



# TOWARDS INDEPENDENT LIVING: COLLECTION OF EXAMPLES FROM EUROPE



European Network  
on Independent Living



European  
Disability Forum

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**Back cover photo:** Jessica Linder Jansson/JAG Association. The photo shows Olof da Silva Olsson and his personal assistant.



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# Introduction

This Collection is a joint initiative of the European Network on Independent Living (ENIL) and the European Disability Forum (EDF). It features examples from different EU Member States, which to a different extent facilitate the right to live independently in the community. It seeks to promote and encourage the development of policies and measures fostering disabled people's independence, in line with Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) – Living Independently and Being Included in the Community. Its overarching objective is to ensure that disabled people can live in the community 'with choices equal to others'<sup>1</sup>.

The publication can be of assistance to a wide range of stakeholders – legislators, policy-makers at national, regional or local level responsible for the development and implementation of disability policies, service providers, organisations of disabled people and other non-governmental organisations. It can be used to identify measures and approaches supporting the realisation of disabled people's right to live independently and participate in the community.

## Independent Living

The definition of 'independent living' used in the survey is the one proposed by ENIL and adopted by the EDF Board:



"Independent Living is the daily demonstration of human rights-based disability policies. Independent living is possible through the combination of various environmental and individual factors that allow persons with disabilities to have control over their own lives. This includes the opportunity to make real choices and decisions regarding where to live, with whom to live and how to live. Services must be available, accessible to all and provided on the basis of equal opportunity, free and informed consent and allowing persons with disabilities flexibility in our daily life. Independent living requires that the built environment, transport and information are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services. It is necessary to point out that Independent living is for all persons with disabilities, regardless of their gender, age and the level of their support needs."

The right of disabled people to live independently is set out in Article 19 of the CRPD, which requires the States to '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 achieve this, they need to ensure that:

- Disabled people can choose their place of residence;
- There is a range of support options available, supporting inclusion and preventing segregation; and
- Public services and facilities are accessible for disabled people.

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<sup>1</sup> CRPD, Article 19.

Further guidance on the realisation of the right to live in community can be found in the General Comment on Article 19, adopted by the Committee on the Rights of Persons with Disabilities<sup>2</sup>.

## The examples

The Collection includes examples from ten EU Member States – Austria, Croatia, the Czech Republic, Estonia, Greece, Ireland, Italy, Romania, Sweden, and the United Kingdom. Many of them are from a survey of good practices conducted by EDF at the end of 2016 and relaunched in 2017 in partnership with ENIL. The survey aimed to gather information about national legislation, strategies and funding, community and support services, projects and experiences. Responses were received from organisations in ten countries, only five of which proposed good practices. To complement the results from the survey, other practices were identified drawing on ENIL's and EDF's experience and networks. The purpose was to ensure representation of both new and old Member States, while covering as many areas as possible.

The examples are divided into four areas, presented in different chapters:

- **Legislation and funding**

Chapter 1 includes examples of a national policy for the provision of state-funded peer support services (Estonia) and a direct payments model, piloted by a DPO (Ireland).

- **Community-based support**

Chapter 2 presents five examples of community-based services, including community support for people with mental health problems living in remote areas (Greece), personal assistance for people with complex support needs (Sweden), supported decision-making (Czech Republic), peer counselling for disabled women (Austria) and provision of housing and support (Croatia).

- **Involvement of disabled people**

Chapter 3 focuses on the involvement of disabled people in policy-making (Italy) and in the work of a non-governmental organisation through co-production (United Kingdom).

- **Self-advocacy**

Chapter 5 describes the establishment and development of an organisation of self-advocates (Romania).

All examples are analysed from the perspective of Article 19 CRPD. Their contribution to the realisation of the right of disabled people to live independently and their limitations are presented.

## Follow up

The Collection does not aim to provide an exhaustive list of examples that facilitate independent living. ENIL and EDF plan to feature additional examples online or in future collections, and would be happy to hear from anyone with a 'good practice' example. Please e-mail [secretariat@enil.eu](mailto:secretariat@enil.eu), with the subject 'Good practice example'.

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<sup>2</sup> Committee on the Rights of Persons with Disabilities (2017) General comment No. 5 (2017) on living independently and being included in the community. Available at [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en).

## Key recommendations

Based on the experience from the ten countries, a number of recommendations can be made on how to ensure the realisation of the right to live independently.

### Recommendation 1: Legislation and funding

- Access to support, such as personal assistance, should be a legal right, to ensure that all disabled people who need support can get it.
- It is important to ensure that all disabled people, regardless of where they live, have equal access to services and chances to live independently (no ‘postcode lottery’).
- Direct payment models should be introduced to allow disabled people more control over their support.

### Recommendation 2: Community-based services

- There should be a range of services available for disabled people to choose from. The development of services should not be limited by assumptions about what is best for a certain group of disabled people (e.g. group homes are the best option for people with intellectual disabilities).
- Personal assistance is a key independent living service. It should be available to all disabled people, regardless of their impairment or age; i.e. people with intellectual disabilities and children should have access to personal assistance.
- Mobile services should be developed as a way to ensure access to quality support for people living in small towns or remote areas, to prevent institutionalisation and ensure a better quality of life for disabled people.
- Guardianship laws, which deprive disabled people of legal capacity, should be abolished and supported decision-making alternatives should be introduced. This will ensure that all disabled people can exercise choice and control over their own lives.
- Peer support is one of the pillars of independent living. Its development should be supported financially by the State, to ensure that all disabled people have access to such support for as long as they need it.
- The provision of housing and support should be separated.
- Accessible and affordable housing options should be made available to disabled people in regular apartments or houses dispersed in the community. The building of group settings for disabled people (or people with low income) should be avoided, as it prolongs their segregation and isolation.

### Recommendation 3: Involvement of disabled people

- Disabled people should be involved at all levels – strategic, operational, monitoring and evaluation.
- The need to involve disabled people should be set in law, to ensure that it is implemented.
- The process should be democratic and transparent – there should be clear rules with regard to who can participate and how, and information about the discussions and decisions made should be publicly available.
- It is essential to ensure that the process is accessible for all disabled people. This might involve the provision of information in accessible formats, organising meetings in accessible places, securing sign language interpretation during meetings or other support. It may also involve providing enough time for consultations.

## Recommendation 4: Self-advocacy

- Accessible information and training about their rights should be made available to all disabled people.
- Development of self-advocacy should be supported financially by the state, as it is essential for empowering disabled people, for supporting their independence and for changing public attitudes.

## The use of ESIFs

One of the examples presented in the Collection (Estonia) involves the use of resources from the European Structural and Investment Funds (ESIFs) to develop and fund services for people with disabilities. These funds, in particular the European Social Fund (ESF) and the European Regional Development Fund (ERDF), can play an important role in promoting independent living. They can be used to fund pilot projects and comprehensive reforms supporting disabled people to live in the community. For example, they can support the development of a range of community-based services, including personal assistance and peer support, the development and testing of various direct payment models, the training of professionals delivering services, the building or renting of apartments and houses in the community and their renovation and adaptation to ensure accessible and affordable housing options are available for disabled people in the community (not in segregated complexes). For further guidance on how ESIFs can be used to support community living, see the Toolkit on the Use of European Union Funds for Transition from Institutional to Community-based Care, available in different languages at: <https://deinstitutionalisation.com/eeg-publications/>.

# Legislation and funding

## State Funded Peer-Counselling – Estonia

### Background

In 2015, the Estonian government officially recognised peer counselling<sup>3</sup> as a support service for disabled people and allocated state funding for its provision. On one hand, this was seen as a measure to advance inclusion of disabled people in society (peer counselling as a social rehabilitation service). On the other, it sought to increase disabled people's involvement in the labour market (peer counselling as a labour market measure). The resources of the European Structural and Investment Funds were also used to support the introduction and provision of the service as an employment measure.

### Description

#### Peer counselling as a social rehabilitation measure

The provision of peer counselling as a social rehabilitation measure is regulated by the Social Welfare Act, which was adopted in 2015 and entered into force in 2016. The aim of the social rehabilitation services is to enable people with disabilities to live independently and participate in the life of the community by building their skills and enhancing their motivation and self-confidence.

The service is funded by the state budget and is administered by the Social Insurance Board (*Sotsiaalkindlustusamet*). The Board is a government agency, responsible for administration of social protection services, such as pensions, family benefits, social benefits for disabled persons, rehabilitation services, special welfare services, and for the assessment of the degree of disability and additional expenses incurred.

A person wishing to use social rehabilitation services applies to the Social Insurance Board, which needs to approve their eligibility. Services are then provided by a rehabilitation service provider, based on a rehabilitation plan. The provider forms a rehabilitation team, consisting of a social worker and other specialists; for example, a speech therapist, an occupational therapist, a physiotherapist, a psychologist and a peer-counsellor. The team prepares a rehabilitation plan, together with the person, setting out the objectives of the rehabilitation and detailing the services needed to achieve these objectives. If peer counselling is included in the plan, then access to the service is granted. For people without a rehabilitation plan, rehabilitation services are provided based on an activity plan.

In order to officially work as a peer-counsellor, one needs to have a lived experience of disability and to take a short introductory course for peer-counsellors. The course covers topics such as an introduction to counselling methodology, data protection, and others.

#### Peer counselling as a vocational rehabilitation measure

Peer counselling as a vocational rehabilitation measure is co-financed by the Estonian government and the European Social Fund. It is administered by the Estonian Unemployment Insurance fund – a public body responsible for providing employment services and for paying out unemployment related benefits.

The aim of peer counselling as a labour market measure is to support disabled people in starting work or maintaining employment. It is part of a range of labour market services offered by the Estonian Unemploy-

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<sup>3</sup> Peer counselling in the area of disability involves the provision of information, advice and support from a person with a lived experience of disability to another disabled person.

ment Insurance Fund to disabled people looking for a job. Other services include working with a support person, free of charge, lending of assistive equipment needed to carry out work, adjustment of workplace and working equipment, provision of therapy and advice and other services.

Peer counselling, administered by the Unemployment Insurance Fund, is available to people with disabilities who are looking for a job and are registered as unemployed or who are currently in employment or education. The procedure is similar to the procedure set out for social rehabilitation services. A person wishing to use peer counselling, or other vocational rehabilitation service, first needs to have their needs assessed by a case manager from the Unemployment Insurance Fund. After an agreement is reached on the purpose of the rehabilitation, the person can choose a service provider from a list of approved providers. The service provider prepares an action plan with the involvement of the person. The plan needs to be approved by the Fund, before access to the service is granted. The maximum number of hours of peer counselling that a person can get is 10.

The organisations providing peer counselling as a labour market service are contracted through a public procurement procedure. There are specific requirements, set out by the Unemployment Insurance Fund, that the providers need to satisfy, for example, related to the education of the peer counsellor.

### Why this is a good example

Peer counselling is one of the key independent living services aiming to empower and build up disabled people's self-confidence. The allocation of state funding for peer support has made the service sustainable. The state funding has also allowed the service to develop and reach more people each year – since the start of the service, the number of people using it and the number of counsellors has been constantly growing. Together with this, the national coverage and the centralised funding have ensured that people with disabilities from all over the country, regardless of their place of residence, can have access to such support.

### Limitations, challenges and lessons learned

With regard to peer support as a rehabilitation service, the complicated eligibility requirements for providers of social rehabilitation are a major challenge for organisations of disabled people wishing to provide peer support. Many such organisations do not have the resources to form a rehabilitation team, in order to be recognised as a rehabilitation service provider eligible to provide peer counselling. As a result, they are excluded from the provision of the service.

Long waiting lists for social rehabilitation services is another challenge. Towards the end of each year, the budget for rehabilitation services is used up and people are put on a waiting list until the following year. While there are no separate lists for peer support, access to the service is linked to access to social rehabilitation in general and thus waiting lists become a barrier for disabled people who need peer support.

There have also been challenges regarding the provision of peer support as a vocational rehabilitation measure. For example, initially peer counsellors were required to have a higher level of education. This was a hindrance to the provision of the service as most disabled people, due to barriers in the education system, have a lower educational level. This requirement has now been revised.

A major limitation of peer counselling in employment is the cap on the number of hours of counselling. In some cases, 10 hours may be insufficient to adequately support a person.

### Further information

For more details about the peer support services and how it is organised, contact Mari Siilsalu, member of Challenge Your Senses, an Estonian organisation of disabled people, at [mari.siilsalu@gmail.com](mailto:mari.siilsalu@gmail.com).

# Direct Payments<sup>4</sup> – Áiseanna Tacaíochta, Ireland

## Background

In recent years, the Irish government has committed to moving to a new, more flexible model of service delivery. Its aim is to enable disabled people to have more choice and control over the services they use and to tailor services better to their individual needs and preferences. The goal is to ensure that disabled people can live independently and participate fully in the community. Despite this commitment, however, individualised funding has still not been introduced as a practice in Ireland. Practical support in the form of individual assistance is typically supplied by direct service providers or by family members.

The first and main organisation in Ireland to offer a Direct Payment model of personalised support to disabled people is Áiseanna Tacaíochta (from Irish - ‘Supported Facilities’). It started as a pilot project in 2010, initiated by four people with lived experience of disability who recognised the problems and inadequacies of traditional models of service provision. At present, the organisation brings together over 30 people with different impairments.

## Description

Áiseanna Tacaíochta (ÁT) supports both self-directed services, where Leaders manage their own service, and family-led services, where family members manage on behalf of a person with a disability. The work of ÁT is underpinned by the philosophy of independent living. Its mission is to provide leadership and support to empower disabled people to direct their own lives and enjoy the same equality and freedoms as non-disabled citizens.

ÁT’s model of Direct Payments aims to give disabled people control over their own budgets and services. It consists of two elements:

### 1) Acting as an intermediary

ÁT acts as an intermediary between its members (called Leaders) and the Health Service Executive (HSE) – responsible for the delivery of health and personal social services in Ireland. It negotiates a personal budget with the HSE on the person’s behalf and supports each Leader to establish and run their own company. The personal budget is transferred from the HSE to ÁT and then goes to the persons’ company account. The Leader uses their budget to choose and manage their own services, usually personal assistance. This means that each person has the opportunity to decide when and how they use their services, ensuring that this support fits in with their lives. It also means that Leaders become employers and assume responsibility for insurance and tax deductions, etc. They are required to provide monthly and quarterly financial reports to ÁT, which then reports to the HSE. In addition, both the Leader’s company and ÁT as an organisation are individually audited. ÁT also reports to the HSE on the compliance with requirements such as governance and personal assistance contracts.

### 2) Supporting people

Because running a company and managing assistants may be challenging, support is an essential part of the ÁT model of Direct Payments.

- **Circles of support:** ÁT helps each Leader to establish a personal Circle of Support to assist them with running their companies. The Circle is comprised of people from the local communities, each bringing their own skills and playing a different part in the company (for example, covering accounting, Human Resources or Health and Safety).
- **Peer Support Network:** Leaders are encouraged to engage in ÁT’s Peer Support Network – a group of disabled people and their families who support one another in pursuing their goals and living actively

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<sup>4</sup> A Direct Payment is a cash payment made directly to an eligible person to enable them to purchase and manage their own care and support services.

in their own communities. It encourages Leaders with experience in directing their own service to connect with new members, advising and mentoring them, training and upskilling them, and sharing their experiences so that success builds upon success.

- **Staff:** The staff also support Leaders, for example, by supplying resources, providing information on setting up and running a company, organising training for Leaders, Circles of Support or for personal assistants, or providing access to the Peer Support Network.

All Leaders pay a small membership fee to ÁT, which covers the costs involved in this intermediary role, as well as those incurred in supporting them with the establishment and maintenance of their company.

### Why this is a good example

A recent evaluation of the ÁT's model, carried out by the Centre for Disability Law and Policy at the National University of Ireland Galway<sup>5</sup>, showed that there have been a number of positive outcomes for disabled people, such as:

- **better level of support:** Having choice and control over when, how and for what to use their support, has allowed Leaders to overcome the numerous limitations imposed by the traditional model of service provision<sup>6</sup> and to have a better level of support.
- **better quality of life:** The choice and control over service provision has allowed Leaders to have support, which is better tailored to their individual needs and preferences and to achieve a better quality of life.
- **increased independence and confidence:** Directing their own services has made Leaders more confident and empowered, which has had a positive impact on their social relationships and inclusion.
- **better social relationships:** Leaders have built better and stronger social relationships and networks in their communities.
- **community and economic participation of Leaders and their family members:** The choice, control and confidence in themselves has permitted a number of Leaders to return to education, to take up gainful employment, and to engage in various community activities. The flexibility of support also allowed family members to return to work, something that was not possible with the previous arrangement.

The evaluation also showed that the model facilitated by ÁT offers value for money through *cost savings and cost efficiencies*. It has allowed some Leaders to stretch their budget further and get more hours of assistance with the same budget. Cost efficiencies come from savings from administration, which is done by the Leader, and from the use of varying pay scales depending on the assistants' skill levels.

### Limitations, challenges and lessons learned

Because of the lack of legal framework on Direct Payments in Ireland, the Leaders are required to establish a company in order to receive payments, which complicates the process. With the adoption of a legal framework, this model could be simplified.

### Further information

More information about the work of ÁT and its direct payment model is available in English at the website of the organisation: <http://www.theatnetwork.com/>.

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<sup>5</sup> Keogh,S.andQuinn,G.(2018)Independentliving:AnevaluationoftheÁiseannaTacaíochtaModelofDirectPayments.Availableat:[http://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/Independent-Living\\_An-Evaluation-of-the-A%CC%81iseanna-Tacaí%CC%81ochta-model-of-Direct-Payments.pdf](http://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/Independent-Living_An-Evaluation-of-the-A%CC%81iseanna-Tacaí%CC%81ochta-model-of-Direct-Payments.pdf)

<sup>6</sup> The evaluation provides numerous examples of limitations imposed on people using the traditional model of service provision. For instance, one person was regularly put to bed at 8 o'clock with a sleeping pill as there was no assistance provided after that time; another was not able to help their child button up – an activity that parents normally do – as the provider would not allow it.

# Community-based services

## Peer-Counselling for women with disabilities – Zeitlupe, Vienna, Austria

### Background

Peer counselling was first available to disabled people in Vienna in 1992, when BIZEPS – a Centre for Independent Living – started a peer-counselling service<sup>7</sup>. In the following years, as peer counselling proved to be a powerful tool for empowerment of disabled people, other such services appeared. However, most of them did not offer counselling by and for women and thus failed to address properly the specific issues faced by disabled women.

Being a woman and disabled often means facing two types of barriers – sexism and disability discrimination. They tend to reinforce each other, making it even harder for disabled women to participate in the community on an equal basis with others.

### Description

The first and only peer counselling service for women with all kinds of impairments in Austria – Zeitlupe – was founded in 2012 in Vienna with the financial support of the City of Vienna, which continues to be its only funder (Fonds Soziales Wien). The initiative for its creation came from ‘Ninlil’ – an organisation of women with and without disabilities working to prevent sexual violence against women with intellectual disabilities and to support victims of such violence. After an agreement was reached with the City of Vienna about the need for such a service, the Board of Ninlil engaged Elisabeth Löffler – a disabled woman and an activist – to set out the parameters and develop the service. She became the first director of Zeitlupe. At present, the staff of Zeitlupe consists of two peer-counsellors. One of them is also the director of the service, responsible for its development and day-to-day management.

The name of the centre – ‘Zeitlupe’ – translates into English as ‘slow motion’ – an effect in filmmaking, where the action appears to slow down. In Zeitlupe’s approach this is used to mean:

- Looking closely at what you are currently doing;
- Taking time to discover new possibilities;
- Giving yourself time to choose between different possibilities.

Zeitlupe provides consultations on topics ranging from personal assistance (for example, funding, organisation and day-to-day management of assistance) to various topics concerning ‘being a woman with a disability’, such as, motherhood, housing, social contacts, relationships, sexuality, funding for different support needs.

The format of consultations is flexible – face-to-face, telephone or email, the latter being mostly for specific questions and answers. Women can also choose the setting in which the consultation takes place – at the office of Zeitlupe, at their home or even in an institution, if necessary. This flexibility allows women who are not able to leave the place they live, to get access to information and support.

Information and advice is mostly provided to women and girls with disabilities. However, it is also available to family members and friends and to people working with disabled women who wish to support their empowerment in certain areas.

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<sup>7</sup> See BIZEPS’ website (in German) <https://www.bizeps.or.at/>

To ensure the quality of the service, Zeitlupe requires that all counsellors, apart from being disabled women themselves, have previous knowledge of and experience with providing peer support. The counsellors also have access to regular interventions and can attend individual supervisions every two weeks and team supervisions every one or two months.

In addition to providing peer counselling, Zeitlupe works actively to raise awareness on both disability and women's issues among organisations active in these areas. The Centre maintains regular contacts with the Independent Living Movement in Vienna (organisations such as "BIZEPS", "WAG" and "Selbstvertretungszentrum") and is also involved in networks of counselling centres for women (for example, "Netzwerk österreichischer Frauen- und Mädchenberatungsstellen"). One of the results from this work is that the visibility of women-specific issues within the Independent Living Movement in Vienna has improved and there has been more focus on women's issues.

### **Why this is a good example**

The peer counselling provided by Zeitlupe contributes to disabled women's empowerment by helping them address the double barriers they face. Women are supported to live independently, to be more assertive and stand up for their own goals and beliefs and for their rights as both women and disabled individuals.

### **Limitations, challenges and lessons learned**

A key challenge is the limited community-based support available to disabled people in their everyday lives. Peer counselling has the potential to empower people. However, if basic support for independent living is not available (for example, in Austria, it is not legally binding for the authorities to provide adequate funding for personal assistance for disabled people), peer counselling alone cannot create the conditions for independent living and full inclusion.

The main limitation is that Zeitlupe's services are only available to people living in the City of Vienna. As Zeitlupe's experience has demonstrated that peer counselling for disabled women is both needed and useful, it is important to ensure that such services are available across the country, not only in one municipality. It is also important to ensure flexibility when it comes to the format and the setting in which the service is provided to allow more people to access it.

### **Further information**

More information about the work of Zeitlupe is available in German on their website <http://www.ninlil.at/zeitlupe/index.html>. You can also contact Marinela Vecerik, director of Zeitlupe at [vecerik@ninlil.at](mailto:vecerik@ninlil.at) or Elisabeth Udl, director of Ninlil, at [udl@ninlil.at](mailto:udl@ninlil.at).

# Supported living for adults with intellectual disabilities – Association for Promoting Inclusion, Croatia

## Background

In Croatia, many adults with intellectual disabilities live in long-stay residential institutions, because of the lack of community-based services and the inaccessibility of mainstream services, such as education, employment and housing. In response to this, the Association for Promoting Inclusion (API) was established in 1997, with a mission to promote deinstitutionalisation of adults with intellectual disabilities and to provide the support needed so that they can enjoy their right to live in the community, on an equal basis with other citizens. API provides support through organised housing, which is a part of the network of state-funded services, overseen by the ministry responsible for social welfare.

## Description

API provides organised housing for adults with intellectual disabilities in the mainstream housing in the community – in rented apartments or apartments owned by the service user. There can be between 1 and 5 persons in a single apartment, depending on the preferences of the service users and their support needs. At the moment, organised housing is provided in five cities (Slavonski Brod, Osijek, Bjelovar and Grubisno Polje, Zagreb and Sibenik).

A person who would like to move into organised housing can directly, or through their parent/guardian, contact the local Centre for Social Welfare, which needs to approve their eligibility for the service. The cost of this service can be covered by the responsible ministry, depending on the material status of the person concerned or their family members. The person can also choose to pay for the service of organised housing, by entering into a contract directly with API.

In organised housing, the person can be provided with support in the following areas: self-determination, household chores, community activities, health and safety, free time, making, maintaining and expanding relationships with other people, employment, and life-long learning.

The aim of the support is to enable the person: to decide where and with whom they will live; to have privacy and to feel at home in their own apartment/house; to decide what they will do during the day; to choose where they would like to work, or in case they are retired, how they would like to spend their day; to use the same services and facilities where they live as other people; to have the opportunity to continue learning; to have meaningful relationships with their family, friends and partners; to take part in deciding who supports them; to receive support adapted to their age; to advocate on their own and others' behalf; to decide how they will be supported; to live a self-determined life.

There are three types of staff working in organised housing – leaders, advocates (mostly rehabilitators, social workers, psychologists or occupational therapists) and assistants. Advocates are involved in person-centred planning, and are responsible for arranging the necessary support. Assistants support the person in their daily activities in the apartment and outside. Leaders (managers) are responsible for managing the staff and finances, and are also involved in directly supporting the person.

Each person has a person-centred plan, which they take part in developing. The level of support is determined by the person-centred plan and varies – it can be occasional, limited, intensive or comprehensive. Occasional support is provided if the person is very independent and only needs support from time to time. In this case, it may be provided by an advocate. Limited support refers to continued support, but restricted to specific activities (for example, support with shopping, with getting to work or taking medication). Such type of support is provided by an assistant. Intensive support refers to daily support with a range of activities, and comprehensive support to 24-hour support in the apartment and outside. Support can be flexible, depending on what is happening in a person's life. Importantly, the person with intellectual disabilities and those close to them are involved in managing the support.

## Why this is a good example

The service provided by API allows adults with intellectual disabilities, some of whom have spent years in institutional care, to live in the community, to form relationships, to work, and to get married if they like. In addition to benefits for them, there are also benefits for the wider community – people with intellectual disabilities become neighbours, employees and friends. This service also allows those living with their family to stay in the house or apartment, once their parents become old or pass away. This would not be an option otherwise, considering that personal assistance in Croatia is very limited and is provided only to persons with physical impairments.

## Limitations, challenges and lessons learned

One limitation of the service is that some people are still under guardianship, given that supported decision making still does not exist in Croatia. This can limit their ability to make decisions and to receive a salary, for example.

A major challenge for the service of organised housing provided by API (and other private non-profit providers) is the limited funding provided by the State per person. This funding has been capped to 5,300 HRK per person/per month, and is considerably lower than that available to State providers (which ranges between 8,000 – 10,000 HRK per person). Out of this amount, API has to cover all the costs of housing and supporting an individual, which presents them with considerable challenges. It also means that the staff working in their service are paid less than those working in state-run services, which makes it difficult to recruit and keep them.

Another challenge is the availability of organised housing in Croatia. Even though it is part of the service offered funded by the State, it is still limited to a small number of people. Many adults with intellectual disabilities living in institutions are not able to access organised housing, because they are too old, have very high support needs or the service is not available where they live.

Finally, even though there is some flexibility in the service (i.e. people can change flat mates or apartments if they are not happy), should they choose to leave the service of ‘organised housing’ altogether and move into their own apartment, they lose the right to support. This is because, in Croatia, funding does not follow the person and there is very limited access to personal assistance.

## Further information

Details about the supported housing service are available in English and Croatian on the website of API at <http://inkluzija.hr>.

# Supported Decision-Making – Quip, The Czech Republic

## Background

Until 2013, the use of both full and partial guardianship for people with intellectual disabilities and mental health problems was allowed in the Czech Republic. Full guardianship was extensively used for people with intellectual disabilities – around 25 000 people were under full guardianship and 5 000 under partial guardianship. In line with the CRPD requirements, in 2013, full guardianship was abolished and a larger range of less restrictive options was introduced. There was, however, a lack of understanding and practice concerning supported decision-making. To address this problem, the Czech organisations Quip and the Association for support of people with intellectual disabilities and their families (Inclusion Czech Republic) started a project called ‘Black and White’.

## Description

The ‘Black and White’ project was started in 2012 with the financial support of the Open Society Foundation and is still being implemented. It aims to support the shift towards a human rights-based approach to disability by building the capacity of individuals and organisations in the area of supported decision-making. It combines activities in the social and legal area, seeking to support disabled people to live independently.

In the social area, the project focuses on introducing and promoting practical methods to work with people with intellectual disabilities and mental health problems based on the principles and tools of Person-Centred Planning. Specific activities include:

- development and testing of methods to work with people with intellectual disabilities and mental health problems and their families;
- training of social workers and other professionals on the new methods;
- creating a pool of “community connectors” – people trained for and able to create and nurture support networks in different parts of the Czech Republic;
- development of a national model of circles of support to ensure sustainability of project results;
- collaboration with universities and municipalities in the development and testing of the circles of support method;
- capacity-building of activists (self-advocates, family members, people with mental health problems) to promote supported decision making.

In the legal area, the project focuses on building jurisprudence on legal capacity and supported decision-making. Activities include:

- analysis of legislation and individual case studies of people with intellectual disabilities and drafting a report ('Black book');
- strategic litigation towards reforming legal capacity jurisprudence;
- providing individual assistance to people, in order to restore or maintain their legal capacity, using less restrictive measures and a structured system of support.

In addition, the project includes activities aimed to raise the awareness of people with intellectual disabilities and mental health problems, their families and professionals (doctors, judges, school and social services staff). It focuses on an alternative model of exercising legal capacity, personalized support for people with intellectual disabilities and mental health problems in decision-making and exercising legal capacity, and the myths concerning the guardianship law (pre-2013). The key players at national level (Ministry of Justice, Ministry of Labour and Social Affairs, Constitutional Court, Ombudsman) were also informed about the findings documented in the Black Book and the proposed method for support networks.

## Why this is a good example

The Black and White project introduced and promoted practical person-centred methods to support disabled people in decision-making and exercising their legal capacity. Person-centred planning is still a new approach in the Czech Republic and these practical tools, together with the experience accumulated, can help ensure that supported decision-making does not turn into substitute decision-making. In addition, within the framework of the project, a number of disabled people were successfully supported to restore their legal capacity and to have more choice and control over their lives. The analysis of the court proceedings helped to identify existing legal and structural barriers to restoration of legal capacity and/or to practical exercising of legal capacity after its restoration. It showed that it is important to combine measures supporting restoration of legal capacity with measures supporting independent living and inclusion.

## Challenges, limitations and lessons learned

Institutionalisation poses a key challenge to the restoration of legal capacity. In the Czech Republic, to be able to restore their legal capacity in full, one should have a support network – relatives and persons living in the same household – who can provide support with decision-making. People living in residential institutions have often lost contact with their friends and family and therefore cannot rely on such informal support. In principle, they could have their legal capacity restored only by using professional support from a public guardian or, possibly, from support services provided.

Another major challenge comes from the lack of support to implement decisions and legal actions. For example, even if a person with legal capacity chose to leave the residential institution, they would not be able to get support with finding housing, the means to pay for it or to cover basic living expenses. As a result, many people, even with support from relatives, often choose not to seek to restore their legal capacity, since it does not provide them with more options, in their view.

Last but not least, traditional paternalistic attitudes of key stakeholders – families, service providers, local authorities, professionals and courts – have also been a challenge.

The main lesson learned is that to facilitate restoration of legal capacity and independent living in the community, it is essential to ensure that adequate support is available both when it comes to decision-making and to the implementing the decisions. For example, it is important to encourage the establishment of organisations that can provide support for people who do not have informal support networks. It is also important to ensure that there is a range of different types of support available in the community and that services for the general population, including housing, are also available to disabled people.

## Further information

More information about the use of person-centred planning and supported decision-making in the project is available in English at: <http://www.kvalitavpraxi.cz/res/archive/033/004199.pdf?seek=1527586582>.

An analysis of the legal cases of legal capacity restoration and the use of supported decision-making is available at: <http://www.centreforwelfarereform.org/library/by-az/legal-capacity-restoration-quip.html>

## Mobile Mental Health Units – Greece

### Background

People with mental health problems living in remote areas of Greece, islands and mountains, were previously often placed in large-scale psychiatric institutions, away from their homes and communities. This was a consequence of the lack of adequate and timely psychiatric support in these areas. To address this problem, the Society of Social Psychiatry and Mental Health (SSP&MH) started a pilot project in the Fokida prefecture in the 1980s, introducing Mobile Mental Health Units. The project turned out to be a success in terms of both impact and cost-effectiveness. As a result, mobile psychiatric units were included in Law 2716/1999 concerning the development and modernisation of mental health services. They became the cornerstone of mental health service provision in Greece, especially in small and remote areas. At present, there are 25 Mobile Psychiatric Units all over Greece.

### Description

Overall, Mobile Mental Health Units (MMHU) seek to facilitate access to mental health services in community for people living in remote areas. They work in two main areas – prevention and rehabilitation of mental health problems and community awareness raising. The specific services offered depend on the needs of the population in the area.

The Society of Social Psychiatry and Mental Health runs two MMHU units – in Fokida and Thrace prefectures. The services they provide include prevention, diagnostics, treatment, social and vocational rehabilitation, counselling, managing crises and acute crises, monitoring and follow-up, and family support.

The staff of the MMHU consists of professionals in various areas, such as psychiatrists, psychologists, social workers, psychiatric nurses, health visitors, occupational therapists, speech and language therapists, art therapists, but also unqualified yet trained personnel, mainly coming from the community.

Teams of professionals from the MMHU regularly visit the area, for which they are responsible, to provide support. Support can be provided at the home of the person or at another community service – for example, the Community Health Centres or General Hospitals (Psychiatric Units, Mental Health Centres, and Health Centres). There is close cooperation between the MMHU and the General Practitioners working at these services.

When needed, home visits are also carried out to minimise or prevent the risk of institutionalisation. These visits can include provision of direct support to the person, for example to deal with and manage the crisis, and to their family, carers and neighbours, if needed.

In addition to providing direct psychiatric and psychological support, the MMHU supports people with mental health problems to deal with practical daily living problems and improve their independent living skills.

At the request of the person, the MMHU can also establish contact with other important people and institutions, such as family members, employers, and priests, to provide information, mental health education or support.

Awareness raising and community education on mental health issues is another important area of work of the Mobile Mental Health Units. It seeks to address the negative social attitudes towards mental illness and thus to prevent stigmatisation of people with mental health problems. It also aims to ensure that the local community accepts and cooperates with the rehabilitation team.

### Why this is a good example

By putting an emphasis on outpatient support in the community, MMHU have played a key role in the process of deinstitutionalisation of mental health care in Greece. The services MMHU offer allow people with mental health problems to remain in the community – to continue to live in their homes, near their families

and friends, to work, to engage in social activities and lead independent lives, instead of being institutionalised. At the same time, the awareness raising and preventive work of the Units helps address the prejudice and stigma related to mental health, thus facilitating the inclusion of people with mental health problems in the community.

### **Challenges, limitations and lessons learned**

One of the main challenges is the cultural diversity of the regions and the need to ensure that all groups have equal access to services and are supportive of the work of the MMHU. To address this challenge, the staff of mobile units actively seek to engage members of different community sub-groups in their work. They started with awareness raising activities aimed at ensuring the support of key people and the community as a whole, before establishing crisis prevention and introducing other activities. This simultaneous work on promotion and rehabilitation helped create a sense of ownership in the local community. The community supported the work of the MMHU because they felt that the needs of the local population were being met.

### **Further information**

More details about the work of the Mobile Mental Health Units is available in English and Greek on the website of the Society of Social Psychiatry and Mental Health at <http://ekpse.gr>. For more information, contact Athina Fragkouli, Vice President of the Society of Social Psychiatry and Mental Health, at [ekpsath@otenet.gr](mailto:ekpsath@otenet.gr).

# Personal Assistance for People with Complex Support Needs – JAG, Sweden

## Background

In 1994, Sweden adopted a Personal Assistance Law, making the receipt of personal assistance a legal right for all disabled people. Personal assistance can be purchased through earmarked cash allocations paid to disabled people, the purpose of which is to pay for the assistance needed. Each disabled person can apply for assistance. After application and acceptance, they are granted a certain number of hours of personal assistance per week. The assistance user can then choose how the assistance is provided – by the municipality, by a user cooperative or by an assistance agency. They can also decide to employ their assistants directly and become an employer.

## Description

JAG is a national, not-for-profit association working on issues related to personal assistance and anti-discrimination. All of its members have intellectual disabilities and, with few exceptions, extensive physical impairments. Many may not have speech.

JAG was founded in 1992 by a small group of people with complex support needs. When the Swedish personal assistance law was adopted, JAG started a user cooperative – a non-profit co-operative of personal assistance service users.

JAG has developed a model personal assistance service for people with intellectual and multiple disabilities that allows users to have choice and control over their assistance. This is achieved through a system of supported decision-making with the involvement of a ‘good man’ (trustee) and the support of a service guarantor. The service is available to both children and adults.

### a) ‘Good man’ (trustee)

According to the Swedish legislation, people who need support to take actions or make decisions are entitled to a trustee – a relative, acquaintance or an independent person. The role of the trustee is to help the disabled person take care of their personal affairs, including finances, and to protect their rights and interests. The trustee should be able to understand and interpret the person’s communication well and should not make decisions against the will of the person.

The trustee supports the person in:

- applying for personal assistance and choosing a service provider;
- appointing a service guarantor and working with them;
- monitoring the service, to ensure that it meets the standards agreed, and
- ensuring that assistance is delivered in a way that is respectful of the disabled person, including recognising their personal integrity.

### b) Service guarantor

If a member of JAG is unable to manage or supervise their assistants, they can have a service guarantor. This can be their trustee or another person.

The role of the service guarantor involves:

- leading and coordinating the personal assistance package according to the individual preferences of the member, including: recruiting assistants, instructing and supervising assistants, putting together schedules, filing reports and providing the data needed under the employer’s responsibility to JAG;
- ensuring that the JAG member gets the assistance they are entitled to;

- ensuring the continuity and safety of the assistance. In cases where personal assistants are not available, the service guarantor must provide assistance themselves.
- ensuring that assistance provided respects the integrity and the dignity of the person.

The position of service guarantor is voluntary. Members of JAG can choose to remunerate the service guarantor (a certain amount per hour) if their assistance grant can cover it. However, the service guarantor's responsibilities must be carried out with or without remuneration.

An agreement is signed between JAG and the service guarantor, setting out their responsibilities. JAG provides on-going support to the service guarantors, which can include information concerning labour law and employment contracts, advice when hiring assistants, and training.

### **Why this is a good example**

The JAG model allows people with intellectual disabilities using personal assistance to have choice and control over their support. They can decide what kind of assistance they need, who, where, when and how it will be provided. In addition, being in charge of the support enables users to be more independent and have more control over the way they live their lives, including where and with whom to live.

The outcomes so far show that JAG's members' physical and mental health has improved substantially, as they get the personalised service they need, by assistants they know well and trust. JAG's adult members have been able to move out of group homes, hospitals and other institutions to a home of their own, with assistance. Quite a few members have moved from their parents' home to live in their own apartment. In addition, JAG's members have developed interests of their own, which they have rarely been encouraged to do before. They have found hobbies and activities that they enjoy doing, with support.

### **Further information:**

Information about JAG is available in Swedish on their website – <https://jag.se/>. Details about JAG's model is available in English at: [http://enil.eu/wp-content/uploads/2012/02/Pa-manual\\_ENG.pdf](http://enil.eu/wp-content/uploads/2012/02/Pa-manual_ENG.pdf)

# Involvement of disabled people

## Co-Production in Social Care – SCIE, United Kingdom

### Background

The term co-production was first used in the 1970s in the USA to explain the better outcomes of municipal services, such as policing, when maintaining close relationships with local communities. It was then transferred to a health and social care context. From the mid-2000s co-production has become a mainstream idea in public policy in the UK and has increasingly been put into practice across both public and voluntary sectors.

In social care, co-production means equal partnership and collaboration between people using services and social care professionals<sup>8</sup>. It involves shifting the balance of power towards people using the services; they are recognised as experts in their own right and involved in the design and delivery of services. Co-production goes beyond participation, which usually refers to limited involvement through consultation, where people are asked to express their views. The rise of co-production in social care is strongly linked with the disability movement, which challenged the power of professionals and demanded ‘nothing about us without us’.

### Description

The Social Care Institute for Excellence (SCIE) is a UK-based independent charity working to improve the quality of care and support services for adults and children. Its activities include development of free resources aimed to improve the knowledge and skills of care staff and commissioners and provision of paid services, such as training, consultancy, research and evaluation. SCIE is an active advocate for co-production in health and social care and was one of the first organisations in the UK to adopt the principles of co-production in its work.

SCIE’s engagement with co-production began in 2010 when an independent review of the organisation’s participation work suggested that its impact could be improved though a co-productive approach. Following on from this, the organisation began to develop its co-production strategy.

The first step was to recruit to the SCIE’s Board a person who uses services and who would also chair a new Co-production Network. Then the Co-production Network was established with membership made up of user-controlled and carer-controlled organisations, equality groups and organisations representing and working with other seldom-heard groups. The Network, which currently has 65 members, meets in full twice a year to give input to SCIE’s strategic decisions. In addition, members of the network are involved in all aspects of SCIE’s work, including recruitment panels and project advisory groups, as well as the equality, diversity and human rights forum, and reviewing SCIE’s new resources. A Co-production, Equalities and Human Rights Steering Group was also established with members of the Network, trustees and SCIE staff. It meets six times per year and its role is to advise SCIE on the development of the co-production strategy and on equality, diversity and human rights issues.

SCIE’s co-production strategy required a number of changes to be made in the culture, policies and practices of the organisation, in addition to the changes in the structure, described above. They involved:

- **Embedding co-production in SCIE’s vision and business objectives:** A new vision and values were developed by the staff and the Board, which strongly featured co-production. One of the business objectives focused on ensuring that the voice of people using services is included in all aspects of the work of the organisation.

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<sup>8</sup> ENIL (n.d.) Co-production. Fact Sheet. Available in English, German, Italian, Lithuanian, Polish and Serbian at: <http://enil.eu/independent-living/fact-sheets/>

- **Staff engagement and training:** A survey was carried out among staff, which revealed a strong appreciation of co-production but also a need for further guidance. In discussions with the Co-production Network and Steering Group, it was decided to introduce mandatory training for all staff members. The training was designed by a group consisting of Co-production Network members, external users and carers and staff. It is delivered by teams of staff, people who use services and carers.
- **Review and revision of recruitment policies and procedures:** Following this review, it was decided that a person who uses services or is a carer would be included in selection panels, except where there was a compelling reason not to do so.
- **Introducing performance measures:** New performance measures, supporting the development of co-production across SCIE, were introduced. They include, for example, a requirement to plan and budget for co-production at the beginning of the projects.
- **Reviewing procurement policies:** Procurement policies were reviewed and revised to address the barriers to co-production and encourage commissioning of user and carer groups when appropriate.

A number of changes in policies and practices concerning SCIE's work with people using services and carers are also introduced, for example:

- **Support and training:** Support and training is provided to people who use services and carers to enable them to take part.
- **Approaches to co-production:** Different approaches to co-production are used to ensure that the needs of specific target groups are met. The best approaches to involvement in different types of work are identified with people who use services and carers. Feedback is provided to people who take part in co-production about the results of their input
- **Compensation for participation:** A fee or equivalent training or other benefits is offered to people using services and carers for their participation. Reasonable expenses, associated with participation in co-production activities, are also covered.
- **Access:** Various access and support needs are addressed, including related to physical accessibility, information, emotional or psychological barriers to participation.

### Why this is a good example

The co-productive approach adopted by SCIE has helped make the work of SCIE better connected to the lives of disabled people. Together with this, it has allowed disabled people to have a say on key issues related to quality of care and support services for adults and children. It helped bring disabled people's voices to the forefront of initiatives like the development of national guidelines for social care, produced with the National Institute for Health and Care Excellence. The guidelines aim to improve outcomes for people who use social care support by ensuring that social care services and interventions are effective and cost-efficient. They do this by making recommendations about best practice.

### Limitations, challenges and lessons learned

The main lessons learned are about the importance of being grounded in the principles of co-production and using the jigsaw approach to implementation to get co-production right. The jigsaw approach to managing change is a whole system approach, consisting of four elements: culture, structure, practice and review. The importance of addressing access issues in everything, particularly for meetings and events, should also be emphasised.

The main challenge is the tension between co-production and income generation. SCIE raises a significant part of its income from commercial sources, by selling its services. In these cases, co-production can be an asset, as it provides credibility to the work of the organisation. At the same time, it adds costs and time to the projects, which can put the organisation at a disadvantage. As a result, it can be difficult for the

organisation to incorporate co-production in smaller contracts and one-off training sessions. In training and consultancy – a new area for SCIE – there have even been activities without user involvement.

Some of the actions taken to address these challenges include a more vigorous promotion of SCIE's co-production offer and the establishment of a system for evaluating the effectiveness of co-production in SCIE projects. It was acknowledged that the approach to co-production needs to be flexible, in order to address the changing business requirements. For example, it needs to be proportionate to the scale and requirements of each project, meaning that the levels of co-production can vary between projects. It was also recognised that good planning and budgeting at the beginning of the projects can help address these challenges.

### For more information

More details about SCIE's co-production approach can be found on the co-production section on the organisation's website: <https://www.scie.org.uk/co-production>

# Participation of Organisations of People with Disabilities – Italy, Tuscany

## Background information

In Italy, people with high support needs without family support are usually forced to live in traditional long-stay residential institutions due to the lack of accessible and affordable housing and support in the community. Approximately 90% of all available residential places are in such institutions. In June 2016, after active lobbying from organisations of people with disabilities and parents' organisations, the Italian government adopted Law 112/2006, aimed at supporting de-institutionalisation and community living of people with high support needs<sup>9</sup>. The law creates a Fund within the Ministry of Labour and Social Policy for assistance of people with high support needs without family support, which allocates resources to the regions to develop alternative housing solutions and provide support at home. The implementation of the Law and the related funding is managed at regional level. The national government has adopted a Decree for the implementation of the law, providing guidance on how the resources of the fund can be used – for example, specifying the general parameters of the housing solutions in terms of dimension (no more than 5 cohabitants) and location (in the community). Each region had to adopt its own regional decree and decide whether to allocate additional funds for the implementation of the law. The Government of Tuscany sought to actively engage disabled people in the development of this decree.

## Description of the practice

In Tuscany, there has been an informal mechanism for consultations on disability issues since 2015, when a roundtable was established at regional level including the main stakeholders – disabled people (through the regional networks of DPOs), service providers, directors of the local units of the public health-care and social system and others. Temporary roundtables are also formed on specific issues of regional competence (for example, autism, healthcare staff training to improve the access of persons with disabilities to general healthcare facilities, access of persons with disabilities to museums, libraries and other cultural facilities and activities) where DPOs and stakeholders with a particular interest in the topic take part.

Participants in consultation tables vary depending on the issue to be discussed – regional rules and regulations, implementation measures or other initiatives to be undertaken by the regional public administration. Usually, there are one or two representatives of the four regional DPO networks and representatives of other DPOs working on the specific topic. The consultation tables are also attended by members of the regional administration with competence on the topic under discussion. Experts from universities and other stakeholders can also be involved.

Until January 2017, consultations with organisations of disabled people were only in the form of discussion meetings. However, the consultations concerning the implementation of Law 112/2006 at regional level were organised and managed in a more structured way, ensuring greater involvement of disabled people from the start and during the implementation. First, a meeting was organised with representative DPO networks to discuss the forthcoming regional regulation. Then the proposal for a regulation was sent to them and they were asked to provide written input. Their proposals and suggestions were then integrated in the regulation, which was submitted for approval to the national level (the Ministry of Labour and Social Policy). Two more meetings were organised in 2017 to support the implementation of the decree. One in June – to design an implementation plan, after the feedback from the Ministry was received, and one in September – to establish more detailed requirements for funding.

<sup>9</sup> The law is a step towards development of alternatives to traditional institutions. However, it has many issues, including very limited funding and scope, which will affect negatively the outcomes for disabled people.

## Why this is a good example

As social protection and health care systems in Italy are under the responsibility of the regional governments, the effective involvement of people with disabilities is essential for ensuring that the implementation of the law is in line with the principles of the CRPD and takes into account the needs and preferences of people with disabilities and their families.

While not ideal, the consultation process that was set up in Tuscany with regard to the regional implementation of Law 112/2016 was a step forward, compared to the previous situation. It gave disabled people more opportunities to provide input and to have a say in the development of the regional regulations. Most of their proposals, which aimed to create more opportunities for people with disabilities to live independently, were included in the regional decree. One such proposal, which was adopted only in Tuscany, allows disabled people to use support even when they live with a non-disabled person, for example a partner. The decision of the Government of Tuscany to allocate additional funds (5.500.000 EUR), doubling the available national budget for the implementation of the law at regional level, was also influenced by the regular consultation with the DPO networks and their ongoing lobbying actions.

## Challenges, limitations and lessons learned

A major limitation of the consultative process is that it is not supported by a legislative act. This makes the process unsustainable – for example, a change in the regional government or its policy could mean that consultations are no longer supported. There are also no rules concerning the composition of the tables, the frequency of the consultations and the issues to be discussed.

There have been a number of challenges to the effective participation of disabled people in the way the consultative process is organised. One such challenge was the lack of accessibility of the consultation process. For example, the documents were not provided in an accessible format for blind persons, captioning or sign language interpretation was not available during the meeting, and there was a broad use of technical language, acronyms and references to previous legislation or other official documents.

Another challenge has been the lack of compensation for the costs associated with the consultation. Participation in such consultations requires a significant financial and non-financial commitment – for example, time or money to pay for travel to the place where consultations are held. The lack of compensation puts organisations of disabled people at a disadvantage compared to other stakeholders, for example service providers, which are generally better resourced.

Finally, the lack of transparency of the consultation process has also been a challenge. The DPOs and their regional networks and other stakeholders are mostly invited separately to participate in consultation meetings and they cannot exchange their views, nor are they aware of each other's positions. As a consequence, during the consultation process on the implementation of Law 112/2016 for example, the requirements concerning housing units were changed to reflect the perspective of healthcare providers, without consulting DPOs and their networks. This change will have a negative impact on the individual autonomy of disabled people living in the housing units and on their freedom to choose.

## Further information

For more information about the consultation process, contact FISH – the National Federation for Overcoming Disabilities (Federazione Italiana per il superamento dell'handicap) Toscana at [toscana@fishonlus.it](mailto:toscana@fishonlus.it)

# Self-advocacy

## Self-Advocacy of Disabled People – Ceva De Spus, Romania

### Background

Most people with disabilities in Romania remain excluded from society. At present, there are still 18,000 people with disabilities living in residential institutions, where they face abuse, violence and inhuman treatment. Those living in the community, in their families, remain isolated and excluded because of the limited availability of support services. Families that have a disabled member live in poverty and are struggling to survive.

There are several non-governmental organisations working on disability issues in Romania, including organisations of people with physical impairments. However, there are no cross-disability organisations of self-advocates, apart from Ceva de Spus (in English – something to say). Ceva de Spus unites self-advocates with physical and intellectual disabilities, working to raise society's awareness about the barriers disabled people face to participate in the community and to show that they too can live an ordinary life.

### Description of the practice

Ceva de Spus started in 2010 in Timisoara as an informal group of people with disabilities living in the community. One year later, as they grew and realised they needed to be more visible, they recruited a support person to help them get organised. In 2012, they started thinking about establishing a formal association and working on its statute and goals and, in 2013, Ceva de Spus was officially registered as a legal entity.

The organisation is run by a Board, consisting of five people – two co-presidents (one with a physical and one with an intellectual disability), two vice-presidents (one with a physical and one with an intellectual disability) and one secretary. The Board reports to the General Assembly, which meets twice a year. The Board meets every week to discuss the work of the organisation, to plan activities for the coming week and to decide what needs to be discussed with the members of the organisation. Active members also meet every week to talk about pending issues and to decide on which activities they would like to get involved in. The minutes from the meeting are then sent to all members.

The staff of the organisation include two self-advocates – one full-time and one part-time – and two full-time support persons. The role of support persons is to help the Board and the members make decisions, for example, by providing information and asking questions. The final decision may differ from the opinion of the supporter but their role is to help self-advocates to put it in practice. Supporters also have project management responsibilities. While all decisions are made by self-advocates, the day-to-day management and reporting is done by one of the support persons. Finally, supporters help self-advocates prepare for meetings and to deliver presentations at conferences, and they translate into easy-to-understand language during meetings.

The work of the organisation is also supported by a Consultative Board. It is comprised of non-disabled people coming from different sectors. The Consultative Board is not involved in decision-making, but supports the organisation with advice and guidance, especially in crisis situations. Members of the Consultative Board meet formally once a year; however, they are constantly in touch with the organisation throughout the year.

Ceva de Spus' work is to support its members to become more active and speak up for themselves. This involves:

- Organising weekly meetings with members, where they can speak about things that are important for them and make decisions about the actions they would like to take.
- Organising training sessions for members to help them improve their skills related to working in teams, communication, strategic planning, story-telling, conflict management, personal budget management, cooking, English language, and other. Activities, such as yoga sessions are also organised.
- Supporting members to understand their rights and learn what to do if they are discriminated against. For example, at the members' meetings, the Convention on the Rights of Persons with Disabilities is read in an easy-to-read format and discussed. Training sessions are also organised.
- Providing financial support to the members to enable them to overcome the lack of support in the community and be more independent and active. Each member has a personal budget, which depend on their disability, the support they have at home, and the number of children they have, can be between 450 and 1000 EUR per year. It can be used to pay for services – for example, to improve the accessibility of an apartment, to get support at home, to access different services in the community, such as psychotherapy, medical services and assistance. The funds for these personal budgets are raised through various fundraising events.

In addition, Ceva da Spus currently works on three main priorities, identified by the members – de-institutionalisation, community living and the use of EU Structural and Investment Funds (at national level), accessibility (at local level) and awareness raising (at local level). They have been very successful in raising awareness within the local community and attracting support at the local level. They have also helped make transportation, traffic lights and playgrounds in Timisoara more accessible.

The work of Ceva de Spus is funded by a foreign donor – the Open Society Foundations Public Health Programme – but they are also supported by the local business sector. They organise various fundraising activities at the local level, which also aim to raise the community's awareness and address stereotypes about disability, by involving both people with and without disabilities. For example, they organise a wine fair and an annual community race, where everybody is welcome to take part, regardless of fitness level. There are plans to start a social enterprise to help fund its work.

### **Why this is a good practice**

- **Independence and inclusion:** Self-advocates have become more confident to make choices and decisions about their lives and to be more independent. Some of them have started jobs. They know what to do if they face discrimination – with whom to speak, what legislation to use.
- **Participation in decision-making:** Self-advocates have become more aware about their rights and empowered to speak up. They are also more engaged with policy-making at local level and have a say in the decisions that affect them.
- **Awareness-raising:** Disabled people became more visible in the local community and better accepted.

### **Limitations, challenges and lessons learned**

The authenticity of the organisation – people with disabilities speaking up for themselves – has been key for the progress achieved at local level. The local authorities were more willing to listen and take actions when disabled people themselves presented a problem or asked for a solution.

There have been a number of internal and external challenges. A key external challenge is related to the barriers some disabled people face when joining Ceva de Spus. For example, people living in protected homes in the area were discouraged from joining the organisation by the manager of the setting.

The internal challenges include poor self-esteem and self-confidence among self-advocates, especially in the first years. Other challenges included a lack of management skills and internal conflicts.

**Further information:**

More information about the work of Ceva de Spus is available in English and Romanian on the organisation's website [www.cevadespus.ro](http://www.cevadespus.ro). You can also contact them at [contact@cevadespus.ro](mailto:contact@cevadespus.ro).

## About the European Network on Independent Living

The European Network on Independent Living (ENIL) is a Europe-wide network of disabled people, with members throughout Europe. ENIL is a forum for all disabled people, Independent Living organizations and their non-disabled allies on the issues of Independent Living. ENIL's mission is to advocate and lobby for Independent Living values, principles and practices, namely for a barrier-free environment, provision of personal assistance support and adequate technical aids, together making full citizenship of disabled people possible.

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## About the European Disability Forum

The European Disability Forum is an umbrella organisation of persons with disabilities that defends the interests of 80 million Europeans with disabilities. We are a unique platform which brings together representative organisation of persons with disabilities from across Europe. We are run by persons with disabilities and their families. We are a strong, united voice of persons with disabilities in Europe.

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