



INDEPENDENT LIVING HEROES

PAST, PRESENT AND FUTURE

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Foreword by ENIL's Outgoing Executive Director

This year's Freedom Drive is dedicated to Martin Naughton from Ireland, a great hero of our Independent Living movement. Martin is the Father of the ENIL Freedom Drive, an event that has made a difference. A strong leader of ENIL, as well as of the Independent Living movement in his country, Martin inspired many.

Martin passed away in October 2016, which was a great loss for ENIL and for the Independent Living movement as a whole. He was the one who had the idea for ENIL to regularly hold a march to the European Parliament. The idea, which became the ENIL Freedom Drive, has proven to be a great success for the growth of our movement. It continues this year in Martin's memory, with the hope of inspiring a future generation to carry on the battle for Independent Living and for the full participation of disabled people.

Martin, whose life is described in more detail later in this publication, founded the Freedom Drive in 2003, with support from the ENIL Board. The idea was the result of a meeting by a committed group of activists in Southampton, England, who wished to revive the Independent Living movement in Europe. The meeting resulted in a decision to mobilise people across the continent through a march to the European Parliament. The Freedom Drive started in Strasbourg, with campaigners vowing to return every two years, until Independent Living was a reality for all disabled people in Europe.

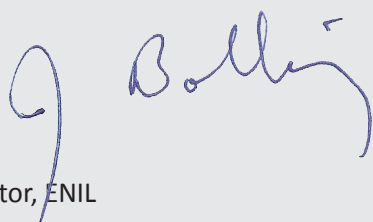
Today, the ENIL Freedom Drive is one of our most important lobbying and awareness raising activities. Held over the course of a week, it is a chance for hundreds of disabled people to come together to meet new and old friends, to exchange experiences on Independent Living and to speak to their MEPs about the importance of Independent Living, accessibility, access to personal assistance and other vital issues. The march is an opportunity for disabled people to be visible, to make their opinions heard and to present themselves as a strong, united voice for change. An active exchange of information and ideas takes place during the events, inspiring young disabled people to learn from their experienced counterparts in becoming the next leaders of the Independent Living movement.

In 2015, the ENIL Freedom Drive moved to Brussels, to better reach the EU policy and decision makers. Despite being Europe's political capital, Brussels is one of the least accessible cities. By hosting the events in Brussels, ENIL exposes the injustice of inaccessibility and campaigns for changes to be made. Over the years, the Freedom Drive has been used to put forth demands, including calls for the EU ratification of the UN Convention on the Rights of Persons with Disabilities (UN CRPD), personal assistance for all and the use of EU funds to support community-based services, rather than institutions.

Campaigners return from the Freedom Drive motivated to make real changes in their communities. The events could not be successful without the campaigners, many of whom overcome immense barriers to attend. Through the Freedom Drive, disabled people show they are active citizens keeping the flame of the Independent Living movement alive.

The 2017 theme for the march and this publication is the Heroes of Independent Living – Past, Present and Future. This publication shares a glimpse of people who have made ENIL and our movement strong. It could not include everyone but highlights some of the key people who made the European Network on Independent Living what it is today.

May this Freedom Drive be another great success! I am looking forward to meeting all and following ENIL in the years to come with Zara Todd in the lead. She will, I believe, make our movement an even stronger resource for the achievement of Independent Living for all disabled people in Europe.

A handwritten signature in blue ink, appearing to read 'J. Bolling'.

Jamie Bolling
Executive Director, ENIL

Why ‘Heroes’?

The term ‘hero’ is contentious in the disabled community. Non-disabled people often tell us that we are heroic and inspirational for doing ordinary tasks like getting out of bed, going to the shops and going to school. This reinforces the idea that disabled people are incapable of living ordinary lives. When we disprove the low expectations, we are considered to be extraordinary heroes, which contributes to the continued oppression of disabled people, is very patronising and far from the truth. Therefore, many disabled people refuse to associate with the labels of ‘hero’ and ‘inspirational’ altogether.

However, at ENIL, we assert that disabled people are capable of truly heroic acts. Activists in the Independent Living movement have made a real and profound difference to the lives of countless disabled people, and have rightfully inspired the next generation of disabled campaigners to follow in their footsteps and continue the great work. These heroes should be recognised and celebrated for their immense achievements. This is why we are reclaiming the word ‘hero’ and celebrating the true heroes of the Independent Living movement with this publication.

Content Summary

This publication explores the Independent Living heroes from the past, present and future who have made ENIL what it is today. We are unable to mention all of the Independent Living heroes across the continent, so we focus on key people who have helped to make ENIL a strong united movement. We begin with our roots, introducing two of the founders of the Independent Living movement in the USA, Ed Roberts and Judith Heumann, and the pioneers who brought Independent Living to Europe – Adolf Ratzka, the founder of ENIL, and John Evans, a key person in the closure of residential institutions in the UK.

We have dedicated a place to honour those ENIL Board members and Independent Living movement leaders who have passed away in the recent years, including Martin Naughton, Peter Lambreghts and Bente Skansgård. Some people who currently play a key role in promoting and advancing the cause of Independent Living in Europe are also presented, such as Gordana Rajkov, Kapka Panayotova, Nadia Hadad and Jamie Bolling. This is followed by a look towards the future of the movement, and the contribution of the ENIL Youth Network founders. Wisdom from the next generation closes this publication, highlighting how important disabled children and young people are to the movement.

Independent Living: the Beginnings

ENIL is an organisation that evolved from the Independent Living movement that first started in the USA and spread to Europe in the 1980s. Below is a brief introduction to two of the American founders, as well as a description of how ENIL was established.

Ed Roberts is considered the father of the Independent Living movement and, for many, Judith Heumann is the mother. Ed Roberts (1939 – 1995) started the first Centre for Independent Living in Berkeley, California in 1972 with a group called the Rolling Quads. Its members, all students at the University of California in Berkeley, were activists, protesting against the arbitrary restrictions placed on them by the rehabilitation counsellors in the centre where they had to live to attend the university.

Judith Heumann (b. 1947) promoted Independent Living on the other side of the country. She was born in Brooklyn and her first fight was to receive her graduation diploma. She was not able to participate in gymnastics and was being blocked from graduating, having incompletes in her records. As Ed had done in his campaigns, Judith turned to the media to show how ridiculous this decision was. She did graduate, fought her way to become a teacher and as of late has held different positions in both the Clinton and the Obama administrations.

As a result of the Independent Living movement lobbying for the adoption of the US Rehabilitation Act of 1974, universities in the USA became more accessible. Disabled students from Europe travelled to study in the USA and were inspired by the movement that Judith and Ed led. They then returned to their countries, spreading the concept of Independent Living throughout Europe.

Building the Independent Living Movement in Europe

Adolf Ratzka



Adolf was behind the founding of ENIL in 1989. Along with comrades in Sweden, he advocated for a pilot project on personal assistance, which was crucial to bringing about the Swedish LSS legislation. LSS was the first legislation in Europe which guaranteed personal assistance as a civil right.

A total of 72 disabled people from more than 20 countries met in Strasbourg in April 1989 for a three-day conference on personal assistance. The idea for the conference was conceived in Cologne at a meeting on Independent Living a year earlier. At a break during the meeting, a handful of people, among them Lothar Sandfort, Horst Frehe, Rachel Hurst, Judy Heumann and Adolf Ratzka discussed what could accelerate the spreading of the Independent Living philosophy. A solution was needed all over Europe, where the vast majority of people with extensive disabilities were still languishing in residential institutions. Lothar Sandfort, a wheelchair user, who at that time was the disability spokesperson for the Green Party in the German Parliament, proposed the idea of using his Green Party contacts to organise a conference on personal assistance. He managed to get the European Green parties to finance the event and arrange access to a large meeting room at the European Parliament.

Adolf Ratzka was asked to present the keynote address. In the presentation, Adolf urged the participants to form an informal, fast and flexible network of disabled people who were committed to the principles of Independent Living. His suggestion was accepted. The first governing board of the European Network on Independent Living - ENIL was elected, with Adolf becoming the chair.

Before this, in 1973, returning to Europe from California, Adolf found himself in Sweden, having received a scholarship to do research at the Royal Institute of Technology (KTH) in Stockholm. At the time, he had no personal assistance and was forced to adjust his schedule to that of the social workers. This meant getting up at 7 o'clock in the morning and going to bed at 10 in the evening, even at weekends. Adolf was used to university life and staying up with friends until late at night. This led him to gather a group of disabled people interested in personal assistance, with whom he started the first Centre for Independent Living (CIL) in Sweden - STIL.

The STIL pilot project proved that disabled people could manage their own personal assistance, with peer support for capacity building. Eventually, personal assistance became a reality in Sweden and has thereafter spread within Europe. The Swedish legislation LSS was adopted in 1993, and was the first legislation in Europe to recognise personal assistance as a civil right.

Adolf went on to establish the Independent Living Institute (ILI) in 1993, also in Stockholm, and still acts as its chair.

John Evans OBE



One of the founders of Project 81, John was a key figure in kick-starting the Independent Living movement in the UK. He chaired ENIL for many years and is still working to bring about deinstitutionalisation and to develop Independent Living throughout Europe.

John Evans was one of the founders of Project 81, which marked the beginning of the Independent Living movement in the UK. Through the project, John made the journey from institutionalisation to living independently and the experience he gained has led to the establishment of one of the first Independent Living schemes in his country. In 1981,

John was one of the first disabled people to travel to the USA from Europe, to learn and explore more about how Independent Living started and how it spread so rapidly in the 1970s. He prospered from what he learned and, once back in the UK, helped set up the first CIL in the country. John was also one of the founders of the National Centre for Independent Living (NCIL) some years later. He was the chair of ENIL from 1996 until 2007 and was involved in setting up ENIL Secretariat in Ireland and Valencia. In 2005, John helped establish the European Coalition for Community Living (ECCL). As an ENIL Advisory Board member, John is still working hard to promote Independent Living and deinstitutionalisation within Europe and to fight austerity.

John is currently a trustee of the Social Care Institute for Excellence (SCIE) in the UK and has run his own disability consultancy for over 20 years. Passionate about co-production, which he has actively worked on for ten years, he believes this is the way forward for disabled people throughout Europe to achieve real change and progress - by working in partnership with politicians, health and social care professionals on an equal basis. He feels that one of our biggest challenges is counteracting the impact austerity has had in many European countries, threatening the very future of Independent Living.

The list of leaders who have gone to the USA, bringing back knowledge on Independent Living, could go on, and would include other ENIL leaders such as Kapka Panayotova and Bente Skansgård. Bente and her father shipped Bente's accessible car to the States, so that she could travel from one place to another to meet the various CILs. More on Bente and Kapka can be found further on in this publication.

Independent Living Heroes: the Past

This section honours several members of the ENIL Board who passed away in recent years. Our Board members are volunteers, tasked with providing ENIL and the Independent Living movement with their strategic leadership. It is their time and effort that enable us to advance Independent Living within Europe.

Sadly, between 2009 and 2017, ENIL lost seven of its Board members. All of them were at the height of their careers, with many plans and energy to change things for the better. All were great people and strong leaders within the Independent Living movement; all left a vacuum behind them. This publication honours these leaders, referring to them as the Independent Living Heroes of the Past. They are presented in alphabetical order, with the exception of Martin Naughton, in recognition of having started the ENIL Freedom Drive.

Martin Naughton



Martin started the ENIL Freedom Drive and spent his life promoting Independent Living in Ireland, Europe and around the world. A charismatic leader, with friends in almost all the countries and at all levels of government, Martin helped shape ENIL into what it is today – one of the key EU-level disability organisations.

The Freedom Drive is just one of Martin Naughton's great achievements. As a co-executive director of ENIL, he worked with the past ENIL Chairs to build the secretariat in Valencia, then in Dublin and to develop personal assistance across Europe. Through his contacts, Martin opened doors for cooperation in research and advocacy on the UN Convention on the Rights of Persons with Disabilities (UN CRPD). A wheelchair user from the age of nine, Martin spent most of his childhood in an institution. Personal experience of the indignity of institutional living gave him the passion and determination to push for achieving Independent Living for all

disabled people. He led the Independent Living movement in Ireland, founding Ireland's first Centre for Independent Living (CIL). Today, there are more than 20 CILs across the country. Martin was very persuasive, never afraid to challenge authority when it came to the rights of disabled people. In 2014, he led a sleep out outside the government buildings that forced ministers to reverse cuts to personal assistance schemes. His most recent appointment was on the Taskforce for Personalised Budgets for People with Disabilities. Martin was influential in the development of the 5-year €100 million plan to get disabled people out of institutions. An expert in personal assistance, he was held in high regard. Many high profile figures have paid tribute to Martin, including Ireland's President Michael D. Higgins.



“As a political activist, Martin Naughton had the vision, skills and determination to build solidarity between all those who strive for equality, dignity and the fulfilment of human rights for all groups in society, making him a valuable ally for a multitude of social justice groups. His struggle for equality in Ireland and internationally has been an inspiration.”

Michael D. Higgins, President of the Republic of Ireland

Debbie Jolly



Debbie was a passionate and successful supporter of Independent Living. As one of the founders of Disabled People Against Cuts (DPAC), she succeeded in raising awareness of the cuts to services impacting on far too many disabled people in the UK.

Debbie Jolly was a tireless campaigner for disabled people, combining anger and determination with joy and vibrancy. She worked for over 20 years on the local, national and international levels. Born and raised in East London, she spent most of her life in Leicestershire with her family. She was one of the founders of Disabled People

Against Cuts (DPAC), often referred to as one of the most effective campaign groups in the UK. DPAC fights against austerity measures, which are having a detrimental, in some cases life-threatening effect on many disabled people.

Debbie worked for ENIL from 2007 to 2009 and joined the ENIL Board in 2013. She was a forceful campaigner on deinstitutionalisation and worked on the ENIL projects in Turkey and Spain. Passionate about grassroots campaigns, she made sure that ENIL engaged with people on the local level in their communities.

Debbie was an appreciated and generous mentor, who was always willing to offer her time. She passionately believed that disabled people should get involved in their communities to make a change. Debbie managed brilliantly to combine academia with activism. After completing her Postgraduate Diploma in Disability Studies at the University of Leeds, Debbie wrote many publications, on Independent Living and the UN CRPD, and was a member of the Academic Network of European Disability Experts (ANED). Having spoken to disabled people about the Convention, she found that they wanted a strong monitoring system in place, as well as sanctions for countries that failed to implement it. Debbie went on to successfully lobby the CRPD Committee to investigate failings of the UK government in upholding human rights of disabled people.



“I will miss Debbie greatly; not just her company, but her ability to educate, to teach, to listen, to inspire a political passion, and to drink more tea than us at any one sitting.”

Paul Darke, an academic, writer and cultural critic

Peter Lambreghts



Peter's life was Independent Living and his work inspired others and led to change in society. He was a strong role model for many in Belgium, but also throughout Europe. His family was of utmost importance. People were shown pictures of his beautiful daughters, his 'princesses'; a symbol for Peter that he was living life to the fullest.

‘Independent Living is not only my job, it's my life.’ This is what Peter Lambreghts said when asked about his connection to the movement, and the sentiment was certainly reflected in his

work. He was a member of many groups, organisations and think tanks on disability. His work spanned a wide range of areas, including awareness-raising, peer support, accessibility, transport and employment. Peter improved accessibility and participation for disabled people in his own village and lobbied EU politicians on personal assistance.

Elected to the ENIL Board in 2010, he went on to work as the Western Regional Coordinator and Senior Officer for ENIL. He shared his time between ENIL and the Flemish Independent Living organisation Onafhankelijk Leven, and was also on the Board of Directors of the European Disability Forum. Peter advocated among disabled people and leaders at all levels in society.

Born in Antwerp in 1971, his parents chose to teach Peter at home, rather than send him to a special school. A user of Personal Assistance for most of his life, he believed that choice, control and participation in society were the key elements for disabled people to live full lives. During his time at the Expertise Centre for Independent Living, he conducted research on personal budgets for disabled people, focused on the financial and economic implications of personal assistance. An author, trainer and a public speaker, Peter was an important figure in the Flemish and European disability movement. His many different skills, translated into actions, made a real difference in the lives of many disabled people.



“We know Peter mainly as an extraordinary man, a great inspiration to many people. With his hard work, strength and strong vision, Peter wanted to change the world: to achieve full inclusion for people with disabilities.”

Onafhankelijk Leven

Manuel Lobato



Manuel was a key figure in the Independent Living movement in Spain. Among his many successes were the establishment of the Spanish Forum for Independent Living, his advocacy for personal assistance and the establishment of ENIL's partnership with the Region of Valencia.

Described as a tsunami of vitality, Manuel Lobato was an activist with integrity and clear ideas. Disabled from birth, he struggled in the Spanish school system, but his parents fought for him to be treated equally. He was compelled to join the Independent Living movement after experiencing discrimination first hand. He had a thirst for knowledge, learning as much as he could about

Independent Living. In his later years, Manuel studied social anthropology and promoted the idea of 'functional diversity'. He saw community living as a right and not just an act of solidarity. Manuel gave numerous lectures and seminars, and attended conferences to raise awareness about Independent Living. He was instrumental in establishing the ENIL Secretariat in Valencia. His contacts and negotiating skills resulted in the successful launch of the Secretariat in 2005, and financial support from the region until 2012.

In 2001, Manuel founded the Foro de Vida Independiente, the start of the Spanish Independent Living movement. Independent Living ideas spread very quickly to different parts of the country, with over 800 members joining the informal network. Manuel was a bold campaigner, always looking for new ways to make an impact. He took part in a lock-in in the Spanish government buildings for 25 hours in awful conditions, demanding the right to personal assistance. Many big demonstrations were planned by Manuel, one during which

protesters built cages around themselves and wore pyjamas to show how inhumanely disabled people were treated. Manuel's courage and creativity greatly inspired many of his successors.

“Manuel was a philosopher with a quest for knowledge. He was a passionate leader of the Spanish Independent Living movement, for which he felt strongly. Without him, independent living would not have spread so successfully and rapidly throughout Spain. Manuel fought against all the odds to make Independent Living and personal assistance a reality in Spain and, indeed, it achieved great things. His legacy lives on in Spain.”

John Evans, a disability activist

Erik Ljungberg



Erik died at his desk in the middle of organising a media debate on accessibility – a death on the battlefield for the rights of disabled people. The right to access public transport was a central focus of Erik's work. He successfully campaigned for improvements to the Gothenburg public transport, a city where he lived.

Erik Ljungberg was a Swedish disability rights campaigner and an ENIL Board member. His work focused on advancing accessibility, especially of public transport, and on raising awareness of disability issues through technology. Erik's website was the main tool of his campaign for accessible transport, through which he was able to show the discrimination

of disabled people by transport companies. He started a blog 'Full Participation Now' in the lead up to the 2010 Swedish elections, to ensure that disability issues and especially personal assistance were placed high on the political agenda. Many disabled people in Sweden use AiAi, an online administrative tool for personal assistance that Erik developed. Erik won awards for his work, including the STIL Prize for Civil Courage in 2005, the Swedish Interest Group for Assistance Users' (IFA) Scholarship in 2010, and the prize for an app which makes it easy for disabled people to find accessible restaurants in Sweden. Erik's ultimate aim was to make disability issues easy to relate to, engaging and appealing to both decision makers and the general public.

“A devoted, diplomatic, kind and creative person, Erik won the hearts of many. Erik is missed greatly in Sweden and in Europe.”

Jamie Bolling, ENIL Executive Director

Bente Skansgård



Bente, the “Mother of Independent Living” in Norway saw to the development of personal assistance in her country. To-day, over 3000 people access and control their assistance in Norway and lead active lives with full participation.

Bente spent her whole working life fighting for the rights of disabled people. Starting her career in accessible housing services, she went on to found ULOBA, Norway’s first Independent Living organisation in 1991. Bente was also one of the founders of ENIL; she acted as Chair and served on ENIL’s Advisory Board. She supported the Spanish Independent Living movement and helped establish the ENIL Secretariat in Valencia in 2005.

Paralysed from a diving accident at the age of 13, Bente spent 4 years confined to her own home, before fighting to go to school and university. She studied Sociology at the University of Oslo and was awarded a scholarship to study Independent Living in the United States. As there was no assistance available at the time, Bente was obliged to make the trip with her father.

A campaigner and a great motivator, Bente believed passionately in peer counselling and learning from one another. Although treated with scepticism, she and four other disability activists established ULOBA to promote personal assistance in Norway. From these humble beginnings, ULOBA has grown into an organisation that gives access to personal assistance services to over 3000 disabled people all over the country.



“Bente’s great project was the struggle for equality. To many of us, she was a guiding star and a role model we aspired to. Bente was not just a source of generous and warm support; she was a highly capable and knowledgeable expert who never lost sight of the ideal of freedom. She was an ideological giant who uncompromisingly held the political banner high.”

Vibeke Marøy Melstrøm, a co-founder at ULOBA

Donal Toolan



Donal sat on a number of high level committees, including an advisory body to the President of Ireland, and was an observer during the drafting of the UN CRPD. He raised awareness of disability rights using the radio, television and theatre.

Born in County Mayo, Ireland, Donal was a wheelchair user from early childhood. By his twenties, he had already gained widespread respect as a disability rights campaigner. In his mission, he joined Martin Naughton and fellow activists, founding a number of advocacy groups, including the

Forum for People with Disabilities (FPD), which he managed. In 1991, Donal was the first disabled person to be nominated as a member of the Council of State, an advisory body to the President of Ireland. In order to get rights-based legislation for disabled people in Ireland, Donal was engaged in the negotiations with the Commission on the Status of People with Disabilities in 1993 and the process leading to the Disability Act 2005. Internationally, Donal Toolan represented FPD, acting as an observer during the drafting of the Convention on the Rights of Persons with Disabilities.

As a journalist, actor and playwright, Donal's work strongly complemented his human rights activism, with its heavy focus on raising the visibility of disabled people and awareness of the barriers they faced. Highlights of his broadcasting career were the RTÉ Radio series "Not So Different" and the RTÉ television documentary series "In from the Margins". For the latter, Donal received a Jacobs award and the National Broadcast Journalist of the Year prize.



"Donal made an enormous contribution to defining the rights of people with disabilities as a question of fundamental human rights. He was a fearless and brilliant campaigner who believed passionately that people with disabilities must lead the fight for dignity and justice for all those affected by disability in all its forms."

Liam Herrick, Executive Director of the Irish Council for Civil Liberties (ICCL)

Independent Living Heroes: **the Present**

The Global Independent Living movement has been fighting for disabled people's rights since the 1960s and, while many disabled people now live independently, our struggle is still in full swing. Independent Living has gained grounds, especially with the adoption of the UN CRPD, where Article 19 entrenches the right to live independently and to be included in the community. However, alongside this important treaty come many problems - the hijacking of our language, cuts to personal assistance services and disabled people continuing to be segregated in institutions.

This section introduces some of our great leaders, actively promoting the development of Independent Living in their countries and within ENIL.

Gordana Rajkov



Gordana is considered the leader of the Independent Living movement in Serbia. As a Member of Parliament, Gordana changed the landscape for disabled people in the Serbian politics. She raised awareness on disability and ensured that in the future, disabled people would not face the same barriers to political participation she did.

Gordana Rajkov, from Belgrade, Serbia, has been a disability activist since 1966. She was an ENIL Board member from 1996 until 2012, when she joined ENIL's Advisory Board.

Gordana founded the Muscular Dystrophy Association of the former Yugoslavia and served as the president of the European Alliance of the Muscular Dystrophy Associations. In both organisations, Gordana lobbied

for changes in legislation and creating measures to protect the rights of disabled people. In 1992, she was invited by Martin Naughton to come to Ireland and join the CIL Dublin, where she stayed until 1995.

Back home, Gordana founded the CIL Serbia, which has since grown into a strong organisation. CIL Serbia has 10 local sections throughout the country, all advocating for Independent Living and the provision of community-based support services, including personal assistance. Since the establishment of the CIL Serbia, Gordana has fought for personal assistance to be included in the Serbian social welfare system, while at the same time piloting the provision of personal assistance. Eventually, in 2011, a new Social Welfare Law was adopted, which included personal assistance as one of the community-based services for disabled people. CIL developed standards for the provision of this service, underpinned by the Independent Living philosophy.

Gordana was the first disabled member of the Serbian Parliament (MP), serving from 2007 to 2012. She saw how important it was for disabled people to have a voice in the Parliament, as her fellow MPs could see first-hand the barriers she faced and how they could be removed. Her presence in the Parliament brought many positive changes in the legislation and Parliamentary procedures, including that the support needs of disabled MPs must now be met. This provision did not exist before Gordana became an MP and it remains in effect for the future.

Elena Pecaric



Elena defied expectations to complete her studies and live independently. The founder of the Independent Living Project in Slovenia, Elena is a strong advocate for community-based services and deinstitutionalisation. She is never afraid to stand up to authorities in the name of Personal Assistance and Independent Living.

Who is a hero? A person who does things that other people do not even dare to think about. That is what Elena did. After spending many long and tortuous years inside an institution for children and youth, she had decided that she would not return

home. She enrolled at a university, having decided that she wanted to study. Despite the fact that, at that time, there were no services to support disabled people to live independently, Elena started living with a friend on her own, the way she wanted to. She relied on volunteers and friends at first to get the required assistance, in order to start living independently.

Elena is much more than just the founder of the YHD Association. She is a pioneer, who has built the road to Independent Living in Slovenia. She was always on uncertain ground and always determined, because she was principally opposed to living in an institution. Elena was the one who had the courage to stand up to experts in public and oppose them on behalf of personal assistance users. When even other disabled people told her that personal assistance was a luxury, she started the Independent Living Project in Slovenia and organised paid personal assistance for disabled people. Long before Article 19 of the UN CRPD became binding, long before the talk of deinstitutionalisation became prevalent in public, Elena had advocated for the right to live in the community and fought against putting people into institutions.

Thanks to Elena's work, a bill on personal assistance was signed into the Slovenian law this year. Coming into effect on the 1st of January 2019, it will guarantee personal assistance to all disabled people in need, up to 24 hours per day.



"Elena is an author, a columnist, an activist, a philosopher and a sociologist of culture. She is a filmmaker, a journalist, a role model, and a former candidate for the President of the Republic of Slovenia; above all, she is a friend and a colleague."

Klaudija Poropat, YHD Association

Corina Zolle



Corina has dedicated her life to her two passions - biology and Independent Living. She founded the Centre for Independent Living in Mainz while still at university, and to this day, remains passionate about the right to personal assistance.

Corina Zolle is a molecular biologist and a powered wheelchair user from Germany. Born in 1966, Corina had to fight to attend mainstream school. She was successful, but felt she could not rely on the support of her teachers. She could only access secondary school by being carried up and down the

stairs by friends. After an operation to fuse her spine at the age of 16, Corina decided to live in an institution for disabled people in order to finish school.

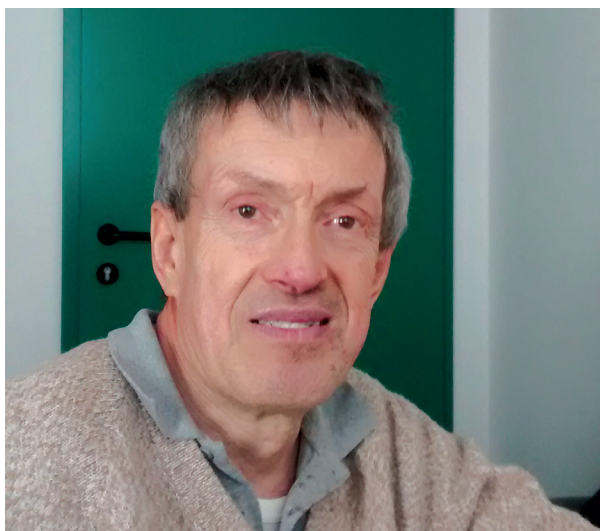
Corina wanted to study medicine at university, but felt this would be too ambitious as a disabled person, so opted for biology, starting at the University of Mainz in 1986. Even then, many doubted she would be able to complete her studies. Her parents paid for personal assistants to carry her up and down the stairs in her first year. She later fought for personal assistance from the authorities.

At university, she first came into contact with the Independent Living movement. Together with three or four other disabled students, she fought successfully to make the university accessible. It was at that time that she founded the Centre for Independent Living in Mainz.

When Corina moved away from home to write her thesis, she had to fight for the right to female personal assistants. It took many years to convince the authorities, but eventually she succeeded. She went on to complete her PhD, with support from personal assistants in all aspects of her life.

Upon finishing her studies, she worked for the CIL in Mainz. After seven years, she returned to science and became a molecular biologist. However, 10 years later she came back to the Independent Living movement and founded a new organisation, where she works as a peer counsellor for personal assistance users. Corina remains very ambitious and says that, at 51, she is still full of plans.

Raffaello Belli



Raffaello co-founded the Centre for Independent Living in Florence and ENIL Italia. He has fought for over 25 years for disabled people to have choice and control over their lives and has written many publications on Independent Living.

Raffaello was politically active from a young age, attending student protests in 1968. He first learned about personal assistance from a friend, but did not realise its connection to the Independent Living movement until he read Adolf Ratzka's papers. It was from then on that he resolved to become part of the fight for Independent Living. He wrote his thesis on Independent Living, making it the first paper on the subject in Italy.

Co-founder of the first Italian Centre for Independent Living in Florence in 1991, Raffaello has been

part of the movement ever since. He attended the founding meeting of ENIL in 1989 in Strasbourg and joined the ENIL Board. In November of the same year, he was on the organising team of the first EU conference on Independent Living in Rome. In 1992, Raffaello helped establish ENIL Italia and, together with CIL Florence, they have been advocating for the self-determination of disabled people in Italy over the past 25 years.

Since 1990, Raffaello has been working at the main Italian Research Institute on Legal Science, writing extensively on equality and the right to self-determination for disabled people.

Kapka Panayotova



Kapka introduced personal assistance in Bulgaria, at a time when most disabled people in Central and Eastern Europe were isolated at home, without support, or institutionalised.

Kapka Panayotova is the current ENIL President and a well-known disability leader and human rights advocate in Bulgaria. Kapka grew up a stubborn and curious child, eager for freedom and with a love for life, characteristics that she carries through her adult life and activism. She credits her parents for having major influence in shaping her personality, for providing her with great love and support, but also with equal responsibility in daily chores as a family member.

Despite learning to read and write at the age of four, young Kapka was referred to a special school due to her disability; a failed attempt fought by tears and a hunger strike. Years later she would put the same zeal and anger in fighting for deinstitutionalisation in Bulgaria.

Having returned from an internship at the John Hopkins University in Baltimore, Maryland, she helped start the Independent Living movement in Bulgaria in 1995. It was then that the Centre for Independent Living Sofia was formed.

Her activism consisted of empowering disabled people in Bulgaria and other Balkan countries, as far as the Caucasus, where she has worked with disability groups in Armenia, Azerbaijan and Georgia. She describes herself as the 'troublemaker' for the government. Her firm ideas about human rights and outspokenness have brought to light many discrimination cases in Bulgaria. This has resulted in the denouncement of key legal provisions, leading to the development of an entirely new Bulgarian anti-discrimination legislation.

Over the last ten years, Kapka has worked as a disability consultant, trainer and researcher in Bulgaria. She has contributed to the International Disability Rights Monitor and the work of the Academic Network of European Disability Experts (ANED).

Baroness Jane Campbell



Baroness Campbell has fought to live an active life, leading to her appointment to the House of Lords in the UK. Independent Living was her goal and with this in mind, she established the National Centre for Independent Living in 1996.

Baroness Jane Campbell is a member of the House of Lords in the UK. She started her life in segregated schools for disabled children where academic achievement was not the top priority. Jane left school at the age of 16, with no qualifications and hardly able to read or write, but did not lack in self-confidence. She continued to study and eventually completed a Master's at the University of Sussex.

Jane has held many high-level posts, including Commissioner of the Equality and Human Rights Commission (EHRC) from 2006 to 2008. She served as Chair of the Disability Committee, leading to the EHRC Disability Programme. A former Chair of the Social Care Institute for Excellence (SCIE) and Commissioner of the Disability Rights Commission, she has witnessed the closure of the Independent Living Fund in 2015 and too many cuts to benefits and support for disabled people.

In 1996, Jane co-founded and directed the National Centre for Independent Living (NCIL), where she worked for six years before being appointed the Chair of the SCIE. She continues as an active leader in the social care field, as a campaigner and advisor on disability rights. As Chair of the British Council of Disabled People, and co-founder of NCIL, Jane saw these organisations through pioneering work in the field of Independent Living, civil rights, peer counselling and equal opportunities. In 1996, Jane co-authored the book entitled 'Disability Politics' and received an honorary title from the Queen in 2001.

Jane was awarded an honorary doctorate in law from the Bristol University and another in social sciences from Sheffield Hallam University. She was appointed to the House of Lords in 2007, where she sits for life ('a life peer') as an independent member. Jane's title is Baroness Campbell of Surbiton.

Vibeke Marøy Melstrøm



Vibeke is the General Secretary and one of the founders of ULOBA – Independent Living Norway. She has spent 20 years campaigning tirelessly for the right to personal assistance in Norway, along with Bente Skansgård.

Vibeke Marøy Melstrøm is the General Secretary and one of the original five founding members of ULOBA - Independent Living Norway. In 1989, at the age of 20, she spent her first year as a disabled person in a rehabilitation institution. It was there that she met Bente Skansgård, who persuaded her to join the working group for personal assistance. Bente became an important role model for Vibeke and, along with others, has inspired her to contribute to the establishment and development of personal assistance in Norway.

For more than two decades, Vibeke and her colleagues have worked tirelessly with disabled people and politicians. Established in 1991, ULOBA has grown into a large organisation with 1400 members and 120 administrative staff. They have played a vital role in the effort to promote equality and to achieve a legal

right to personal assistance in Norway. This resulted in the adoption of the Norwegian personal assistance legislation, which came into force in January 2015.

Vibeke has dedicated her entire adult working life to ULOBA and sees herself as an Independent Living activist with a 30-year track record. From 2007 to 2015, Vibeke served on the Board of ENIL – during the last five years as its Co-chair. She has since joined ENIL's Advisory Board and has initiated the establishment of the Bente Skansgård's Independent Living Fund, where she serves as a member of the Board.



“Strong, proud and visible! Vibeke is a strong woman who has inspired and continues inspiring many of us to raise awareness about Independent Living. Hundreds of people gather on the streets of Oslo each June with Vibeke in the lead, making a difference not only in Norway, but also in Europe, changing our lives for the better.”

Jamie Bolling, ENIL Executive Director

Nadia Hadad



Nadia is passionate for everyone to have access to Independent Living, no matter which part of the world they live in. Her work leads her back to her roots in Africa, where the UN CRPD and Independent Living advocacy are yet to make a real difference.

Nadia's origins lie in Morocco, the country of her parents, where she spent a part of her teenage years. She became an anti-discrimination activist at a young age. Returning to Belgium to complete her secondary education, she studied civil engineering and specialized in mechanical conception and water resourcing. She also studied human ecology, environment coordination and philosophy. Nadia interned with different NGOs, in India, Ecuador, Cameroon and Palestine, among other, and has worked for the Belgian Technical Cooperation.

In 2003, while working as a cooperation-developer in the rural area of Senegal, Nadia had a car accident and became disabled. After two years of rehabilitation in Belgium, Nadia took the decision to combine disability and development cooperation as her future career. She joined several organisations and became the Vice President of the Consulting Council for Persons with Disabilities in Brussels. She also worked as an international policy officer for the Platform for Disability and Development Cooperation (PHOS).

Nadia is currently on the Board of GRIP (Equal Rights for Each Person with a Disability) and a number of other organisations. She is a member of the Belgian Supervising Commission within the independent mechanism for the implementation and monitoring of the UN CRPD in Belgium, a member of the International Disability and Development Consortium (IDDC) and of the Fundamental Rights Platform (FRP) Advisory Panel.

Since 2013, Nadia has been a Board member of ENIL and in 2017 was elected to the Board and the Executive Committee of the European Disability Forum. As a Brussels native, Nadia has helped ENIL move from Dublin to Brussels in 2015, to be closer to the EU institutions.

Jamie Bolling



Jamie has led the European Network on Independent Living on its development journey from 2009 to 2017. A woman who never sits still, she refers to the Independent Living movement as her farm – a farmer never takes a vacation. It is the same for ENIL. The organisation never sleeps. No matter the day of the year, there is an email in the box. That is thanks to the great engagement and diversity of our movement.

The Executive Director of ENIL from May 2009 until October 2017, Jamie Bolling has three passports, two daughters and a passionate drive for Independent Living.

Based in the north of Sweden, Jamie was introduced

to Independent Living in 1993 and was trained at STIL – the Swedish Independent Living organisation – at a time when it was chaired by Adolf Ratzka. Having Adolf as a mentor helped Jamie learn about the importance of empowerment, the need for disabled people to express their self-determination and to take control of the services that allow one to live a life with full participation. Jamie became the chair of STIL in 1996 and is currently a Board member of the organisation.

Jamie combines her experience in politics as a county councillor and from different appointments at the local, regional, national and the EU level, with her vast knowledge of the international disability movement. Being herself an immigrant in Sweden, she experienced discrimination and has actively advocated for equality and human rights. Jamie was a member of the Fundamental Rights Platform's Advisory Panel from 2010 to 2014, where she promoted the rights of disabled people.

ENIL has become stronger and larger under Jamie's direction. However, having served the organisation for eight years and having overseen the move to Brussels, she has decided to hand over the steering wheel to a younger person. Jamie's future work will be with Adolf Ratzka and the Independent Living Institute in Stockholm, where she will be the organisation's director and a coordinator of the Disabled Refugees Welcome project.

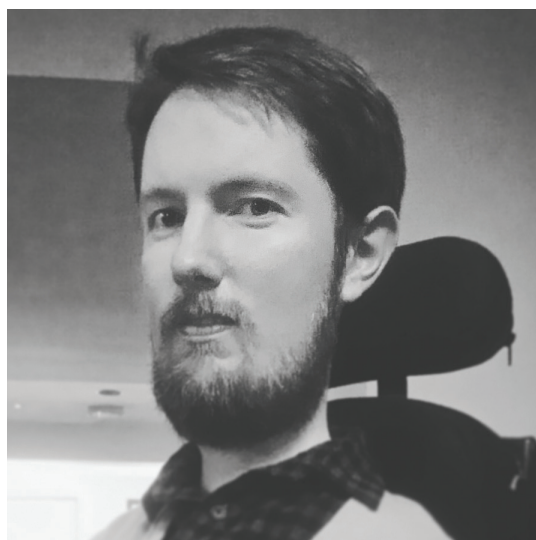
Independent Living Heroes: the Future

The heroes we have honoured so far have done vital work to further the cause of Independent Living. However, as ENIL knows, it is important to remember that established leaders cannot indefinitely continue to campaign. Young people are a group who traditionally face even more barriers to getting their voices heard. It is, therefore, a paramount duty of our movement to provide capacity building and allow space for the development of the skills of young disabled people. They are the future leaders and they must be able to develop their own ideas and to have their say.

The ENIL Youth Network aims to do just that. It is one of the only cross-impairment groups of young disabled people in Europe and it is the only one with free and open membership. Since its inception in 2012, the Youth Network has grown from just 16 committed young activists to a group of over 600 enthusiastic young disabled people. The Youth Network gives disabled young people a chance to campaign on the issues that matter to them and to connect with other young people experiencing similar barriers at a local, national and the European level. The Youth Network informs young disabled people about different aspects of the Independent Living movement and builds their capacity to become leaders. This is done through webinars, study sessions and collaboration on an informal level.

In the next section, we present the founders of the Youth Network and the future of our movement.

Miro Griffiths



Miro has been involved in several youth networks and disability organisations from a young age. He advises civil society and governments on issues relating to Independent Living. Miro is in the final stages of his PhD and lectures at a number of universities in the UK.

Born in Merseyside, England, in 1989, Miro became actively involved in disability rights as a teenager and has continued focusing on issues of social justice throughout his personal, academic and professional life. Growing up as a young disabled person, Miro recognised early aspects of marginalisation and exclusion, and began to question why it was a struggle to attend school, access support and engage in his local community. He became politically active when introduced to the social model of disability, which helped him to articulate disability as a consequence of how society functions. Miro was in-

involved in numerous youth networks and organisations, meeting influential figures such as Tara Flood, John Evans and Zara Todd - these connections opened the opportunity for dialogue with other committed activists and campaigners.

Miro constructs arguments that go beyond the personal experience, using data, stories from campaigners and literature to highlight key issues affecting disabled people. In 2007, aged 17, he was appointed to a strategic and confidential advisory network with the UK Government, where he stayed for six years. Throughout his work, Miro continues to advise local, national and international civil society organisations and governments on issues pertaining to Independent Living, disability hate crime and the impact of political ideologies. He lectures at a number of universities and holds board positions with, amongst others, the Alliance for Inclusive Education, DadaFest and the ENIL Youth Network.

Miro's academic background includes a Master's in Disability Studies. He is currently in the final stages of a PhD exploring young disabled people's experiences of political activism and social movements.

Radoš Keravica



In June 2017, Radoš was awarded his second Master's degree in Human Rights Law from the Central European University, where he wrote his thesis on deinstitutionalisation in the EU. Radoš is currently working as a disability rights expert in Serbia.

Radoš has been active in the national youth organisations since his early twenties, where he was involved in community volunteering, youth work and youth policy. In 2011, he joined Disability Rights Promotion International (DPRI), the global collaborative project led by York University, Toronto, in the role of the Regional Officer for Europe. The project focuses on the worldwide monitoring of the rights

of disabled people. Working for DRPI until 2016, Radoš had the opportunity to learn about disability rights and to be inspired by the DRPI co-directors prof. Marcia Rioux and the former UN Special Rapporteur on Disability Mr Bengt Lindqvist.

In 2014, Radoš attended ENIL's study session for young disabled people and joined the ENIL Youth Network, leading to a position on the ENIL Youth Board. Ever since, he has contributed to the network's development, organization and facilitation of study sessions and outreach activities to expand the ENIL Youth Network. He obtained his first Master's degree in International Economics from the University of Novi Sad, Serbia. In 2016, he received a full scholarship from the Central European University (CEU) in Budapest, to study Human Rights Law, which he completed in 2017. His thesis research focused on the role of the EU in advancing the process of deinstitutionalisation in the EU Member States and accession countries. Radoš was the representative for Serbia in the European Association of Service Providers for Persons with Disabilities (EASPD) program "Disability Leaders of Tomorrow – DLOT", aimed at building the capacities of service providers in 15 Central and Eastern European countries.

Currently, Radoš is working as a consultant for UN OHCHR Serbia as a Disability Rights Expert. He is the author of numerous publications and monitoring reports related to disability rights, rights of people living with HIV, social inclusion and youth, social services and indicators for implementation and monitoring of the UN CRPD.

Agnes Sarolta Fazekas



Agnes is currently finishing her PhD on access to higher education for disabled students. During her time on the ENIL Youth Board, she has facilitated several study sessions, represented disabled young people on the Council of Europe Advisory Council on Youth and has built a strong relationship between ENIL and the Erasmus Student Network.

Agnes is a Social Policy PhD fellow, focusing on access and inclusion of disabled people in higher education at the Faculty of the Social Sciences, Eötvös Loránd University in Budapest, Hungary. During her Master's degree programme, she made her first

contact with ENIL and spent her Erasmus work placement at the ENIL Secretariat in Dublin, with Martin Naughton as her mentor. In October 2012, Agnes participated in the ENIL Study Session “Supporting young disabled people to become future leaders of the Independent Living movement”, which had a huge impact on her personal and professional life. Agnes is very passionate about improving access and the inclusion of young disabled people in education, international mobility and youth activities. She has since facilitated a number of study sessions and led the latest one for ENIL in 2017, with a training style that inspires young people to realise their leadership potential.

During her term on the ENIL Youth Board, Agnes represented disabled young people on the Advisory Council on Youth of the Council of Europe (2016-2017) and coordinated the ENIL Youth Education Working Group. Having contributed to the inclusion and diversity agenda in the youth sector, Agnes is looking forward to seeing more cross-sectoral commitment towards the inclusion of all youth, including disabled youth.

Agnes has succeeded in building a strong relationship between ENIL and the Erasmus Student Network (ESN). Thanks to her commitment, disability and diversity are now being mainstreamed within ESN. Although Agnes will step down from the ENIL Youth Board at the ENIL 2017 Freedom Drive, she will continue to be actively involved in ENIL, working in the field of access and inclusion in both non-formal and formal education, higher education, international mobility, and social policy in the international context.

Stelios Kypouropoulos



An active participant in the ENIL Freedom Drives from 2009 to 2015, Stelios brought his passion for Independent Living to his home in Greece. He was one of six disabled people to establish I-living. Following this, Stelios was elected to the ENIL Board in 2015.

Stelios Kypouropoulos is a 32-year-old psychiatrist and sexologist, living in the suburbs of Athens, Greece. He is a quadriplegic disabled person, requiring 24/7 personal assistance. Although the Greek Government ratified the UN CRPD and the Optional Protocol, there is still no legal framework for hiring one's own Personal Assistants, which would be paid by the state. Therefore, Stelios lives with his family, a situation which is the norm for many disabled people in Greece.

Stelios' interest in the Independent Living movement started when he participated in the 2008 conference “25 Years of Independent Living in Sweden”. It was his

first experience of the Independent Living ideas and philosophy, and it changed his perception of disabled people's role in society. For the first time, he met all the living legends and experts on Independent Living in Europe and became inspired to attend the ENIL Freedom Drive to learn more. In 2012, Stelios was selected to take part in ENIL's first Study Session, “Supporting young disabled people to become future leaders of the Independent Living movement.” He then brought a group of 24 Greek members (11 disabled people, 11 PAs and 2 supporting staff) to the ENIL 2013 Freedom Drive. After this trip, seeing their situation with different eyes, the group established I-Living, the first Independent Living organization in Greece, in 2014. Finally, in 2015, Stelios was elected to the ENIL Board.

Wisdom from the Next Generation

This year, the ENIL Freedom Drive is focusing on children and young people. It is easy to forget that disabled children want to participate fully in society, but often do not have the carefree childhoods of their peers and can experience discrimination from a very early age. They are experts in their own needs and develop their own opinions and ideas about how an equal society can be created. It is crucial that the Independent Living movement fights for children and young people to be heard, and to have as much choice and control over their lives as their peers. Children and young people need to be provided with the space to voice their issues and they are to be treated with the respect they deserve.

This section introduces Wilma, an energetic young girl campaigning for Independent Living, with great promise for the future. Wilma will attend the 2017 Freedom Drive with her parents.

Wilma Hallgren



To Wilma, Independent Living means a lot. It means that she can do the same things as her friends. Already, Wilma is a TV star, having appeared twice to talk about having a disability and claiming the right to do all of the things that her peers do.

Wilma Hallgren has just turned 8. She lives in Kungälv, Sweden with her parents Anna Hallgren and Axel Stenhammar. She has a muscular disease, which means that her muscles are weaker. She can walk and run around like a non-disabled child, but uses a wheelchair so she does not run out of energy and strength.

She is a first grader in the Swedish school system. In her spare time, she likes to play with her friends and go to amusement parks. She also plays volleyball, soccer and cello. She came in contact with Independent Living through her mom, who has the same condition and uses personal assistance.

To Wilma, Independent Living means that she and her family can do the same things as other families with or without disabilities. She does not mind having a disability, since her friends do not treat her differently from anyone else. That is very important and makes her happy. She wishes the same for all kids in the world.

Wilma has been on the Swedish television twice. She was first interviewed with her mom on having a disability and finding support and benefits. She then appeared in a children's programme, where she was able to show that disabled children can do the same things as all the other children.

She is active in the Independent Living movement, as she believes all children have the right to be treated equally and to live a full life.

A Strong Network

The Independent Living movement would not be what it is today without the network of activists who fight for their rights and the rights of their fellow disabled people every day. It would not have started without the pioneers who brought the ideas of Independent Living over from the States, and who fought hard to get the Independent Living ideas recognised in Europe. They passed on their knowledge to the heroes of the present, who continue to work hard in their communities. Without the network, young disabled people would not be able to gain the history and knowledge of the Independent Living movement, would not have mentors to inspire them and to learn from, and would not be propelled to carry on the campaign for Independent Living in the future. Maintaining and growing a network of passionate Independent Living activists is critical for the movement, to be able to move forward until Independent Living is a reality for disabled people throughout the world. ENIL would like to thank all of the heroes featured in this booklet, from the past, present and future and those not mentioned. Every single one of you is an important link in this vibrant and active network for Independent Living.

Closing Words by Zara Todd, ENIL's New Executive Director



No disabled person should be alone in fighting to realise Independent Living. Every disabled person, including those living in institutions, should know what their rights are and have the support to realise those rights. Everyone should be able to celebrate living their life free of barriers and discrimination.

That is why ENIL is here. ENIL's strength is that we are not just individuals fighting for a cause, but a movement driven by the belief that everyone should have the opportunity to have choice and control in their lives and be part of the community.

I lead an ordinary life. This is my biggest act of rebellion and the way I champion Independent Living. People have not expected me to live independently, to have an education, to have a job or to be an active part of society and yet I do all of this, and more. Every time I do anything ordinary, it challenges assumptions and expectations that I shouldn't, but I do.

While I have and do experience barriers in doing the ordinary things in life, I have been incredibly fortunate to have had many people in my life support me to achieve these things, as well as giving me opportunities to do more than I ever imagined. I have learned that by living how I want and embracing choice and control, I have, unintentionally, shown disabled and non-disabled people that Independent Living is not only possible, but also preferable.

I have spent the whole of my life advocating for other disabled people to have access to their rights. For me, everybody deserves to have choice and control over their lives. I may not agree with their decisions, but I will always defend their right to have the choice.

I have worked advising governments and organisations; I have worked for charities, NGOs and disabled people's organisations, all focused on improving the lives of disabled people. Throughout this work, I've developed a particular interest in how I can support and amplify the voice and views of other disabled people.

This has led me to do a lot of work focused on supporting disabled children and young people to have a say in their lives. Six years ago, this led me to become a driving force in the establishing of ENIL's Youth Network and in five years, the network has grown from 16 members to over 600 today. For me, the rapid and continued growth of ENIL's Youth Network is evidence that Independent Living is something disabled young people still have to fight for and a right we are ready and willing to defend for ourselves and future generations.

About the European Network on Independent Living

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

ENIL has Participatory Status with the Council of Europe, a Consultative Status with ECOSOC and is represented on the Advisory Panel to the EU Fundamental Rights Agency's Fundamental Rights Platform.

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