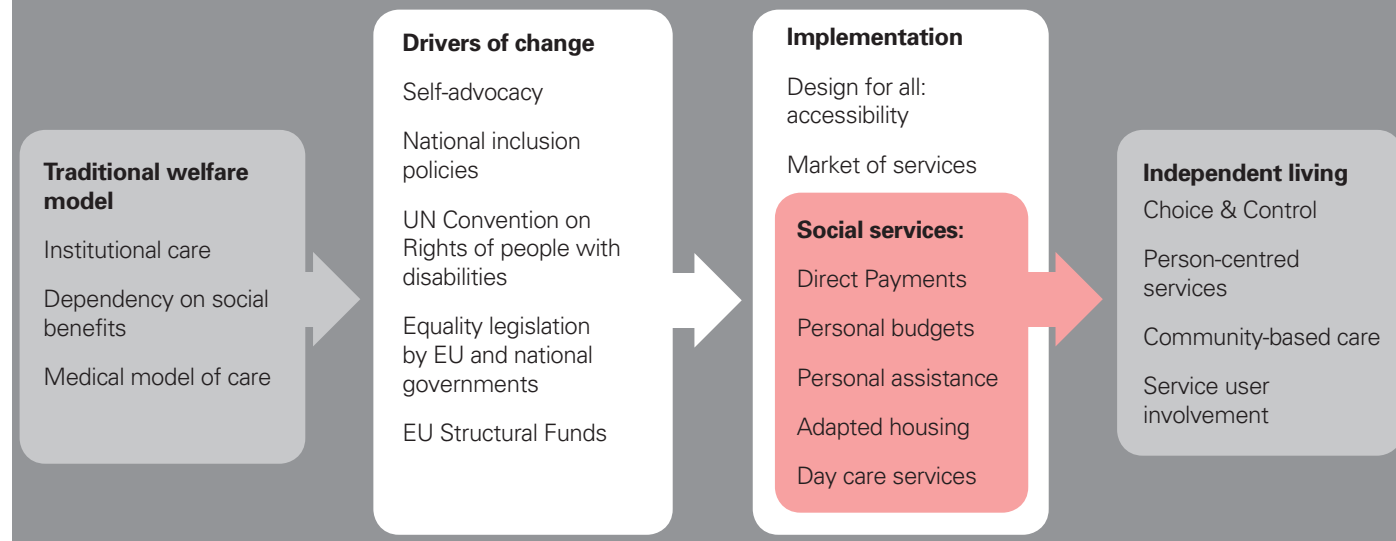
have support persons who teach us and provide support with this. But they are employees of the day care centres or institutions. Sometimes these workers change jobs. Support persons also have other duties. Each group activity is highly dependent on the institution's wishes to support such groups. Often, because of changes in staff or management, a group which was very active becomes inactive, because it is unassisted.

Since 1 January 2013 people with intellectual disabilities are able to get services of assistant, but now it's more like an assistant-companion. The opinion of our self-advocacy movement is that we need assistants in everyday issues. We have a lot of specific problems. One of them is personal budget planning. We all need help with this. We cannot be completely independent without the right support. We need to start a dialogue on the issue of personal assistance. Only we can say where we need help. It is our right. It is important for us to participate in new service development. At present, we are involved together with Inclusion Europe in a Project called „Pathways 2“. We have discussed topics like easy – to – read language and lifelong learning. In Latvia there are not enough materials in easy-to-read language and we often do not have enough information available to us. Also, lifelong learning in Latvia is very new. It has been very difficult to get into these programs. We are now talking about it with people who can change this situation. We need to learn a lot, so that we can express and justify our opinions. Poor education and lack of good support are barriers for the decision-making process. Providing quality alternative services will enable us to live independently, to be full members of society and contribute to the social, economic and political processes. ”

Making choice and control a reality

The transition from the traditional welfare model based on an institutional and more medical model of care towards the independent living approach fostering choice and control is a long-term process. People with disabilities, European and national policies, the UN Convention and EU Funds can help promote independent living.

However these legislative principles need to be implemented to ensure people with disabilities have access to a range of services and schemes which enable them to live independently, with the support of social services. The diagram depicts the process in a simplified way.



3. Independent living: an overview of policy and legislation in six European countries

The following section will look at disability policies and the promotion of independent living in six countries: Austria (Vienna), Estonia, Romania, Spain, Sweden and the United Kingdom (England). These countries were selected because they represent different welfare traditions in Europe. The short profiles are based on information gathered by ESN staff from public sources and the knowledge and experience of ESN members collected at ESN's Spring Seminar in April 2013. The profiles do not cover all aspects of a country's disability policy, but provide an overview of the policy and practice on independent living, with a particular emphasis on personal budgets and personal assistance schemes.

Austria

The concept of independent living for people with disabilities has become more present in national legislation and has been influenced by service user groups and the UN Convention on the Rights of People with Disabilities, ratified in 2008. The availability of choice between different services still depends on regional regulation and local availability; traditional forms of service provision dominate.

Overview of national and regional legislation

Although the social insurance does provide 'care allowances' (direct payments) for people with disabilities, they are at such a low level that they do not suffice for people with severe care needs to live outside an institution or their family home or to hire a personal assistant³. Needs assessment is based on a medical model⁴, focusing on physical (dis)abilities.

In addition, there is a federal scheme for personal assistance in the workplace and on the way to work - this is funded by the Ministry of Social Affairs. An assistance

conference estimates the hours of support and personal assistance service points organises the assistance. In 2010, 345 people received support at work⁵. As Austria is a federal state, the introduction of specific personal assistance schemes is a regional competence. Personal assistance outside the workplace is only provided in three federal states: Upper Austria, Tyrol and Vienna.

Personal assistance and personal budgets

Housing services and social services for people with disabilities are regulated by the nine federal states. Service providers are often well-established non-governmental organisations, some (but not all) of which are moving towards a more person-centred, community-based approach. Nevertheless, the basic structure of traditional service provision (residential care, day care etc.) has not changed and people with disabilities are rarely involved in service design⁶. The Austrian self-advocacy movement had a strong influence on independent living and non-governmental 'Independent Living Centres' actively influenced the development of legislation on personal assistance in three federal states⁷.

"All countries develop differently, as they have different cultures and structures. Therefore it is interesting to see how they each develop over time."

Jamie Bolling from the European Network on Independent Living

³ Universal Periodic Review Austria Submission of the Österreichische Arbeitsgemeinschaft für Rehabilitation (ÖAR) – Dachverband der Behindertenverbände Österreichs (ÖAR) – Austrian National Council of Persons with Disabilities for the 10th session of the UPR Working Group. (2011). <http://www.oear.or.at/ihr-recht/un-behindertenrechtskonvention/universal-periodic-review/berichte/UPRsubmissionforAustriaOEARfinal.doc>. p.5

⁴ Flieger, P., Brozek, D., Huainigg, F., Karoliny, K., Sporschill, D., Stockner, H. (2005). ANED country report on the implementation of policies supporting independent living for disabled people. <http://www.disability-europe.net/content/aned/media/ANED%20Independent%20Living%20report%20-%20Austria.pdf>. p.10

⁵ Ibid.

⁶ Ibid. p.7

⁷ Stockner, H. (2011). Persönliche Assistenz als Ausweg aus der institutionellen Segregation von Menschen mit Behinderungen. <http://bidok.uibk.ac.at/library/stockner-assistenz.html>

Personal Assistance Scheme, Vienna

The City of Vienna introduced a monthly direct payment for residents with severe physical disabilities between the ages of 18 and 65. The City sees service users as experts in their own care: they prepare a self-assessment which is followed by a joint assessment between social workers and the service user⁸. This assessment is based on the need of support, rather than on medical conditions. The service user can choose if s/he wants to employ the assistant him/herself or if a service provider does this on their behalf. More than half of recipients employ personal assistants directly.

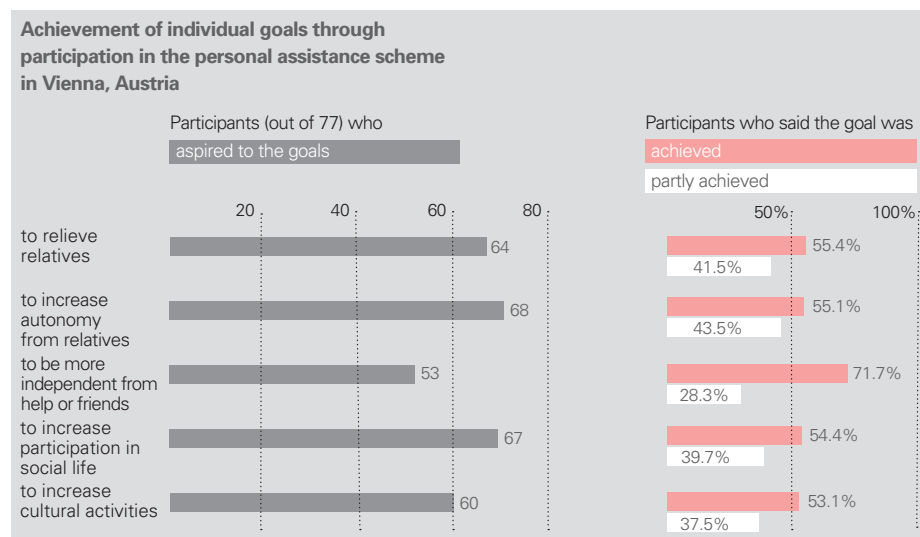
The direct payment can be up to 8000 Euro per month and the average amount per service user is currently 4600 Euro⁹. Direct payments for personal assistance are higher than in other federal states. However, the scheme is only provided to 11.7 persons in 100.000 inhabitants due to the tight eligibility criteria¹⁰. In March 2013, 215 people received the direct payment. The personal assistance scheme in Vienna involves service users and self-advocacy organisations in the design and implementation of the

service. Three non-governmental counselling centres organise peer support and provide information and training about personal assistance.

An external evaluation revealed positive impacts in terms of health, independence and ability to work¹¹. More than two-thirds of the interviewed service users are satisfied or very satisfied with the personal assistance scheme and stated that the support in terms of hours and funding is sufficient. The service users confirmed that the personal assistance scheme helped them to achieve individual goals. The evaluation also showed that the service improved outcomes, such as autonomy from relatives, more participation in social and life and better health.

Future

During the economic crisis, Austria spent more on social security contribution which was then reduced by a recovery on the labour market and there were no cuts in social services¹². In order to develop consistent national policies for personal assistance, a task force in the Ministry of Social Affairs was established in 2011¹³.



⁸ Fonds Soziales Wien (2012). Selbstbestimmt Leben mit persönlicher Assistenz. Wien

⁹ Plohovits, M. (2013). Personal Assistance in Vienna – Evaluating the Experience of Service Users. Presentation at ESN Spring Seminar 2013. www.esn-eu.org/raw.php?page=files&id=662

¹⁰ Stockner, H. (2011). Persönliche Assistenz als Ausweg aus der institutionellen Segregation von Menschen mit Behinderungen

¹¹ Mayrhofer, H., Sutterlüthy, M. (2008) Modellprojekt Persönliche Assistenz (PA) Wien, Endbericht der Begleitforschung. http://behinderung.fsw.at/downloads/PAB_Endbericht_20080331.pdf

¹² Sozialschutz in Österreich 2012 (2012). Bundesministerium für Arbeit, Soziales und Konsumentenschutz. Wien

¹³ Plohovits, M. (2013). Personal Assistance in Vienna – Evaluating the Experience of Service Users

Estonia

In Estonia, recent legislation puts a greater emphasis on independent living in all spheres of life. However, the right to choice and control is not guaranteed for everybody because of the lack of resources, especially at municipal level. The UN Convention on the Rights of People with Disabilities was ratified by the Estonian parliament in 2012.

National legislation

The Social Welfare Act of 1995 regulates support services for people with disabilities. An amendment in 2004 focuses on independent living in several services. It commits to provide equal opportunities, participation and independence for people with disabilities. It covers education, transport, employment, housing, access to public buildings and entitles people with disabilities to “appoint a support person or personal assistant, if necessary”. However, the provision of many support services is still foreseen in care homes or even hospitals and the Social Welfare Act “fails to create a sufficiently effective legal basis for individual needs to be met in the best way possible.”¹⁴

The Social Benefits Act for People with Disabilities of 2001 regulates cash benefits for people with disabilities. These benefits finance state-run rehabilitation services, which aim to increase the ability to cope independently and to strengthen the capacity for work. Almost three quarters of people participating in rehabilitation service say it has improved their ability to live independently¹⁵.

However, rehabilitation services have not increased the employment rate of people with disabilities. This may be because of a focus on medical support, rather than on independent living in its widest sense. (A person with disabilities over 65 is not eligible for these services.) During the last years, efforts have been made to increase the possibility for people with disabilities

to work. The Töötukassa, a governmental body, offers job training, assistance at the workplace and finances adoptions at the workplace.

The Ministry of Social Affairs is responsible for the implementation of the UN Convention and cooperates with the Estonian Chamber of Disabled People. Self-advocacy organisations of people with disabilities participate in the planning, implementation and evaluation of services.

Role of local government

According to the Local Government Organisation Act of 1993¹⁶ municipalities are responsible for the management and financing of support services which include transport, housing, counselling services, day care centres and personal assistance. There are many small municipalities (with as few as 200 inhabitants) in Estonia. These municipalities have problems with service delivery due to their limited human and financial resources. Larger cities like Tartu or Tallinn cooperate actively with NGOs and service users, but smaller rural municipalities do not manage to include service users and younger people with disabilities in service design.

Personal assistance and personal budgets

Personal assistance covers all areas of life, such as domestic help, assistance in education, work and transport. However, there is no coherent national provision of personal assistance because municipalities decide if they provide the service and choose eligibility criteria. The needs assessment is carried out by a municipal social care worker according to municipal eligibility criteria.

The service user is involved in the recruitment of the personal assistant and agrees together with the municipality and the assistant on the tasks. Many municipalities have limited financial resources and they can decide if the service user has to contribute up to 20% to the

¹⁴ University of Kent (2006). Deinstitutionalisation and community living – outcomes and costs: report of a European Study. http://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLCountryreportEstonia.pdf. p.10

¹⁵ TRAVORS project (2009). A review of the situation of people with disabilities in Estonia. http://www.travors.eu/download_material/subhABOUT%20TRAVORS/ENGLISH%20site/backgroundreport_estonia.pdf. p.8

¹⁶ Estonian Ministry of the Interior. <https://www.siseministeerium.ee/the-functions-of-local-government/>

service costs¹⁷. The salary of personal assistants is rather low and service users have identified a lack of support in finding a personal assistant¹⁸. Consequently, the availability of personal assistance depends on the wealth of a municipality and the size of its population.

Impact of the crisis

Since the financial crisis local authorities have had less money to spend for the provision of services and benefits. Staff expenses in the social services sector have been reduced¹⁹ which has put a stronger pressure on the provision of services. Large staff shortages in the health and social sectors have also been exacerbated by the emigration flows of the professionals westwards to other EU Member States²⁰.

Future developments

In November 2012 the Ministry of Social Affairs started work on a national development plan for protection of rights of persons with disabilities for 2014-2020. The initiative is being finalised by the end of 2013 and will aim to ensure effective and comprehensive implementation of the UN Convention and improving their abilities to live independently²¹. In addition, the Estonian Government wants to engage more people with disabilities in the labour market. According to an Estonian ESN member, the government plans a reform of employment policies for people with disabilities from 2014. This reform will be based on providing more support and benefits that enable people with disabilities to work.



¹⁷ Sakkeus, L. (2009). ANED country report on the implementation of policies supporting independent living for disabled people. http://www.disability-europe.net/content/aned/media/EE-7-Request-07%20ANED%202009%20Task%205%20request%20template%20MP_approved%20by%20author_to%20publish_to%20EC.pdf. p.9

¹⁸ Ibid

¹⁹ Ibid. p.36

²⁰ Hauben, H., Coucheir, M., Spooren, J., McAnaney, D., Delfosse, C. (2012). Assessing the impact of European Governments' austerity plans on the rights of people with disabilities. p.23

²¹ Sixth Disability High Level Group Report (September 2013) on the Implementation of the UN Convention on the Rights of Persons with Disabilities p.34. http://ec.europa.eu/justice/discrimination/files/dhlg_6th_report_en.pdf

Romania

In recent years the independent living approach has become a more widespread concept in Romania, although few services offer real choice and control in practice. There is still some way to go in the transition from social protection based on institutional care towards more person-centred services provided in the community. In March 2011 Romania adopted the UN Convention on the Rights of People with Disabilities; however it has not yet developed any comprehensive strategy for its implementation²².

Overview of national legislation

The Ministry of Labour, Family and Social Protection, the National Authority for Disabled Persons and local government share responsibility for the social inclusion of people with disabilities. The 2006 national law Regarding the Protection and Promotion of the Rights of Disabled Persons is the main legislation outlining the provisions for the social inclusion of people with disabilities and a person-focused approach to service provision. It emphasises that service users may choose their living arrangements.

The National Strategy for the Protection, Integration and Inclusion of Persons with Disabilities (2006-2013) sets out the key objectives. Its fundamental principle is that a disabled person should have freedom “to make (their) own decisions”, be able to “manage the complementary personal budget”, choose the services they use and the providers of such services “based on individual service contracts.”²³

Despite its emphasis on social integration, the National Strategy does not make explicit the requirement to replace the existing long-stay institutions with community-based services. While the Government has made a commitment to closing all institutions for children by 2020²⁴, no such commitment was made to close institutions for adults with disabilities and replace them with community-based services.

According to research conducted by the Institute for Public Policy in Romania the number of beneficiaries of community services has increased since 2007²⁵. However, EU Structural Funds have continued to be used to refurbish, extend and in some cases build new residential care facilities. While good examples do exist, they are not well-documented and are therefore not reproduced across the country.

Role of local government

Municipalities are responsible for providing, developing and financing basic social services, which aim to keep the person in the community and prevent their social exclusion. The counties are responsible for specialised social services. They are also in charge of staff training (including training of personal assistants). The National Strategy calls on the counties to prevent institutionalisation and close down or restructure current institutions²⁶, however there is little monitoring of real progress. The overall responsibility for overseeing the implementation of national disability policies from its eight regional offices across Romania lies with the National Authority for Disabled Persons²⁷.

Personal assistance and personal budgets

Social services at county level (or in the case of Bucharest - the municipality) are responsible for conducting the assessment to determine eligibility and level of assistance required. The scheme differentiates between an assistant who is a family member and a professional assistant, who is used in cases where additional professional knowledge is required (e.g. for those with sensory impairments or a person with neurological or physical disorders). The professional assistants are employed and funded by the municipality. People with disabilities do not yet have the legal basis for employing personal assistants themselves²⁸. While a so-called “complementary personal budget” does exist in legislation, in reality it is only used

²² Fifth disability high level group report (May 2012) on the implementation of the UN Convention on the rights of persons with disabilities p.83. http://ec.europa.eu/justice/discrimination/files/dhlg_5th_report_en.pdf

²³ English translation of the National Strategy on the social protection, integration and inclusion of people with disabilities for the period 2006 – 2013

²⁴ The strategy for “Steps to the reform of child protection system in Romania - challenges and progress made” was shared with the European Expert Group on Transition from Institutional to Community-based Care on 20 November 2012

²⁵ Presentation of Institute for Public Policy, Romania at Romanian National Social Services Conference, Cluj 27-28 May 2013. http://www.esn-eu.org/userfiles/Documents/News_2013/Cluj/Elena_Ercus.pdf

²⁶ Disability Online Tool of the Commission (DOTCOM) D2 De-institutionalisation. <http://www.disability-europe.net/content/romania-d2-de-institutionalisation>

²⁷ Website of Directorate for the Protection of Persons with Disabilities (DTT) in the Ministry of Labour, Family and Social Protection for the Elderly. <http://www.anph.ro/anph.php?m=anph>

²⁸ Disability Online Tool of the Commission (DOTCOM) D5, Availability of personal assistance schemes. <http://www.disability-europe.net/content/romania-d5-availability-personal-assistance-schemes>

to cover various household bills, such as radio/TV, telephone and electricity²⁹. At the moment there is not enough information publically available to allow for evaluation of the effectiveness and the take-up of personal assistance scheme.

Impact of the crisis

The economic crisis has led to the merger and often closure of social services in the public and the NGO sector³⁰. This has led to there being less choice between services for people with disabilities - service users in rural areas are often the most affected

by the curtailing of services. In many cases this has meant that families have had to provided care themselves³¹.

Future developments

The Government is currently developing a National Strategy for 2014-2020, which will replace the current disability strategy. Furthermore, the Romanian Ministry of Regional Development has recently launched a public debate about the decentralisation process and administrative regionalisation, which is likely to have some implications for social services.



²⁹ English translation of 2006 National legislation Regarding the Protection and Promotion of the Rights of Disabled Persons (Law no. 448/2006). <http://www.inclusiune.ro/content/view/23/47/>

³⁰ Hauben, H., Coucheir, M., Spooren, J., McAnaney, D., Delfosse, C. (2012). Assessing the impact of European Governments' austerity plans on the rights of people with disabilities. p.33-35

³¹ Ibid. p.53

Spain

Recent Spanish national legislation promotes the right to make choices for people with disabilities. However, the availability of different services depends on regional regulation, and budget cuts during the financial crisis have led to restrictions in service users' choices.

Overview of national legislation

There are two recent national regulations that support people with disabilities to live independently. The Act Equal Opportunities, Non-discrimination and Universal Accessibility for people with disabilities acknowledges the right for people with disabilities to make decisions about their lives and to participate actively in the community³². However, there are concerns that a greater emphasis has been put on residential care options than on community-based approaches³³.

The Act on the Promotion of Personal Autonomy and Care for Dependent Persons³⁴ (LEPA) of 2006 entitles dependant people to cash benefits and to care services options provided by public or private providers. However, a self-advocacy organisation, the Independent Living Forum, criticises that the medical focus of the Act and regrets that it does not take the social approach of article 19 in the UN Convention³⁵.

Role of regional and local government

The application of the two acts is the responsibility of the Autonomous Communities (regions with legislative powers). The actual possibility to choose between services depends therefore on the region and on local service availability. Community services are organised by the municipality, but more specialized services are organised by the Autonomous Community. Various services are in place, but there is no flexibility to combine different services. In many rural areas, services are only provided by the municipality because there is no developed private market.

Personal assistance and personal budgets

The LEPA Act entitles people with disabilities to personal assistance: personal assistants are hired for a number of hours to help service users at home, at work or in education. The needs assessment is carried out according to a medical approach based on functional capacities rather than on the need for support. A commission consisting of a doctor, a social worker and a psychologist who are appointed by the Autonomous Community, decides the level of dependency and proposes of range of services to the service user. Only people with the highest dependency level are entitled to a monthly payment for personal assistance. The regions are free to develop their own legislation for personal assistance and can set additional conditions to apply for the service.

The self-advocacy movement influenced the creation of Independent Living Projects in Guipúzcoa, Barcelona and Madrid. They offer personal assistance services, where service users are actively involved in their needs assessment, get a direct payment for personal assistance, can decide if they want to employ their assistant on their own or if it will be managed by the Independent Living Centre³⁶. These projects are also financed under the LEPA Act.

Impact of the crisis

The LEPA Act also foresaw a cash payment to family carers and for the carer to be registered in the social security system. According to ESN members, this option proved to be the best solution in rural areas where fewer care services are available. In addition, many people choose to have support from family carers and the funds were regarded as an instrument to empower disabled people and their carers. The Autonomous Communities organised training and support for family carers as well as measures that monitored the use of social benefits provided by the Act. Nevertheless, funding of the LEPA Act proved to be difficult during the financial

³² Cabrero, J. (2010). Análisis de la situación en España del artículo 19 de la Convención internacional sobre los derechos de las personas con discapacidad (diversidad funcional): Derecho a vivir de forma independiente y a ser incluido en la comunidad. <http://www.forovidaindependiente.org/node/262>. p.5

³³ Ibid. p.8

³⁴ Verdugo, M. Á., Río, C. J., Campo Blanco, M.(2009) ANED country report on the implementation of policies supporting independent living for disabled people. <http://www.disability-europe.net/content/aned/media/ANED%20Independent%20Living%20report%20-%20Spain.pdf>. p.4

³⁵ Ibid. p.5

³⁶ Foro de Vida Independiente y Divertad. <http://www.forovidaindependiente.org/node/377>

crisis, and social security contributions have been cut for family carers from July 2012³⁷. As a result, many service users had to opt for existing social services rather than home care.

Moreover, with the changes of the LEPA Act in 2012 people who have already been assessed with dependency grade III have to wait until 2015 to get the dependent status³⁸. Government funding to the regions was reduced in 2012 by between around a quarter in most regions³⁹. Although there are increasing numbers of applicants under the LEPA scheme, Autonomous Communities cut budgets for independent

living⁴⁰. The number of recipients of the personal assistance payment fell by 41% between 2008 and 2011⁴¹.

Future developments

In August 2013, the Association of directors and managers of social services reported that there were 8999 people in one month who could not be considered under the LEPA Act because they died waiting for their entitlement or their grade of dependency was lowered⁴². There are concerns that the system established by the LEPA Act based on more choice will be dismantled.



³⁷ El Pais (18 July 2012). http://elpais.com/elpais/2012/07/18/inglisch/1342622879_143861.html

³⁸ Ibid

³⁹ Hauben, H., Coucheir, M., Spooren, J., McAnaney, D., Delfosse, C. (2012). Assessing the impact of European Governments' austerity plans on the rights of people with disabilities p.58. http://www.enil.eu/wp-content/uploads/2012/12/Austerity-European-Report_FINAL.pdf

⁴⁰ Ibid. p.77

⁴¹ Ibid. p.73

⁴² La Asociación Estatal de Directores y Gerentes en Servicios Sociales. (11 September 2013). http://www.balancedeladependencia.com/La-Asociacion-Estatal-de-Directores-y-Gerentes-en-Servicios-Sociales-advierde-de-que-hay-150-beneficiarios-menos-cada_a2355.html

Sweden

In Sweden the independent living approach is implemented to a high degree, giving service users a choice of provision and control over service design. However in recent years the Government has expressed its concern with the cost of independent living and a review of national legislation is likely. Sweden ratified the UN Convention on the Rights of People with Disabilities in December 2008.

Overview of national legislation

The Support and Service for Persons with Certain Functional Impairments Act of 1994 placed emphasis on universal design and argues that people with “permanent and lasting” disabilities have the same right to participate in community life as others. It introduced the right to personal assistance, since revised by the Social insurance Act 2010.

A ten-year strategy “From Patient to Citizen: A National Action Plan for Disability Policy” was passed in 2000. Its objective was to mainstream disability policies across all sectors, to prevent and fight discrimination against people with disabilities and to ensure that the right to independent living was realised by all. A new strategy for 2011-16 further emphasised the rights of disabled people in many areas: accessibility, technology, education, employment, public health, social affairs, justice, transport, media, culture and sports.

To support the mainstreaming of disability policy the Government established a cross-Ministerial working group, involving civil servants from health, social affairs, employment, culture, justice and finance Ministries. The Swedish Agency for Disability Policy Coordination (Handisam) plays an important role in co-ordinating, monitoring and accelerating disability policy and raising awareness of the UNCRPD among service users, public authorities, politicians and other stakeholders.

Role of local government

The responsibility for service provision lies primarily with the municipalities and county councils. Under the 1994 Act, municipalities fund, coordinate and provide personal assistance for those with lower level needs. Those with more serious and multiple disabilities would be referred to the county council. Under the Social Services Act of 2001, municipal social services are required to involve service users in the design and implementation of the service plan. In addition the 2008 Act on Free Choice Systems transfers the decision over the provision of social and health services to the individual⁴³.

Personal budgets and personal assistance

Personal assistance has been a legal right since 1994 and is not means-tested. The scheme covers service users who have “permanent and lasting needs”, including physical, sensory and intellectual disabilities as well as those with long-term health conditions. Both children and adults are eligible for personal assistance allowance. This means that when the service user reaches the age 65, they are able to keep the same number of hours of personal assistance granted to them, but the number of hours cannot increase. (However people who become disabled over the age of 65 are currently not covered.) If the recipient needs more help, he or she can have additional help through the regular home-help services. In addition, people with disabilities cannot obtain the assistance allowance if they live in group housing or a residential facility.

The municipality and the national Social Insurance Agency conduct a needs assessment and determine the number of hours of assistance to which a person is entitled. Assessment takes the form of an open-ended interview with the service user and is followed up at least every two years. If a person does not agree with the result of the assessment, they can appeal to civil courts. Once the needs assessment

⁴³ Website of Government of Sweden. Social services in Sweden. Published 19 December 2011. <http://www.government.se/sb/d/15568/a/182986>

is conducted and eligibility is determined, the scheme essentially works as a kind of voucher system. Rather than allocating money to purchase services and support, the service user is allocated a number of hours per week. The municipality funds the first 20 hours, the Social Insurance Agency takes responsibility beyond the 20 hours. All service users are paid a national set amount (approximately 30 Euros per hour⁴⁴) to spend on the care they require.

The service user has a choice of providers of personal assistance, between public, for-profit and non-profit actors. According to figures from 2013 around 40% of service users employ personal assistants through their municipality, 47% through private companies, 10% through cooperatives, 3% their own company⁴⁵. The Swedish cooperative model, such as the Stockholm Cooperative for Independent Living (STIL), has an internationally recognised model for personal assistance delivery.

Impact of the crisis

Sweden is one of the few Member States which has been able to contain the worst effects of the crisis. However, due to concerns over the long-term affordability, there have been changes to the criteria in needs assessment of people with disabilities, which have resulted in less hours of personal assistance being granted.

Future developments

The personal assistance scheme is currently undergoing a review by the Ministry of Labour and Social Affairs (ending in February 2014). Discussions are focused on ensuring that future measures aiming to control the costs of personal assistance will not have a negative impact on the quality of the scheme⁴⁶. Recent reforms have seen the tightening of eligibility criteria with the introduction of age restrictions and stricter guidelines for those with higher-level needs.



⁴⁴ Presentation of Camilla Blomqvist, Municipality of Stenungsund. A voucher system of personal assistance, ESN Spring Seminar, Helsinki 18 April 2013. <http://www.esn-eu.org/raw.php?page=files&id=664>

⁴⁵ Ibid

⁴⁶ Website of the Government Offices of Sweden. Ministry of Health. Published March 21, 2013. <http://www.regeringen.se/sb/d/16823/a/212758>

United Kingdom

In the United Kingdom (UK), independent living and choice and control for people with disabilities is well-developed. Municipalities play a key role in promoting independent living agenda through a wide range of services, including personal budgets, direct payments and personal assistance schemes. However, concerns have been raised about the impact of impending reforms to disability and housing benefits on independent living.

Overview of national legislation

In 1990 the National Health Service and Community Care Act paved the way for people with disabilities to stay in their own homes, while receiving support services. The Community Care (Direct Payments) Act of 1996 introduced direct payments for people with disabilities between the ages of 18-65 and opened up the opportunity for service users to use direct payments to employ personal assistants. Originally, only people with physical or sensory impairment were eligible for direct payments. Today the legislation allows any person with a disability over the age of 16 to access a personal budget.

The next Government published an Independent Living Strategy in 2008, which set out actions aiming to improve access to housing, education, employment, leisure and transport opportunities and that they participated in family and community life. The Strategy aimed to contribute to the implementation of the UN Convention on the Rights of People with Disabilities, signed and ratified by the Government in 2007.

Role of local authorities

The National Health Service and Community Care Act of 1993 gave municipalities responsibility for the management of care, from needs assessment to delivery.

Municipalities manage a wide range of services, including personal assistance, supported housing, rehabilitative services, day care facilities, provision of equipment of home adaptations and services in conjunction with health needs. Under the 1996 Community Care Act, the power to allocate personal budgets lies with the municipality. The responsibility for some disability and social care issues now sits with the devolved administrations in Wales, Scotland and Northern Ireland.

Personal budgets and personal assistance schemes

Since the 1996 Community Care (Direct Payments) Act, adults with disabilities have been able to choose whether they take their personal budget as a direct payment, or leave local councils with the responsibility to commission the services, but still choose how their care needs are met and by whom. A third option is to have some combination called a "council-managed personal budget". An example of this is the "individual service fund", most often used for people still living in residential care. Under this kind of budget, the money is held by a care provider, but the service user is able to choose how some or all of this money is spent.

The UK, in particular England, has one of the highest numbers of personal budget holders in Europe⁴⁷. More than 400 000 people have access to a personal budget⁴⁸. As of March 2012, 53% of service users in England were signed up to personal budget scheme⁴⁹. Direct payments have traditionally had a higher take-up among younger adults, while take-up has been lower among people with mental health problems and older people with care needs.

In 2008 a national evaluation (IBSEN) on the 'individual' budget scheme was conducted after 13 local authorities across England piloted the scheme over a two year period. The evaluation found

⁴⁷ Presentation from Jos Huys, Affiliated Researcher, Institute for Social Law, Catholic University Leuven, Belgium, ESN Spring Seminar, Helsinki 18 April 2013. <http://www.esn-eu.org/raw.php?page=files&id=785>

⁴⁸ Press release of Association Directors of Adult Social Services (20 June 2012). http://www.adass.org.uk/index.php?option=com_content&view=article&id=816&Itemid=470

⁴⁹ Ibid

that personal budgets were “generally welcomed by service users because they offered more opportunity for choice and control over support arrangements than conventional social care arrangements.”⁵⁰ However, there were variations in outcomes between different groups of users. Satisfaction was highest among mental health and (physically) disabled service users, but lower with older people.

Impact of the financial crisis

In December 2010, the UK Government announced that the Independent Living Fund (introduced and extended since 1988), which supports people with severe disabilities to live independently, would be closed to new applicants. It would continue as a national scheme only until 2015, after which, local government will take over funding. However, since local government has suffered budget cuts, many municipalities are likely to tighten eligibility criteria, catering only to those with the highest needs.

In April 2013 the ‘Personal Independence Payment’ replaced the ‘Disability Living Allowance’. The new payment system continues to offer mobility support for people with disabilities and long-term health conditions between the ages of 16-64⁵¹, but based on tighter eligibility criteria. Under new rules, individuals are assessed by an independent health professional on their general mobility as well as their ability to complete a number of key everyday activities. The aim is to increase the labour market participation of people with disabilities.

Future policy developments

The Government is currently developing a Disability Strategy, which will aim to support people with disabilities to play a more active role in society. After launching a consultation, the report entitled “Fulfilling potential – Making it happen”, which recommends that people with disabilities receive appropriate support and intervention “at key life transitions” to enable them to exercise their right to education, employment and independent living.



⁵⁰ The IBSEN project (2008) National evaluation of the Individual Budgets Pilot Projects. <http://php.york.ac.uk/inst/spru/research/summs/ibsen.php>

⁵¹ Website of UK Government on the policies of all government departments. Simplifying the welfare system and making sure work pays. <https://www.gov.uk/government/policies/simplifying-the-welfare-system-and-making-sure-work-pays/supporting-pages/introducing-personal-independence-payment>

Overview of countries

	UK (England)	Sweden	Austria	Spain	Romania	Estonia
UNCRPD adoption⁵²	Yes	Yes	Yes	Yes	Yes	Yes
Role of national government	Legislation; funding for high-level needs	Legislation; funding under the Social Insurance Agency higher level needs	Personal assistance at work scheme	Legislation	Legislation	Legislation
Role of regional and local government	Commissioning, funding, needs assessment	Needs assessment, funding for lower level needs	Region: Legislation of Personal assistance Upper Austria, Tyrol and Vienna Local: Provision of services and Personal assistance in 3 regions	Region: Application of laws on independent living Local: Provision of services	Provision of services, assessment by county level	Provision; Funding
Direct payments?	Yes	Voucher system for a certain amount of care hours	Yes	Yes	No	Yes
Personal budgets?	Yes - local government	No	No	No	No	No
Personal assistance?	Yes – paid by personal budgets	Yes	Personal assistance schemes outside the workplace in 3 federal states	Yes	Yes - paid by municipality	Yes - paid by municipality
Impact of the crisis	Tightening criteria for welfare benefits; stronger link to work	Tightening of eligibility criteria	No cuts on social services	Tightening of eligibility criteria, cuts for family carers, cuts in direct payments	Merger and closure of public services with rural areas most affected	Services depend on wealth of municipality

⁵² United Nations, Convention and Optional Protocol Signatures and Ratifications. <http://www.un.org/disabilities/countries.asp?id=166>

4. Challenges and opportunities for social services

As has been seen in the above profiles, countries are at different stages in developing and implementing policy for independent living. The following draws on the knowledge and experience of ESN members – senior managers and professionals in public authorities – in promoting choice and control for service users at local level. At ESN’s Spring Seminar 2013 two key questions were explored:

1. *What challenges do social services face in the implementation of the independent living approach?*
2. *How can social services promote independent living for service users? What kind of support do they need from other stakeholders to do this?*

1. Challenges in system design and implementation

Members noted that there is a **lack of empathy** for people with disabilities and a general reluctance to spend money on independent living. Welfare systems are still based on compensation for various deficits, rather than on empowerment based on abilities and strengths. In Austria, Romania and Spain, traditional forms of service provision rarely involve service users. The **failure to involve service users** and families (where appropriate) in the design of services (e.g. for personal assistance) was seen as a serious shortcoming by ESN members attending the Spring Seminar 2013.

Legislation in most EU countries promotes independent living, but there is a serious **implementation gap**, especially in rural areas. In Spain and Austria federal structures have led to an uneven implementation of independent living. In many rural areas of Austria, Spain, Estonia and Romania, services are simply not in place. ESN members also noted that quality is at least as important as quantity: one good service that enables a person to have control or his or her

life is better than an option between several services that do not promote independence.

There is a **lack of resources** in many countries to stimulate a market that would allow users to exercise a choice between providers or to employ a personal assistant, who could help put them in control of their life. In Estonia, small municipalities do not have adequate resources to set up systems of choice and measures such as personal assistance. In Sweden and in the UK, care eligibility criteria have been tightened and budget cuts in Spain have led to a decrease in payments for personal assistance.

2. Role of public social services

Service users and professionals can work with politicians to help **shift political attitudes and priorities** towards independent living. It is important for politicians to understand the meaning of choice and control and to prevent the access to choice from only being seen as a financial burden. The involvement of service users is especially important here. Strong advocacy movements in Sweden and, to a lesser extent, in Austria led to the introduction of personal assistance schemes.

“We need to open our minds and look for more simple solutions to promote choice and control for service users. Sometimes it is better to put the complex procedure aside and simply listen to the person in front of us”.

Carlos Santos Geurrero from the Autonomous Region of Galicia in Spain

Different welfare models shape the policies that promote independent living. It has proven difficult to create change in long-established structures – such as traditional institutional and day-care – as in Estonia, Romania, parts of Spain and Austria. ESN members would like to encourage fellow managers and professionals in public and private social services alike to be **open to reform familiar structures and processes**. New service providers (including cooperatives of people with disabilities) can help ‘disrupt’ traditional provision in a positive way. The range and quality of services should be balanced and quality standards (e.g. qualifications for personal assistants) could be introduced.

Social services in local and regional authorities can **make people aware of the options and their rights** and support them to get to the point where they can make choices and feel empowered.

All stakeholders involved in that process should seek feedback from service users. Cooperation between professionals and users like ‘co-production’ in Stockport, UK, or peer support in Vienna, Austria, are good examples of the active involvement of service users.

Social services should **build partnerships** with other public services and private actors in the housing, health, education and employment sectors. This is necessary for people with disabilities to achieve social inclusion. Different funding streams could be pooled into one personal budget, as in the case of the UK’s ‘Right to Control’ pilot programme. Partnerships could also extend to employers who could help raise the labour market participation of disabled people. Cooperation with trade unions could help balance the rights of people with disabilities (and their cooperatives) as employers and of personal assistants.



5. Policy and human rights background

A wide array of international and European legal instruments and declarations aim to prevent discrimination, guarantee equal opportunities and promote independent living. They emphasise that every person, young or old, in spite of disability or illness, should enjoy the same rights and responsibilities; these rights are not negotiable and cannot be restricted or removed due to arbitrary criteria.

Article 19 of the [United Nations Convention on the Rights of People with Disabilities](#)

holds that people with disabilities have an equal right to “live in the community, with choices equal to others.”⁵³ The Convention requires that signatory States take effective and appropriate measures to ensure that the rights of people with disabilities are protected and that their full inclusion and participation in society is safeguarded. This encompasses rights for a disabled person to:

- choose with whom and where they want to live
- access a range of community support services based on individual needs
- and ensure that mainstream services are available on an equal basis to others.

The Convention also contains an ‘optional protocol’, which allows for individual complaints to be submitted to the UN’s Committee on the Rights of Persons with Disabilities.

The UN Convention has been ratified by 24 EU Member States – the exceptions being Finland, Ireland and the Netherlands. A handful of EU Member States have chosen not to adopt the optional protocol: Bulgaria, Czech Republic, Denmark, Estonia, Poland and Romania. In 2010, the European Union itself as a legal entity also adopted the Convention thereby committing itself to ensuring that all legislation, policies and programmes at EU level comply with its

provisions. Member States party to the Convention are required to periodically inform the UN Committee on the Rights of Persons with Disabilities about the measures taken to implement it.

In an effort to play its part in promoting the rights of people with disabilities enshrined in the UN Convention, the EU put in place the [European Disability Strategy](#) for 2010-2020⁵⁴. This strategy commits the European Commission to empower people with disabilities to enjoy their full rights and remove everyday barriers in their lives so that they can participate in society and the economy. To achieve this objective the Commission has identified eight areas of action, which it form its work in the ten year process:

- accessibility to services and assistive devices;
- full participation in society;
- equality and non-discrimination;
- active inclusion in the labour market;
- inclusive education and training;
- social protection against poverty and social exclusion;
- equal access to health services;
- and promoting rights for people with disabilities in EU’s external policy making

The strategy is now being implemented against a backdrop of challenges triggered by the economic and financial crisis. Its aim is to support the work of Member States by promoting awareness of ‘design for all’ approaches to products, services and environments. Access to [EU Structural Funds](#), in particular the European Social Fund and the European Development Fund, serve as additional instruments to support Member States’ efforts to develop quality mainstream and specialised community-based services, from housing, healthcare and employment to education, culture and leisure.

ESN members see the potential to invest European Funds in the development and implementation of choice and control and to use European tools and projects to promote mutual learning and practice exchange amongst local and regional authorities. The ESN Spring Seminar 2013 in Helsinki is an example of the opportunities that European funding can provide.

⁵³ Article 19 UN Convention on the Rights of Persons with Disabilities. <http://www.un.org/disabilities/default.asp?id=279>

⁵⁴ European Commission DG Justice. European Disability Strategy 2010-2020. http://ec.europa.eu/justice/discrimination/disabilities/disability-strategy/index_en.htm

6. Conclusion and next steps

The United Nations and the European Union endorse the independent living approach; national legislation has been passed in many countries. Thanks to progressive practice and self-advocacy, many disabled people do have choice and control. Yet, it is clear from this report that there is a long way to go until all people with disabilities gain real control over their lives and can live independently. There is a gap between the high legislative principles and their financing and implementation.

One of the challenges lies in the inconsistent levels of development of independent living within and between

countries. Rural areas and smaller municipalities face particular difficulties in delivering such schemes. During the financial crisis, in more advanced countries eligibility criteria have been tightened. It is also worth noting that labour market participation is still very low among people with disabilities, which means that they are more likely to live in poverty.

The next step for ESN is to launch a mutual learning process on independent living and choice and control. ESN will work with disabled people, national government and service providers to support progress in making independent living a reality for all.

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