

ENIL 2017 Freedom Drive REPORT



Dedicated to Martin Naughton, the founder of the ENIL Freedom Drive European Network on Independent Living

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Introduction

"I loved the atmosphere and meeting people from around the EU and beyond!"

"It was incredibly interesting and empowering, and I wish I had the energy to talk more with other participants and organisers."

Quotes from the Freedom Drive participants

From 25 to 28 September 2017, the European Network on Independent Living (ENIL) held the 8th edition of its Freedom Drive. The Freedom Drive brought together around 300 Independent Living activists from 19 countries, from as far South-East as Armenia, to Iceland in the North-West, in a week of activities to highlight to policy makers and the public the importance of equality, human rights, citizenship and Independent Living for disabled people.

As one of ENIL's key campaigns – held every two years since 2003 – the Freedom Drive provides supporters of the Independent Living Movement with the unique opportunity to meet Members of the European Parliament (MEPs) and promote human rights issues, as well as to share experiences and ideas with colleagues from around Europe. The first six editions of the event took place in Strasbourg, until 2015, when for the first time the venue was changed to Brussels for strategic reasons.

The ENIL 2017 Freedom Drive was dedicated to Martin Naughton – the father of the ENIL Freedom Drive – whom we lost in 2016. It also paid tribute to other heroes of the Independent Living movement, such as Peter Lambreghts, Debbie Jolly and Donal Toolan. At the same time, the week-long campaign celebrated the Independent Living heroes of the present and the future, and the achievements of the disabled community, with many young

disabled people joining the march for Independent Living through Brussels and other events.

The Freedom Drive consisted of several events, culminating with a march from the European Parliament to the European Commission, under the theme 'Independent Living Heroes: Past, Present and Future'. It started with a series of motivational workshops on 25 September, where Freedom Drivers had the opportunity to exchange ideas and experiences on a variety of topics from "How to monitor the implementation of UN CRPD" to "Being a proud disabled person". Additionally, a briefing for MEPs on the Effect of Austerity on Access to Independent Living in the EU, hosted by MEP Marek Plura (EPP), was held at the European Parliament. Participants also had the chance to meet with the Commissioner for Employment, Social Affairs, Skills and Labour Mobility Marianne Thyssen and other EU officials and organizations. One of the highlights of the week was a discussion on the right to independent living of disabled children and young people, and their families, with a commitment of the Vice-President of the European Parliament Mairead McGuinness to ensure disabled children's voices are heard at EU level. The new leaders of ENIL were also elected by the organization's General Assembly, and will take the organization forward as it embarks on the implementation of its 2018 – 2022 Strategic plan. Finally, the ENIL Youth Board was formed during the ENIL 2017 Freedom Drive, based on an online and in person voting system.

The main goals of the ENIL 2017 Freedom Drive were:

- To raise the key concerns of the European Independent Living movement with the European policy and decision makers in Brussels;
- To raise awareness about the need for an accessible Brussels our European capital;
- To remember the leaders of the European Independent Living movement who left us in 2016, such as the founder of the Freedom Drive, Martin Naughton, as well as our colleagues Peter Lambreghts and Debbie Jolly, and to celebrate and inspire current and future leaders;
- To discuss how to make the Independent Living movement more inclusive of children with disabilities and other voices that may not be heard;
- To facilitate an exchange of ideas and knowledge on Independent Living, with the aim to inspire Independent Living activists;
- To provide opportunities for development of new ideas, strategies and partnerships.

Among the main Freedom Drive demands were the end to institutionalisation of disabled people across Europe, access to personal assistance in all countries, full implementation of the UN Convention on the Rights of Persons with Disabilities and the end to cuts to support services and benefits for disabled people.

ENIL owes much of the success of the Freedom Drive to the generous support and cooperation of the European Union, ULOBA, STIL, GIL, the City of Brussels and the Brussels

Region. ENIL would also like to thank the Police of Brussels, Capitale Ixelles and the STIB/MIVB for their collaboration in making the ENIL 2017 Freedom Drive possible.

Participation

Around 300 people from 20 countries participated in the 8th edition of the Freedom Drive. All of them were Independent Living activists, both disabled and non-disabled people. The majority of Freedom Drivers were representing their national or local Centres for Independent Living (CILs), but there were individual participants as well. Most came with their Personal Assistants and others were accompanied by guide or service dogs. There were many more who wanted to join the Freedom Drive, but were prevented due to lack of financial resources to cover their travel and accommodation costs. Therefore, they joined ENIL virtually, through social media networks and showed their support. For example, the Board of the Spanish organization FEVI wrote a letter to all Spanish MEPs on the occasion of the ENIL 2017 Freedom Drive.

The countries represented in Brussels were: Albania, Armenia, Belgium, Bosnia and Herzegovina, Bulgaria, Estonia, France, Germany, Greece, Iceland, Italy, Ireland, Lithuania, the Netherlands, Norway, Portugal, Serbia, Sweden, Turkey and the United Kingdom.

Similar to previous Freedom Drive editions, Members of the European Parliament, the European Commission officials, the European Disability Forum and other European NGOs and DPOs joined some of the Freedom Drive activities.

Freedom Drive Declaration

The Freedom Drive Declaration outlined the main barriers disabled people face, and which ENIL is campaigning on. Specific recommendations were set out for MEPs, to be used by country delegations to help them formulate their own demands. In addition to MEPs, the Freedom Drive Declaration was aimed at the European Commission, which also participated in different Freedom Drive events.

The Freedom Drive Declaration can be found <u>here</u>.

Events

Motivational and capacity building meetings

The first day of the ENIL 2017 Freedom Drive, 25th September, was dedicated to five workshops, which provided participants with an opportunity to learn something new on a variety of topics and to exchange experiences and ideas with activists from other countries. The topics covered included:

1) Setting up a Centre for Independent Living (CIL) – facilitated by Diogo Martins from Portugal and Stelios Kympouropoulos from Greece;

2) Setting up a national Youth Network – facilitated by Zara Todd and Rebecca Farren, both from the United Kingdom;

3) Monitoring the UN CRPD – facilitated by Nadia Hadad from Belgium and Rados Keravica from Serbia;

4) Being a proud disabled person – facilitated by Charlie Willis from the United Kingdom;

5) Being an ally to your child (for parents and carers) – facilitated by Patrick Vandelanotte from the Belgium organisation Grip.

The day was full of lively discussions, shared experiences, new friendships and interesting debates. All materials used by the workshops facilitators can be found <u>here</u>.

Meetings with Members of the European Parliament

The **Swedish delegation** met five MEPs, among them Anna Hedh, Malin Björk and Cecilia Wikström. They discussed key issues for disabled people in Sweden: personal assistance, the cuts to support services for disabled people, and the need MEPs' involvement at the national level. Deinstitutionalisation was also on the agenda, as well as the need for personal assistance in all EU countries.

The **British delegation** consisted of 6 Freedom Drivers, with representatives from ENIL, NUS (National Union of Students) UK, Sisters of Frida and ALLFIE (the Alliance for Inclusive Education). They met with 5 MEPs and 1 assistant from across the political groups. A range of topics were discussed, including the impact of Brexit and austerity on disabled people, the need for more accessible housing in Europe, freedom of movement for disabled people and what the EU can do to fulfil its commitments as a signatory of the UN CRPD. The delegates felt that the meetings were useful in raising the MEPs' awareness on the issues facing disabled people, and will continue working with MEPs on inclusive education and the portability of Personal Assistance.

The **Lithuanian delegation** met Vilija Blinkevičiūtė MEP. The main issues discussed were the European Accessibility Act and the Istanbul Convention – both of which are being discussed in the European Parliament. Mrs. Vilija Blinkevičiūtė's expressed willingness to support ENIL on a long-term basis, particularly through the EU Funds for Our Rights Campaign.



The **Bulgarian delegation** met six MEPs – Sergey Stanishev, Emil Radev, Angel Jambazki, Svetoslav Malinov, Peter Kurumbashev and Vladimir Uruchev. Three main topics were discussed: accessibility, the UN CRPD implementation, and the problems with territorial expert medical committees.

Briefing for Members of the European Parliament

On 26 September, ENIL held a briefing in the European Parliament on the Effect of Austerity on Access to Independent Living in the EU. The briefing was hosted by MEP Marek Plura (EPP).

After **MEP Plura's** introductory words, **Jamie Bolling** (former ENIL Executive Director) noted that disabled people have been disproportionately affected by cuts, while according to the UN CRPD, support should not be reduced. On the contrary, investment in person centred services should increase.

The next speaker was **Eleanor Lisney from Disabled People against the Cuts – DPAC (United Kingdom).** Eleanor explained how DPAC used the UN CRPD Optional Protocol to file a complaint against the UK Government. This resulted in a report of the CRPD Committee, in which it concluded there have been grave and systematic violations of disabled people's rights in the UK.



Former Minister for Social Affairs Deputy Prime and Minister Sweden, of Bengt Westerberg gave a brief overview of the history of the system of Personal Assistance in Sweden. While he is confident that the PA system was and is a success, he also warned that it is under pressure at the moment.

In the panel, Kapka next Panayotova from the CIL Sofia (Bulgaria), Corinne Lassoie from EVA, Ensemble Vie Autonome (Belgium), Aurélie Baranger, from Autism Europe (EU) and Stelios Kympouropoulos from I-Living (Greece). gave all testimonies about the effect of

austerity on the right to independent living for them personally and in their country in general. The general conclusion was that, although the UN CRPD has been in force for a decade, investments in institutions and segregation still outweigh initiatives for inclusion. There is still a lot of work to change the perception about disability and put the vision of the UN CRPD into practice.

After the testimonies, several MEPs took the floor. **MEP Helga Stevens (ECR, Belgium)**, **MEP Marek Plura (EPP, Poland) and MEP Mairead McGuinness (EPP, Ireland)** reaffirmed their commitment to work towards the implementation of the CRPD. They promised to work together with Member States to raise awareness about disability rights and keep inclusion high on the agenda.

Secretary General of EASPD Luk Zelderloo summarised the discussion with the four key messages:

- Disabled people want rights, not pity;
- The crisis could have been used to get rid of an outdated system and change to innovative person centered services. This did not happen; instead, the crisis had a disproportionate impact on disabled people;
- The mentality must change from cost to investment. From a patronizing to an empowering model. Work must be done in co-production, with disabled persons at the steering wheel;
- The EU can provide financial support to facilitate independent living.

ENIL Youth Network General Assembly and Board meeting

The second day of the Freedom Drive was dedicated to the ENIL Youth Network. The first official youth General Assembly took place, bringing together 25 participants.



Two of the Youth Board members, Miro Griffiths and Rados Keravica, presented a brief summary of the work and achievements of the network after the last Freedom Drive:

• The number of Youth Network members has increased to 241 full individual members and 48 associated individual members;

• The number of members of the Facebook group has reached 661;

A total of 4 study sessions in

cooperation with the Council of Europe Youth Department were organized. All of them took place in the European Youth Centre in Strasbourg, with an average number of 30 participants. Their outcomes include video campaigns, a short film, a training manual and more. These are available on the ENIL website;

• A total of 5 task groups were formed to create the space for youth members to pursue their ideas and interests, contributing to goals of the network. They were on the following topics: education, Independent Living, employment, fundraising, sex and relationships;

• A total of 3 webinars were organized;

• Youth network members were involved in many events, where they represented the ENIL Youth Network and established links with new partner organisations.

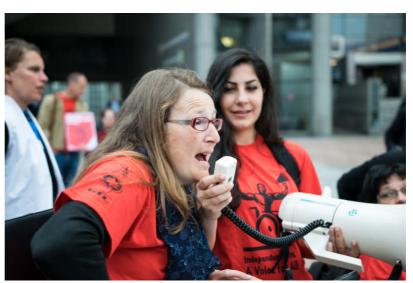
Voting for the new Youth Board took place in two stages. Online voting was held before the Freedom Drive. The second part of the voting was during the Youth General Assembly on 26 September. Six persons were selected out of eleven candidates: Andrey Sosnov, Beyza Unal, Kamil Goungor, Marijeta Mojasevic, Rados Keravica and Rebecca Farren.

The Youth General Assembly was followed by the first Board meeting. At this first meeting, it was agreed that during the first full Board meeting, a new youth strategy and activity plan would be discussed.

Freedom Drive March

The Freedom Drive March is the culmination of the week-long event. Its theme this year was **'Independent Living Heroes: Past, Present and Future'.** More than 300 Freedom Drivers and supporters gathered in the Parliament square on Wednesday morning, 27 September, equipped with banners, whistles, megaphones and all sorts of noise making gadgets, in order to stand proud, strong and visible behind their demands for independent living.

After the motivational speeches, Freedom Drivers moved from the European Parliament towards the Commission. Slogans such as "Proud. Strong, Visible", "Institutions are NOT "Rights, Solutions", NOT Charity" and "Nothing about us" Without us, were shouted and the atmosphere was exciting.



The march ended in front of the Autoworld museum and

conference centre, where a stage was erected for Independent Living leaders to address the participants.

Freedom Drive Conference

The ENIL 2017 Freedom Drive Conference took place at the Autoworld museum and conference centre, following the march. The theme of this year's conference was "Independent Living: A Voice for All!" It highlighted the importance of full inclusion and self-representation within the disability community, including that of disabled children and young people. It sought to highlight that children's and young people's voices are often lost in disabled people's organizations (DPOs) and in the Independent Living Movement.

The aim of the conference was to learn from children's rights advocates and experts about some of the main barriers faced by disabled children and young people. It provided an

opportunity to discuss how the right to independent living relates to disabled children and young people and what we can do to ensure that disabled children and young people are not forgotten as rights holders under the UN Convention on the Rights of Persons with Disabilities. At the same time, the conference was a way of recognizing the strong Youth Network and aimed to promote its active contribution to ENIL's work.



The conference brought together disabled children and young people, children's and disability rights experts and advocates, representatives of the European Commission and Members of the European Parliament.

Each session started with a presentation delivered by a child or a young person – the 6-year-old **Maja Lorentz** from Sweden, the 8-year-old **Wilma Hallgren**, also from Sweden, and the 16-year-old **Julie van Tichelen** from Belgium.

They shared their everyday experiences as disabled children, spoke about what helps them live independently, and what barriers they face.

The conference was opened by the Commissioner for Employment, Social Affairs, Skills and Labour Mobility **Marianne Thyssen** and the President of the ENIL Board **Kapka Panayotova** (Bulgaria).

The **Commissioner** expressed her admiration for the young self-advocates on the conference panel. She emphasized the right to independent living and the possibility of every child to exercise choice and control over their lives and develop skills and talents.

While acknowledging the significant shortcomings in inclusive education systems, both in early and higher education, leading to higher rates of poverty and unemployment among disabled people, Ms Thyssen also stressed the commitment of the EU to leave no one behind. With this consideration, she highlighted the key EU initiatives, such as the Recommendation on Investment in Children, the European Structural and Investment Funds Regulations, the European Pillar of Social Rights and the European Accessibility Act. All of these intend to benefit disabled people, including disabled children, by achieving greater inclusion, accessibility, equality and the right to independent living.

Representative of the Brussels region noted the importance of making the city accessible for disabled people and informed the participants about the recent initiative by the Brussels Parliament to translate the UN CRPD into regional legislation. This in an important step in ensuring that the decisions of the Brussels Government regarding its disabled residents are assessed based on the UN CRPD.

In her short opening statement, the President of the ENIL Board, **Kapka Panayotova** congratulated the participants on the successful march and highlighted the fact that independent living is applicable to everyone, irrespective of their age. She noted, however, that independent living is not implemented by everyone in the same way, but rather by each person in an individual manner.

First of the child self-advocate speakers was 6-year-old **Maja Lorentz** from Lund, Sweden, who was supported by her father Magnus. Coming from a family of two parents, an older sister and twin younger brothers, Maja shared her experience of living with a disability, as well as her thoughts on what helps her live independently and why independent living is important to her. She noted the importance of personal assistance, which enables her to live an independent life, but also allows her parents to care for all their children equally. On a daily basis, having choice and control over her life as a child means Maja can decide what games she wants to play or what music she wants to listen to. Most importantly, Maja noted that if it weren't for the availability of personal assistance from early childhood, she would not be able to live with her own family, get to grow up at home and know her siblings, something which is of great importance to her.

Despite all the support they receive, Maja shared her and her family's struggles during travel and lack of access to the built environment, including playgrounds and theatres, as well as to children's activities.

Maja also mentioned her work as an activist for the rights of people with functional variations, and especially people with intellectual disabilities. For the past five years, Maja and her parents have been trying to raise awareness about the right to independent living on the regional and national level in Sweden.

Maja emphasized that *it is vital for disabled people to live and not just survive*. And to achieve this, she advocates for personal assistance and other services which enable disabled children to grow up in their families.

After the opening session and the keynote speech by Maja Lorentz, the **1st panel** commenced, with the topic of **Children's right to live independently in the community – state of play**. Members of the panel were **Tara Flood**, Director of the Alliance for Inclusive Education (UK), **Sir Roger Singleton CBE**, Consultant at Lumos (UK), 16-year-old child self-advocate **Julie van Tichelen** (Belgium), and **Bengt Westerberg**, the Chair of the Board of the Swedish Institute for Disability Research.

Julie opened the discussion, sharing what independent living means to her as a young disabled woman with Spinal Muscular Atrophy. She began by highlighting the importance of inclusive education in her life and her parents' determination to ensure that she can attend mainstream education, even before it was a right in Belgium. She mentioned some of the ways her school meets her access needs: for example, by installing a stair elevator in the school building; and by using a digitalized system that allows Julie to follow classes from home on days when she needs to regain energy. In addition, teachers allow Julie to complete her assignments and take her exams on her laptop, which makes it possible for

her to get as much from education as her non-disabled peers. Although young, Julie is already fascinated by biomedical research and aspires to become an expert in the field.

Julie shared what freedom and choice meant to her in her daily life. For example, she has the right to decide what time of the day she needs personal assistance. She also noted the liberating role of the electric wheelchair and assistive technologies, such as robotic arms for eating independently. These make Julie less dependent on others, therefore allow her more freedom and independence in her everyday life. As Maja, Julie also highlighted personal assistance as an important factor in exercising her right to independent living.

Julie faces a number of barriers in her life, which prevent her from enjoying full freedom and equal opportunities. Among these is inaccessibility of transport and venues, such as restaurants, leisure and shopping centres. As a 16-year-old student, Julie cannot get a weekend or holiday job like many of her friends, because of the physical barriers, but also because of the unwillingness of employers to hire her due to her disability.

Julie concluded with an encouraging statement - to be determined and not to give into the negative criticism and the lack of expectations. She instead recommended to rely on the people we love and trust, and to find support in those who believe in us. She advised not to be afraid to ask for help when it's needed and to try new things, as they can open a world full of new possibilities.

Following Julie, disability rights activist and Director of the Alliance for Inclusive Education **Tara Flood** continued the discussion by sharing her experience as a "special school survivor". Having been forced to live in an institution from as early as 16 months to almost the age of 16, Tara had to live away from her family and rarely got the chance to see them. She noted that this negatively affected her relationship with her family forever, in contrast to her brother, who was able to grow up at home. The experience of living in a segregated institution also instilled a great sense of marginalization and negative attitude towards her disability, and the idea that as a disabled person it was her responsibility to change and to fit in. While she hasn't overcome all the challenges, Tara proudly noted that she has now successfully embraced herself and her community, and it is especially due to her experience in a segregated residential school that she began her activism for inclusive education.

Based on her personal experience, Ms Flood highlighted the strong and undeniable link between inclusive education and independent living, and noted that inclusive education is a right under Article 24 of the UN CRPD. She also mentioned the General Comment No 4, which sets out the steps governments must take to implement Article 24.

Tara also highlighted the key barriers to achieving inclusive education. The first is connected to language - the way we speak of and (mis)understand what inclusion means. She pointed out that inclusion is often mistaken with integration. While the latter implies the adaptation of the person to the environment, inclusion is achieved through making structural changes to current systems, in order to allow all individuals to participate and make use of all the opportunities. In case of inclusive education, it means making the necessary adjustments to the school system to enable students with varying types and

degree of support needs to have the same access to knowledge as their non-disabled peers. The second hindering factor noted by Ms Flood is 'normalization'. The need to 'normalize', to 'fix' disabled children in order to make them fit in leads to the segregation in special institutions of those who do not fit into the norm. In the UK, in order for disabled children to be accepted in mainstream schools, they have to demonstrate their ability to be included. Local authorities and schools have the last word whether or not they find the child fitting and acceptable for the mainstream education system, something which non-disabled children do not have to face.

A vital point made by Tara Flood was that inclusive education benefits all children, not only disabled children. She concluded by saying: "*if we get it right for disabled children, we inevitably get it right for all children*".

Sir Roger Singleton CBE, currently a consultant at Lumos (UK), continued the discussion by addressing the reasons why children are still being placed in institutions, despite the UN CRPD. He highlighted six main factors. The first is the historic legacy of the medical community's approach towards disabled people - the 'out of sight, out of mind' principle. For generations, parents of disabled children were advised to place them in institutional care, so the society developed a mentality that requires a great amount of effort and time to de-root. Secondly, public policy increasingly favours institutional responses to issues, including when it comes to those relating to disabled people. In addition, public prejudice and anxiety towards disability, as well as the vested interests of those running and working in institutions play an important role. Austerity measures, increasingly the main response by governments to economic challenges, also mean that often states withdraw their support to community-based care programmes, hitting disabled people the hardest. Finally, there is the challenge in engaging the wider public on issues related to human rights.

Finally, Sir Roger noted the necessity of maintaining and developing the momentum of the disability rights movement, and provided some recommendations for the future. He highlighted the importance of a sustained and targeted advocacy, especially on issues of funding provided by the EU. He also emphasized the great importance of sharing personal experiences and the impact on policy makers by disabled people themselves. Lastly, he urged for more research into and advocacy of economic arguments, as there is still a widespread misconception about the high cost of community-based services versus institutional care.

The current Chair of the Board of the Swedish Institute for Disability Research, widely considered the 'father' of the disability rights reform which established personal assistance as a civil right in Sweden, **Bengt Westerberg** took the floor to present Sweden's deinstitutionalization process. He began by presenting the long legacy of inclusive education in Sweden and pointed out that the country closed down its institutions long before the introduction of personal assistance, since the 1960s. In 1994, the right to personal assistance was introduced, which also applied to disabled children and persons who have limited autonomy of managing their assistance. Mr Westerberg noted, however, the recent worrying developments in Sweden, as in other European countries, which include significant setbacks in the provision of community-based services. In 2017, 90% of the first-time personal assistance applicants have been rejected, a picture that is greatly different and alarming compared to the one five to ten years ago.

The **second panel**, focusing on the future, consisted of **Mairead McGuinness**, Vice-President of the European Parliament, **Julius Opdebeke** from the European Commission, the 8-year-old self-advocate **Wilma Hallgren** from Sweden, and **Michela Costa**, Head of Global Advocacy at Hope and Homes for Children/Opening Doors for Children Campaign (Belgium).

Eight-year-old **Wilma**, who delivered her own presentation in Swedish, shared what she would like adults to do in order to make her life better. Wilma explained that she requires a wheelchair and a night-time ventilator to help her when sleeping. She also requires someone – a personal assistant – to keep an eye on her while she is asleep. Although she has one, Wilma pointed out that she still cannot have sleepovers at a friend's house, because her night time assistance is only available at home. This is something that Wilma wished to change, to allow her to enjoy time with her friends, just like her peers do. She also expressed a wish to be able to do different activities, such as sports, in her own way and as much as she wants, and finally to be accepted by the society the way she is.

After Wilma's brief and honest presentation, Vice-President of the European Parliament **Mairead McGuinness** congratulated her courage to speak in front of such a big crowd and to be an advocate at such a young age. Ms McGuinness went on to highlight the importance of children's voices in the work of promoting children's rights. She also noted the crucial role that NGOs have in the process of de-institutionalization, both as watchdogs of misuse of EU funds and in documenting best practices. At the same time, she advised to look into and try to understand the reasons behind the reluctance to change of those working at institutions, in order to find ways of tackling the significant resistance against de-institutionalization.

Julius Opdebeke, from the Disability Unit at the European Commission, continued the discussion by focusing on the role of the EU in improving the situation of disabled children. He started by presenting the Commission's Investing in Children Recommendation, which asks Member States to provide parents with a decent income and access to support services. This is especially important for parents of disabled children. The initiative is limited, however, as social policy is the responsibility of Member States, and the Commission can only support the steps taken by national governments. Mr Opdebeke noted the success of the European Disability Strategy 2010-2020 and stressed that the problem is not so much the lack of rights, but their implementation. Similarly, he pointed out that there is a misconception about the lack of funding, while the problem is the lack of innovative projects. As an example, he noted that when it comes to ESF programmes for children (2014-2020), only 30% of the funding has been committed so far. This is due to weak management capacity in many Member States, but also due to the lack of good projects, which are must be sustainable. Therefore, he encouraged community-based service providers and CSOs to seek funding at local level if they have sustainable project ideas. Lastly, Mr Opdebeke hoped to see a more active engagement by children's' ombudsmen, which exist, but often do not act to their fullest potential in Member States.

The last speaker of the panel was Michela Costa, Head of Global Advocacy, Hope and Homes for Children/Opening Doors for Children Campaign (Belgium). She spoke about providing alternatives to institutional care for children, noting that families should be supported to be able to raise their children at home. If, in exceptional cases, this is not in the best interest of the child, care by extended or foster family should be viewed as a solution. She reinstated the well-known fact that most children living in institutions have at least one family member. Therefore, the first step in taking those children out of residential homes is to identify their family members and provide them with support services, so that they are able to raise their children. This is especially important for disabled children, as parents of these children often face higher financial and social pressure to put their children into institutional care. She called for a paradigm shift in the way we understand services for children and families in the community and to create what she called an 'enabling environment'. Ms Costa pointed out that, if all necessary preconditions are in place, including proper health services, inclusive education, accessibility of the environment, most parents would be willing and able to raise their disabled children within the family. She also pointed out that, for most parents, giving up their children is a tragic and dramatic decision. In addition to creating enabling systems, Ms Costa noted the need for a strong position against placing more children into institutions - of closing the doors into institutions once and for all.

Ms Costa added that the social workers need to engage with families in a way that empowers those families, saying that "*it is not sufficient to take the social workforce out of the institutions, you need to take the institution out of the social workers*". The need to educate and raise awareness among the general population was also pointed out, as in many countries the idea of fostering children, especially disabled children is still inconceivable. Lastly, Ms Costa continued the argument made earlier by Sir Roger Singleton, about economic arguments. She said that the society needs to be better informed about the higher returns on investment of community-based services and how it provides better and long-term outcomes for disabled children and adults, and for the society at large.

The conference was **concluded** by ENIL's newly appointed Executive Director **Zara Todd**. Ms Todd expressed her strong conviction that independent living is for everyone, regardless of age or impairment. She called for discussion on the highest level, not just about one group, but about everyone's right to live independently as part of their community, throughout their lives.

ENIL General Assembly

ENIL has 275 individual members, 289 Youth Network members and 80 member organisations from 52 countries. Sixty-eight voting members (both member organisations and individual members) from 18 countries took part in ENIL's General Assembly (GA) on 27 September 2017.

Chaired by Bengt Westerberg, the main part of the GA was the election of the new ENIL Board. There were 12 candidates for the 9 places: Christian Bayerlein from Germany, Tove Brandvik from Norway, Maria Dahl from Sweden, Nadia Hadad from Belgium, Stelios Kympouropoulos from Greece, Kapka Panayotova from Bulgaria, Armen Alaverdyan from Armenia, Tara Flood from the UK, Anna Hallgren from Sweden, Michael McCabe from Ireland, Rados Keravica from Serbia and Sonali Shah from the UK.



Following the approval of the proposed Constitutional changes, 5 existing Board members were elected to serve one more term. The successful candidates were Tove Brandvik, Maria Dahl, Nadia Hadad, Stelios Kympouropoulos and Kapka Panayotova. In addition, 4 new Board members were chosen to serve 2 terms. Those elected were Armen Alaverdyan, Tara Flood, Anna Hallgren and Rados Keravica. All four regions of Europe are represented on the Board and Rados and Stelios will represent the ENIL Youth Network.

The proposed Nominating Committee was also approved. The new members are Mari Siilsalu for the North, Gregor Fajida for the East, Mathilde Fuchs for the West and Vanya Pandieva for the South.

Ines Bulic briefly presented the ENIL Strategic Plan for 2018-2020, which will be published by the end of the year. It was also agreed that ENIL would continue to charge no membership fee until the next GA.

At the end of the GA, ENIL's outgoing director Jamie Bolling gave the floor to her successor, Zara Todd, who encouraged members to further engage with ENIL in the coming months and years.

North Regional Meeting

The ENIL 2017 Freedom Drive ended with a meeting of the Northern region of ENIL. There were 25 participants from Norway, Iceland, Estonia and Sweden. During the meeting, which was chaired by Tove Brandvik (ULOBA, Norway), participants presented the key concerns in their countries. Not surprisingly, these were related to personal assistance and institutionalization (as an inevitable consequence of bad PA policies and attitudes towards disabled people). It turned out that, despite the differences between the countries, there were also many similarities. Contacts were exchanged and future communication strategy was discussed. It was agreed that the region could become stronger with joint actions.

Freedom Drive publication

ENIL published the Freedom Drive booklet entitled "Independent Living Heroes: Past, Present and Future", which presents those who have made ENIL what it is today. The booklet can be downloaded from this <u>link</u>.

Useful links

- ENIL 2017 Freedom Drive webpage: <u>http://enil.eu/enil-2017-freedom-drive-24-28-september-brussels/</u>
- ENIL Facebook Page: <u>https://www.facebook.com/ENILsecretaria/</u>
- ENIL 2017 Freedom Drive Facebook page: <u>https://www.facebook.com/ENIL-Freedom-Drive-124127045055/</u>

ENIL is thankful to the European Commission, ULOBA, the Brussels Region, the City of Brussels and STIB/MIVB for generously supporting the organisation of the ENIL 2017 Freedom Drive.

