IJDSJ | ISSN 2753-5827 (Online)

SPECIAL ISSUE DIGEST

IJDSJ | December 2022

**Number 1: Independent Living**

Edited by

Teodor Mladenov

(University of Dundee)

and

Ines Bulic Cojocariu,

Lilia Angelova-Mladenova,

Natasa Kokic and Kamil Goungor (ENIL)

(European Network on Independent Living)

© International Journal of Disability and Social Justice (IJDSJ). This work is licensed under a CC BY-NC-ND 4.0 license (see https://creativecommons.org/licenses/by-nc-nd/4.0/)



The International Journal of Disability and Social Justice (IJDSJ) Special Issue Digest is published once or twice per year, to accompany Special Issues of the main journal.

ISSN 2753-5827 (Online)

Publisher: IJDSJ

Place of Publication: Leeds, UK

Contact: IJDSJcontact@gmail.com

**Image/illustration credits**

Page v: ENIL

Page 2: Sinn Féin via flickr - attribution 2.0 Generic (CC BY 2.0)

Page 5: Quotation source: https://www.youtube.com/watch?v=6dPKhFUpthU. Photo of Kapka Panayotova by Desislava Petrova (reproduced with permission of photographer)

Page 10: ENIL

Page 13: Quotation source: https://merce.hu/2019/04/28/igazan-senki-nem-akarja-latni-mi-tortenik-ma-a-pszichiatriakon/. Photo of Gabor Gombos by Péter Zsolnai (reproduced with permission of photographer)

Page 14: Jernej Furman via flickr - attribution 2.0 Generic (CC BY 2.0) [modified to remove background]

Page 15: ENIL

Page 18: Courtney M. Privett (reproduced with permission of artist)

All other images Creative Commons, no attribution required.

**Table of Contents**

**Editorial**

**Independent Living in Europe and beyond: past, present and future** – pages iv-vii

Teodor Mladenov, Ines Bulic Cojocariu, Lilia Angelova-Mladenova, Natasa Kokic and Kamil Goungor

**01** **Declare Independence: Independent Living, Oppositional Devices, and Heterotopias** – pages 1-2

Miro Griffiths

**02** **When legislation is not enough: the adverse environment for independent living in Hungary** – pages 3-4

Gabor Petri, Agnes Turnpenny and Aniko Bernat

**03 The role of participatory instructors in Hungarian Higher Education. Results of qualitative research to support the voices of disabled people in academia –** page 6

Anikó Sándor, Csilla Cserti-Szauer and Vanda Katona

**04** **A Disability Rights Approach to a Constitutional Right to Housing** – pages 7-9

Áine Sperrin

**05** **Independent Living in Post-Socialist Countries: between Familialism, Deinstitutionalisation and Re-institutionalisation** – pages 11-12

Darja Zaviršek and Svenja Fischbach

**06** **Personal Assistance in Scotland: A Postcolonial Perspective** – page 14

Jim Elder-Woodward

**07 The Challenges of Promoting Independent Living in Türkiye** – page 16

Melike Ergün, Lilia Angelova-Mladenova and Bahar Yavuz

**08** **Transitioning to independent living in the community: trajectories and crossroads in the context of Lithuania** – pages 17-18

Violeta Gevorgianiene and Egle Sumskiene

Editorial

iv

**Independent Living in Europe and beyond: past, present and future**

Teodor Mladenov, Ines Bulic Cojocariu, Lilia Angelova-Mladenova, Natasa Kokic and Kamil Goungor

**1. Introduction**

This magazine is a Digest version of the forthcoming Special Issue of the International Journal of Disability and Social Justice (Vol. 3, Issue 1). The Digest provides a Plain English overview of and introduction to the contents of the main journal, suitable for the busy reader.

Our aim, in putting together the Special Issue, was to celebrate Independent Living. The issue includes articles and shorter pieces that focus on matters of current concern. A series of short films of interviews with Independent Living activists available at www.ijdsj.online completes this multi-media project.

Independent Living is a social movement and an idea. It means that disabled people should be able to have choices and be in control of their lives, instead of being controlled by others.

Organisations that fight for Independent Living are often called Centres for Independent Living, although other names are also used. These organisations are led and controlled by disabled people. The first Centre for Independent Living was created in Berkeley in the United States in 1972.

Since 1972, other organisations that fight for Independent Living were created in many other countries, including in Europe. One of these organisations is the European Network on Independent Living. It was created in 1989 by disabled people who wanted to fight for Independent Living in Europe.

The European Network on Independent Living organises an event every two years called the Freedom Drive. During the Freedom Drive, disabled people from different European countries gather in Brussels in Belgium to demand Independent Living.

This special issue is edited by people from the European Network on Independent Living. It celebrates 50 years since the creation of the first Centre for Independent Living and the 10th Freedom Drive that took place in 2022.

**2. The meaning of disability and independence**

Disabled people from the Independent Living movement oppose the traditional understanding of disability and independence. This traditional understanding is maintained by the wider society. It is also maintained by many professionals in ‘caring’ roles such as doctors, nurses and social workers.

For many ‘caring’ professionals, disability means that something is wrong with the person – the problem lies within that individual. For Independent Living activists, disability means that society treats disabled people badly. For many ‘caring’ professionals, independence means the ability to cope on one’s own. For Independent Living activists, independence means having choice and control in one’s life and that does not mean having to do everything by yourself or with no support.

v

BLANK PAGE

[Position of Image Celebrating 50 years since the birth of Independent Living as a movement and the 10th ENIL Freedom Drive. Image is taken at a Freedom Drive March and shows a woman holding a placard that reads ‘Institution no solution!’]

Having choice and control in one’s life requires having control over the support one receives to survive and thrive. Examples of support that help the person be in control include accessible buildings and transport, appropriate assistive technologies and personal assistance.

vi

The meaning of disability and independence promoted by the Independent Living activists is included in the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). However, many professionals and wider societies still understand disability and independence in the traditional way. As a result, the support that disabled people receive continues to restrict their choices and control.

**3. Independent Living and the state**

The Independent Living movement has criticised ‘caring’ professionals for controlling and restricting disabled people. ‘Caring’ professionals have been supported by the state. This support for ‘caring’ professionals has increased after the World War II.

Some state programmes have locked up disabled people in big institutions. Other state programmes have forced disabled people to live together in smaller institutions or ‘group homes’. This happened in different parts of Europe and continues to happen now.

The Independent Living movement wants disabled people to be free from the constraints of institutions. Some ‘caring’ professionals think that wanting this means that disabled people are ‘ungrateful’. People from the Independent Living movement disagree and think that helping disabled people to live in the community is the right thing to do.

**4. Independent Living and the market**

The Independent Living movement promotes choice. This choice may seem to be like the choice people have when they can buy and sell things on the market. But there are differences.

Some people think that markets are better for people than state programmes because markets encourage competition and improve quality. Some people who promote competition also think that markets work best when people are left to cope on their own, without support. However, Independent Living requires that people receive support to help them survive, thrive and make choices.

Many people who promote markets and competition argue that state programmes should be cut. Independent Living advocates argue that state programmes should be preserved, but changed. State programmes should not restrict disabled people in institutions or at home. State programmes should help disabled people to be free from restrictions, participate, have more choices, and be in control. This is what it means to live a dignified life.

Markets require people to compete. In contrast, Independent Living requires disabled people to support each other.

**5. Independent Living and the family**

In some countries, there are not enough state programmes supporting disabled people. There, disabled people rely on their parents or other relatives for support. The family members who most often support disabled people are their mothers.

It is good that disabled people have somebody to rely on when the state does not provide support. But parents sometimes restrict the choice of their children to protect them. Some parents continue to restrict their disabled children when their children become adults. The result is similar to state programmes that put disabled people in institutions.

The Independent Living movement recognises that parents are helpful and important. However, disabled people also need support provided by people who are not their parents. This helps the parents become more independent too.

vii

**6. Independent Living, closure of institutions and personal assistance**

The Independent Living movement demands the closure of institutions for disabled people. Instead of institutions, the state should provide support for Independent Living, including personal assistance.

Some states in Europe have renovated big institutions for disabled people to make them nicer. Some states have created new, smaller institutions. The renovated and the smaller institutions may be somewhat better, but they still restrict disabled people.

Some states in Europe have created personal assistance programmes. This is good because it helps disabled people to live outside institutions. Personal assistance is when you are supported by a person who follows your instructions. With personal assistance, you choose what to do, how to do it, and when to do it. But some personal assistance programmes restrict disabled people. They prevent disabled people from choosing what to do, how to do it, and when to do it.

The Independent Living movement criticises old and new institutions, as well as restrictive personal assistance programmes.

**7. The pillars of Independent Living**

Independent Living requires many supports, in addition to personal assistance. These supports are known as the pillars of Independent Living. The pillars of Independent Living include:

* access to buildings;
* access to transport;
* having one’s own home;
* access to information;
* access to assistive technology;
* personal assistance;
* access to education in ordinary schools;
* having enough money to live well;
* being able to find a job;
* support in using services and talking with professionals;
* support from other disabled people;
* access to healthcare;
* and support with making decisions.

The articles in this special issue discuss some of these pillars in detail. We invite readers to read this Digest and the forthcoming Special Issue of the IJDSJ and listen to the interviews that have been recorded with activists. We hope that this will help everyone to understand the pillars of Independent Living and imagine the future of Independent Living in Europe and beyond.

**More information**

Teodor Mladenov works at the University of Dundee and helps ENIL as a volunteer. Ines Bulic Cojocariu, Lilia Angelova-Mladenova, Natasa Kokic and Kamil Goungor work at ENIL. For more information, please contact Teodor: tmladenov001@dundee.ac.uk, or Ines: ines.bulic@enil.eu.

1. **Declare Independence: Independent Living, Oppositional Devices, and Heterotopias**

1

Miro Griffiths

**1. Introduction**

This article explores how disabled activists used an idea called Independent Living. Independent Living is important to disabled activists because it promotes the idea that disabled people should have choice and control over their life. The idea came from disabled people feeling angry and frustrated about not having enough support, and not being able to use support to do the things they want to do with their life.

In this article I use two concepts: a) the 'oppositional device' and b) 'heterotopias'. I use these concepts (ideas) to understand how independent living could improve disabled people’s lives and focus attention on creating social change across society.

The oppositional device is a concept developed by someone called Brian Holmes. It is a way of thinking about how ideas can be used to challenge existing ways of doing and thinking about things.

Heterotopias is a concept developed by Michel Foucault. It is a way of thinking about how places and spaces (like social movements, buildings, and community groups) can disrupt and challenge existing ways of thinking about and doing things.

I believe that Independent Living should be understood as an oppositional device, and disabled people campaigning for accessible and inclusive support can be understood as a heterotopia. This will help us to understand how disabled people, and their ideas, can help to build accessible and inclusive societies.

**2. Summary of the main points of the paper**

Independent living can and should be understood as an 'oppositional device'. An oppositional device is a tool that can help people to think and act differently. It can also help people to challenge current arrangements and ways of doing or thinking about things. It is often used by people who want to resist being treated in a negative way. For example, disabled people – and their allies – can use the idea of Independent Living to resist and oppose being excluded from their communities, and not receiving enough support to follow their aspirations.

I explored what Independent Living means or could possibly mean, and how it can help people challenge injustice. I did this by thinking about independent living across four ways that are important to how societies are organised:

(a) Technologies of production – this means thinking about how Independent Living can help disabled people to be free to live the life they want;

(b) Technologies of sign systems – this means thinking about how Independent Living can signify important things, for example, rules and laws;

(c) Technologies of power – this means thinking about how Independent Living can be used to force people to do things or be subjected to certain experiences;

(d) Technologies of the self – this means thinking about how Independent Living can help people feel liberated or passionate about campaigning for a better world.

Independent Living is important to activists and social movements. We can think about independent living social movements as heterotopias. This means thinking about activist networks and social movements as spaces where it is possible to experiment with ideas and activities that will help improve disabled people’s access to, and use of, support. These spaces can be important for reimagining what an accessible and inclusive world would look and feel like.

2

To illustrate these ideas, I refer to data from two studies involving disabled people. The first study includes data from interviews with disabled activists in the UK. The second study includes data from young disabled activists from across European countries. You can learn more by reading the full article.

**More information**

This article was written by a disabled academic activist called Miro Griffiths. Miro works at the University of Leeds in the School for Sociology and Social Policy and at the Centre for Disability Studies. His research is funded by the University of Leeds and the Leverhulme Trust. More information about Miro can be accessed here: https://essl.leeds.ac.uk/sociology/staff/1040/miro-griffiths.

You are welcome to contact Miro if you want to learn more about his research and/or this article: m.griffiths1@leeds.ac.uk.

[Position of a photo from a protest (circa. 2017) by disabled people in Ireland, calling for the Irish government to ratify the UN Convention on the Rights of Persons with Disabilities]

**2. When legislation is not enough: the adverse environment for independent living in Hungary**

3

Gabor Petri, Agnes Turnpenny and Aniko Bernat

**1. Introduction**

This article reports on an investigation into the views of disabled people from Hungary on Independent Living.

Independent Living means that people are able to live in the community and do not have to live in institutions. It means that they receive enough support and equal rights. In Hungary, disabled people have been talking about Independent Living and why it matters since the 1970s. Today, they use the UN Convention on the Rights of Persons with Disabilities (CRPD) and other human rights laws to fight for their right to live in the community.

In our study we asked disabled people to talk about their lives so we could understand the problems that they face. Ninety-three people talked to us, including people with physical disabilities, deaf people and people who are hard of hearing people, people with visual impairments, autistic people and people with an intellectual disability. Some parents of disabled people also talked to us. We wanted to know what the main barriers were to disabled people's independent living.

**2. Summary of Main Points**

We found seven main barriers to independent living.

2.1 Inappropriate social support

Many people told us that they do not receive enough support from the social welfare system. For example, they do not have support over the weekend or in the evenings. Others mentioned that day centres do not provide good services and they did not like to go to these places. Many people said that disability benefits (there were many different types) were very little and they were not enough to live on.

2.2 Inappropriate healthcare

Many people told us that in hospitals and clinics they do not get the kind of service they need. Sometimes doctors or nurses are unkind to them. They thought that the main problems with healthcare are that there are not enough staff and staff are underpaid. Sometimes people do not receive enough information about their own conditions.

2.3 Exclusion from the labour market

Almost everyone we talked with said they had difficulties finding jobs. Many people have not had a job for many years. Others are working in jobs that they do not like or they are too qualified to do. Several people said that they had to change jobs very often. There is stigma in jobs as well: many employees do not like to work with disabled people.

2.4 Lack of accessibility and assistive technology

Several people told us that they had difficulties because places are inaccessible where they live: transport, offices, other buildings are difficult to use for those who use a wheelchair or have mobility problems. Autistic people also said (continues next page)

that they have problems because of sensory issues. Assistive devices like wheelchairs are difficult to obtain and often not of good quality. Homes need adjustments, too, but the government does not give enough funding to help to people to make adaptations to their homes.

4

2.5 Low income and housing problems

Many people we talked with said that they were living in poverty. Many did not have income from jobs so they had to live on benefits that were low. Housing is also a serious problem because renting a flat is expensive. Some people who lived in institutions said moving out of institutions was difficult because they could not find somewhere affordable to live.

2.6 Restricted decision-making opportunities

Guardianship is still present in Hungary and a lot of people – mostly people with an intellectual disability (learning disabilities) – have guardians who make decisions on their behalf. Some people are under guardianship because their parents think that this is the best option to protect them. Every disabled person who was under guardianship told us that they did not like it and wanted to gain full legal capacity.

2.7 Prejudice and stigma

Almost everyone we talked to said that they experienced stigma or prejudice throughout their lives. For example, people are subjected to rude comments in the street, or by staff in hospitals, in shops, in schools, on transport etc. This was one of the problems people talked about the most.

2.8 Facilitators of independent living

People also mentioned things that they thought helped them to live in the community. For example, many people have friends, neighbours, colleagues or others they know who help them every day. Others said having a mobile phone or a computer with internet access helped them find friends and find or receive information that is crucial to them. Civil society organisations also helped many people, for example to find friends, to get a job or to learn about advocacy.

**3. Summary**

We found that disabled people in Hungary still face serious barriers to independent living. These barriers often reinforce each other and exacerbate people’s problems, affecting their physical and mental health. We also found that those with high support needs, people with intellectual disabilities and autistic people are likely to face the most barriers. People did not think that new and better laws have a real impact in real life. Many of them thought that the problems they have are permanent, persistent and not changing.

In Hungary, even though there are human rights laws like the CRPD and other relevant legislation, people do not believe these are them helping them very much. We think that the way forward might be for the disability movement to think about enhancing their advocacy to focus on issues outside laws.

**More information**

For more information, you can email Gabor Petri at petri.gabor@gmail.com.

5

‘What we are doing is a revolution. Getting out of institutions, getting out of our homes where we are stuck because of being disabled – it is a revolution.’

Kapka Panayotova, the ‘good witch of Independent Living’

In background, a photo of Kapka

**3. The role of participatory instructors in Hungarian Higher Education. Results of qualitative research to support the voices of disabled people in academia.**

6

Anikó Sándor, Csilla Cserti-Szauer and Vanda Katona

**1. Introduction**

This paper presents a method called 'We teach together! The Participatory Higher Education Method'. This method involves disabled and non-disabled people teaching together at a university. They work with students who are going to be special needs teachers. This is important, because disabled people usually do not have the opportunity to take part in the training of teachers. With this method, they can share their life stories and help students to understand what it means to be a disabled person.

**2. Summary of the Method**

The research we conducted focused on an inclusive seminar. An inclusive seminar is a class for students and during this class disabled and non-disabled teachers talk about disability history, disability movements, Independent Living and self-determination. Student carry out projects together with disabled persons and present their work at the end of the year. They learn how to assist disabled people and how to respect disabled people's life decisions. They understand what 'Nothing about us, without us!' truly means in practice.

Teaching together like this is great. But it can also be challenging. It takes much time and effort. For example, training materials are not always available in easy-to-understand versions. They have to be translated and transformed into an accessible format. Sometimes disabled teachers face barriers to participation - they find themselves having to stay at home, because there is no accessible transportation or personal assistance.

It is important that disabled people are equal members in this process. At Eötvös Loránd (ELTE) University, where this co-teaching method is used, the teachers who are disabled people are paid for their work and have a contract for each seminar.

**3. Summary of the Main Results**

We highlight that the method facilitates a unique opportunity that enriches the diversity of teaching methods used in inclusive seminars, thus supporting the co-construction of knowledge. These seminars might be the first significant meeting and cooperation between students and disabled adults. They help shape the students’ attitudes in positive ways. However, further work needs to be done to increase the level of involvement and inclusion of the participatory instructors, because this can lead to more self-determination in their lives. In our experience, more financial, social and human resources have to be mobilised to support the process in academia.

If someone wants to use this method, they should plan carefully and they should not rush the process.

**More information**

Anikó Sándor, Csilla Cserti-Szauer and Vanda Katona work at the ELTE University in Hungary. They research the participation of disabled people. If you have questions or comments, please write to Anikó: sandor.aniko@barczi.elte.hu.

Anikó, Csilla and Vanda thank all of their co-workers and students from the university and the organization that provided money for the research.

**4. A Disability Rights Approach to a Constitutional Right to Housing**

7

Áine Sperrin

**1. Introduction**

This article discusses how introducing a Constitutional right to housing could promote the right to independent living for disabled people in Ireland. Currently there is a Constitutional protection to private property, but this does not guarantee housing. Ireland has ratified the United Nations Convention on the Rights of Persons with Disabilities since 2018.

**2. Key Points**

2.1 Independent living and the Irish experience

The right to independent living has been secured through campaigns by disabled people internationally. The text of the United Nations Convention on the Rights of Persons with Disabilities recognizes the right to have choice over where and with whom you live. It includes the right to access any technology or supports you need to live a life of your choosing. It also promotes equal access to community services for disabled people. In Ireland the campaigns for independent living have not had the same support as in other countries.

2.2 Housing system in Ireland

Until the last 10 years, owning your own home in Ireland was the experience for the majority. With the housing crisis however, it has become more difficult to afford your own home. It has also become extremely difficult to rent from a private landlord. Public housing stock is low and is often of poor quality. The government relies on private construction industry and investors to finance and build housing. The attitude towards housing has become about profit and because of this there are over 10,000 people homeless.

In Ireland there are many barriers to disabled people choosing where they live and who they live with. This paper discusses those which the authors considers most important.

2.3 Housing built with low quality materials

Due to little or no regulation of construction materials standards, thousands of houses across the country which were built in the last 30 years have become unsafe to live in. This is causing serious physical and mental health harms to everyone affected. As disabled people have accessibility requirements for their homes and generally experience lower financial security, this crisis is affecting them in a unique way.

2.4 Inaccessible housing

Housing standards in Ireland require only very low levels of accessibility. Houses built since 2006 must be suitable for a wheelchair user to visit, not to live. This has resulted in a shortage of housing which is accessible to wheelchair users and their families.

BLANK PAGE

8

[Position of illustration of a cluster of cheerful houses (decorative)]

2.5 Invisible homelessness

9

Adults with intellectual disabilities are continuing to live with their parents or family members such as siblings because they cannot access supports to live independently. These adults are being prevented from moving out of home, an experience which non-disabled people take for granted. The quality of life for these adults and their family members is impacted as their living conditions are inappropriate.

2.6 Lack of personal assistance

The right to live independently includes a right to personal assistance. In Ireland personal assistance services are not equal across the country. Even for people who do have personal assistance, the service is not always of a high enough quality and people have to pay from their own income to have their needs met. Not having enough personal assistance is a significant barrier to being able to live independently.

2.7 Institutions for disabled people

Ireland has a long history of housing disabled people and older people in institutions or community homes. This has resulted in a lack of individual and independent style services to support people to live in their own homes. Often disabled people have no choice but to live in institutions or nursing homes because there are no accessible houses and no personal assistance to allow them to have choice over their daily lives.

**3. Summary of Main Implications**

All of the barriers to housing and independent living for disabled people in Ireland are connected. If a Constitutional right to housing is introduced, we must recognize that housing must be accessible and built using good quality materials. For disabled people to enjoy their housing rights they must have access to personal assistance and community based supports. Otherwise disabled people will remain invisible in institutions, living in their family homes against their will or homeless.

**More information**

Dr Áine Sperrin is currently a Post-Doctoral researcher with the Re(al) Productive Justice Project at the Centre for Disability Law and Policy, University of Galway. Her Phd research focused on independent living in post-conflict countries for adults with intellectual disabilities. Her email is: aine.sperrin@nuigalway.ie.

10

 **‘The purpose of disability activism is to propose a way to organise society that benefits everybody. Not just Disabled People.’**

**Miro Griffiths**

[Background photo of Miro Griffiths taken during the 2022 ENIL Freedom Drive]

**5. Independent Living in Post-Socialist Countries: between Familialism, Deinstitutionalisation and Re-institutionalisation**

11

Darja Zaviršek and Svenja Fischbach

**1. Introduction**

This article compares the situation of people with disabilities in Slovenia and Serbia. These two countries were part of the former Yugoslavia in the period 1945-1991. As a result, Slovenia and Serbia have similar histories, laws and attitudes concerning people with disabilities. We consider the similarities and differences between the two countries that can be observed today.

Similarities: in both Slovenia and Serbia, supporting people with disabilities to move out of residential institutions is a slow and incomplete process. New institutions are being created. People with disabilities are forced to rely upon their families for support and are often told what to do and how to live their lives.

Differences: in Slovenia, the idea of independent living and the rights of persons with disabilities are known by many people. These ideas are applied in many parts of the country, but they are not applied well. People with disabilities continue to be told what to do by their families and by doctors and social workers. In Serbia, the idea of independent living is still largely unknown. There are some individual projects designed to support independent living in Serbia, but these are few and far between.

In both countries, most of the people who support people with disabilities are women. This area of work is highly gendered. In Serbia, many of these women go to other countries to seek work. As a result, there are not enough women left to support people with disabilities. This is not the case in Slovenia.

**2. Key points**

Slovenia and Serbia make an interesting comparison because both countries were part of the former Yugoslavia from 1945-1991. In both countries during this period, people with disabilities were separated from the rest of society. They were placed in institutions run by the state. They were also considered to be ‘unable to work’ and treated as ‘invalids’ who could not live independently.

After 1991, both Slovenia and Serbia started to move people with disabilities out of institutions. People with disabilities started receiving support to live in communities, together with people without disabilities. But this process was slow and poorly organised. Some well-written disability laws were also created in both countries, which inspired hope.

In both Serbia and Slovenia, there is currently not enough support for people with disabilities to live in communities. In Slovenia, this support still receives less money than institutional care. In Serbia, support for people with disabilities to live in the community is only provided by some municipalities.

Personal assistance is support for people with disabilities to live in the community. In Serbia, there is personal assistance, but it is given to very few people and is insufficient to help them to live independently. Slovenia is the only country of the former Yugoslavia with a law on personal assistance. This law is the Personal Assistance Act of 2019.

12

Understanding the situation of women in Slovenia and Serbia is important when thinking about disability. When Slovenia and Serbia were part of socialist Yugoslavia, women were encouraged to have regular jobs and earn money. Now, women are told not to work or to work at home as “carers” for persons with disabilities, children and old people. This includes working as foster carers, family helpers, “long-term care” workers and personal assistants.

**3. Summary of the main implications**

The new approach to disability rights and inclusion is to move people with disabilities out of institutions and to help them to live independently in the community. This approach is very different from the old approach to disability. The old approach impacts negatively on people. Sadly, this old approach is still applied in Serbia and Slovenia.

The new approach to disability treats people with dignity and respect. It also promotes self-determination. Self-determination means that people with disabilities have choice and control in their lives. This requires that doctors, social workers, and other professionals listen to people with disabilities and do not treat them as incapable of having a voice. This has not yet been achieved in many countries in Eastern Europe.

Both Serbia and Slovenia rely on women to support people with disabilities in their families. But many women leave Serbia, and some women leave Slovenia to seek work abroad. This leaves people with disabilities in Serbia and parts of Slovenia without support from their families. This is worrying. But it may force politicians to consider providing support that does not rely on families. Such support could increase the self-determination of people with disabilities. But it requires politicians to invest in support in the community and personal assistance, rather than building more institutions.

**More information**

Prof. Darja Zaviršek is a Disability Studies and Gender Studies researcher and Professor of Social Work at the Faculty of Social Work, University of Ljubljana. Her email is: Darja.zavirsek@fsd.uni-lj.si.

Svenja Fischbach is doctoral student within the ASTRA project at the Faculty of Social Work, University of Ljubljana. Her email is: Svenja.Fischbach@fsd.uni-lj.si.

The authors thank Teodor Mladenov for inviting them to write in this special issue and the anonymous reviewers for valuable comments and suggestions. The article is funded by the National Research Agency of Slovenia (project number: P5-0058).

**'Look, a lot of people have seen and are seeing what happens in institutions. And most are looking away. But if you or your family member has been confronted with what happens to people who live in institutions, it's no longer a choice, it's a necessity to act. I had no choice in that respect, I had to take action.’**

13

**Gabor Gombos**

[Background photo of Gabor Gombos]

**6. Personal Assistance in Scotland: A Postcolonial Perspective**

14

Jim Elder-Woodward

**1. Introduction**

Personal assistance is the key to Independent Living. In Scotland, the government is having discussions with various people and organisations to make personal assistance more like standard social care. This could involve personal assistants undertaking the same training, registration and regulation as care workers in local authorities and care providers. Although no final decisions have been taken, the outcome of this rule would limit the opportunities Independent Living gives to disabled people.

In this article I examine this situation, by considering how powerful people often try to find ways of keeping power, even when changes are made to take it away from them. The approach I use is called ‘postcolonial theory’. Postcolonial theory originally described the power which conquering countries keep after leaving their colonies.

**2. The Move from Institutions to Community Care**

The academic Niklas Altermark uses postcolonial theory to help understand the situation facing disabled people when they move from institutional to community care. Disabled people were supposed to have more say over their lives once they left the institutions. But the power of the professionals still lived on after people left the institutions. Controlling aspects of institutional living transferred over to such community supports as ‘group homes’.

**3. 'Fake' Personal Assistance**

Personal assistance was developed by Independent Living activists to allow freedom of choice and control over their lives, including the supports to their lives. However, not all existing personal assistance programmes achieve this goal. I consider this in relation to the Swedish disability activist Adolf Ratzka’s observations on personal assistance programmes around the world. He argues that some of the existing personal assistance programmes are ‘fake’, or not truly in line with Independent Living principles and practices.

**4. Professionals Keeping Power**

In my full length article, I describe how power has generally been maintained by local front-line professionals in Scotland, when they implement national legislation. I tell of how local disabled people’s organisations have been excluded from participating in the development of personal assistance at the local level.

**5. Summary of Conclusion**

The paper concludes by suggesting that further studies may highlight where and how personal assistance becomes ‘fake’ within different states. These studies would benefit from following the more rigorous method proposed by the academic Teodor Mladenov in his European study of what makes ‘good’ personal assistance.

**More information**

About the author: Jim Elder-Woodward is a Disabled Activist and Vice Chair of Inclusion Scotland.

**Piss on Pity at ENIL Freedom Drive**

15

[Background photo from a Freedom Drive March]

**7. The Challenges of Promoting Independent Living in Türkiye**

16

Melike Ergün, Lilia Angelova-Mladenova and Bahar Yavuz

**1. Introduction**

In this commentary we discuss the challenges faced by individuals and organisations promoting independent living in Türkiye. In addition to the dominant charity-based perspective towards disability, a key challenge in the recent years has become the increasing and systemic attack on human rights and human rights defenders and delegitimising the rights-based perspective. Together with this, the difficult political situation in the country puts disability issues at the bottom of the political agenda and makes it difficult to strengthen the independent living perspective.

**2. Summary of Main Points**

We explore the challenges experienced by people and organisations promoting independent living in Türkiye. Independent Living means that disabled people have the same choices as everybody else about where they live and how they live. Independent Living is a right.

Türkiye has signed an international agreement on the rights of disabled people (the United Nations Convention on the Rights of Persons with Disabilities). It has promised to make sure that disabled people will receive the support they need to live independently and participate in the community. This has not happened yet.

One reason is that most people see disability as something that only needs charity and medical treatment. Another reason is that the state relies on families to provide care and support. Many large organisations of disabled people also share these views.

There are also organisations that promote and defend the right of disabled people to live independently. However, in the last few years it has become more and more difficult for them and for other human rights organisations to exist and to work. This is because the government views organisations promoting human rights as enemies. The government checks closely the work of these organisations and does not allow them to speak about human rights or to criticise state policies. Some human rights defenders are falsely accused of being traitors and taken to court. There are human rights organisations that have closed down.

In this context, it is important that the different disability organisations work together to promote the rights of disabled people. To be able to carry out their work, human rights organisations also need better access to resources.

**More information**

The authors of this article are Melike Ergün and Lilia Angelova-Mladenova (European Network on Independent Living, Brussels, Belgium) and Bahar Yavuz (Association of Women with Disabilities [ENG-KAD], Ankara, Türkiye).

**8. Transitioning to independent living in the community: trajectories and crossroads in the context of Lithuania**

17

Violeta Gevorgianiene and Egle Sumskiene

**1. Introduction**

The Lithuanian Government has started building small group homes for people with disabilities. The aim is to move people with disabilities into group homes when the old, big institutions are closed. But group homes are like small institutions and hinder Independent Living.

People who live near the group homes do not understand the right to Independent Living. They do not support people with disabilities. People with disabilities cannot find a job, get personal assistance, and do not have support to make decisions. People with disabilities need these and other similar services in the community. But the Government lacks the money for important services because the money is instead being invested into group homes.

Researchers from Vilnius University in Lithuania visited some of the group homes. They talked with the residents and social workers there. The researchers also talked with the neighbours and with people on the street. They asked the neighbours if they meet with people with disabilities, talk with them and made friends. The researchers also read many online texts about group homes. They wanted to know what people think about Independent Living. This article describes what the researchers found.

**2. Summary of Main Points**

2.1 People with disabilities are ignored

Nobody asks people with disabilities what they think about group homes. Their right to participate in the making of decisions about their lives is ignored. Other people talk, plan and decide for them.

2.2 The attitudes of people in the wider community are often unfriendly

Local communities know little about the rights of people with disabilities. Neighbours do not want group homes in their community. Sometimes neighbours are unfriendly towards people with disabilities who live in the group homes.

2.3 Journalists talk to the neighbours

Journalists write about the unfriendly attitudes of the neighbours. But they rarely talk to people with disabilities. Journalists rarely write about friendships with group home residents.

2.4 People meet but do not communicate

The neighbours of the group homes see people on the streets, in the shops, buses or cafés. But they rarely (continues next page)

communicate with people with disabilities. People with disabilities and their neighbours have little trust in each other. The government does not help to build trust.

18

**3. Summary of the Conclusions**

The researchers conclude that people with disabilities and their neighbours depend on each other. They can learn to trust each other, work and spend leisure time together. This requires support for Independent Living instead of building new institutions. Independent Living can make the whole community more friendly and connected.

**More information**

Violeta Gevorgianiene and Egle Sumskiene are researchers at Vilnius University in Lithuania, at the Institute of Sociology and Social Work. They focus on disability studies. You are welcome to contact them if you want to learn more about their research: violeta.gevorgianiene@fsf.vu.lt and egle.sumskiene@fsf.vu.lt.

[Position of illustration by Courtney M. Privett entitled ‘We All Belong’. Under a blue-sky and sunshine, twelve people are in a row, facing forward, holding hands. The group is diverse, including men and women, older people and younger people, someone who is a wheelchair user, people of different body sizes, people of different ethnicities and religions (the latter signalled by a woman wearing a hijab)]



Full length versions of articles and commentary included in this Digest will be published in Volume 3, Issue 1 of the International Journal of Disability and Social Justice (IJDSJ).

The IJDSJ is an Open Access journal, free to read online.

**independent living is not doing things by yourself**

**it is being in control of how things are done**

**Judy Heumann**

[Pagination is the same in this version as in ‘flipbook’]

[This is the last page]