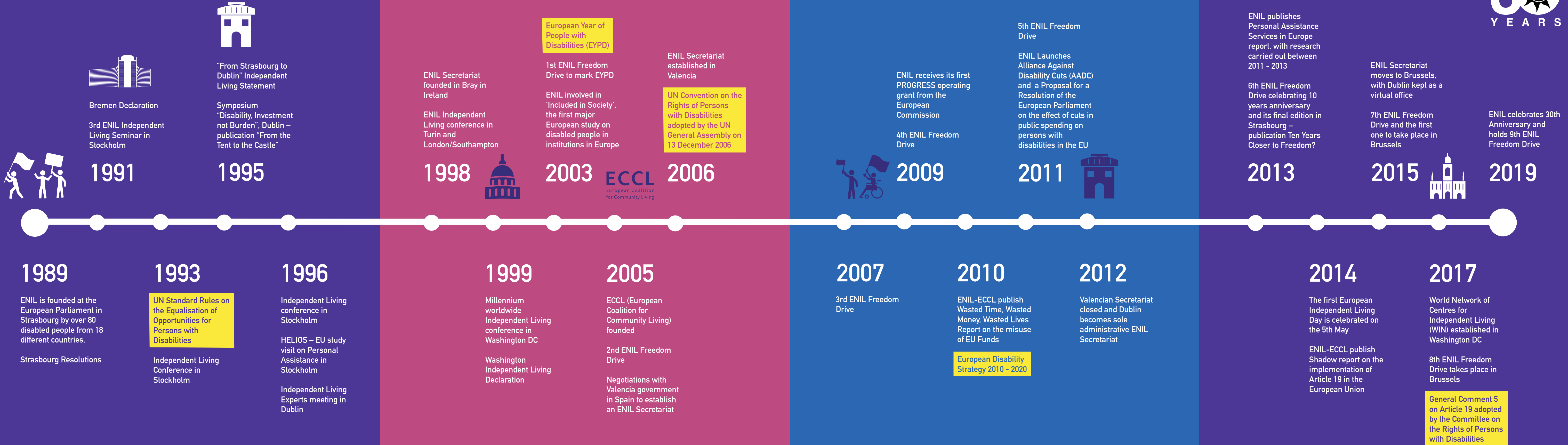


European Network on Independent Living (1989 – 2019)



+ 1992 - Birmingham Conference Statement on Independent Living

+ 1997 - European Independent Living Conference in Berlin

+ 2008 - ENIL-ECCL conference at ULØBA in Norway

+ 2016 - ENIL launches EU Funds for Our Rights Campaign

30 Years of the European Network on Independent Living

The history of the Independent Living in Europe, and the European Network on Independent Living – ENIL cannot be confined to a timeline or a poster. To mark our 30th anniversary, we have decided to take you through some moments of ENIL's history and to show how much of ENIL's beginnings and the Independent Living philosophy on which ENIL was built on survive to this day. The world and Europe today are very different from that momentous year of 1989, but a strong Independent Living movement is still much needed. Looking back helps us take stock of where we have come from and gives us resolve to stay STRONG, PROUD AND VISIBLE in the years to come.

Banding together to fight the system

“We, disabled people from the Netherlands, UK, Denmark, Italy, Switzerland, Sweden, France, Austria, Finland, Belgium, USA, Hungary, Federal Republic of Germany and Norway have come together from April 12-14 1989 at the European Parliament, Strasbourg, France. This conference has focused on Personal Assistance Services as an essential factor of Independent Living, which itself encompasses the whole area of human activities, e.g. housing, transport, access, education, employment, economic security and political influence.”

So began the Strasbourg Resolutions, adopted during the meeting in the European Parliament in Strasbourg in April 1989, where the European Network on Independent Living – ENIL was founded. The meeting was sponsored by the Greens and called for a world-wide network of organisations and individuals which subscribed to the Independent Living ideology, that would work within Disabled People's International (DPI). The starting point was a European network, focusing on personal assistance, non-discrimination, deinstitutionalisation and peer support. This became ENIL – a network separate from DPI.

In his keynote speech, Adolf Ratzka defined the purpose of such network as a place for “exchange of ideas, technical support and training”, among centres for independent living and other initiatives working at the local level. The network was, however, to be highly politicised, to fight oppression and take the power back from professionals, making disabled people the ones in charge of their lives. Adolf spoke about the strengths of working together:

“In providing examples for each other and in sharing our experiences we need each other. We all are in the same situation, we all face oppression in our society. Once we realize this, it is only a small step to see that we have to support each other, that we must band together to fight the system and together make this a better world. All of us here probably have had this fundamental experience that all you need is to get together a bunch of crips and politicians will listen - provided you play your cards right. Each of us can profit from joining in. Only together can we gain political power. That is the only power to move things. For this reason we have to organize ourselves.”

The Strasbourg Resolutions (April 1989)

Already during this first meeting in Strasbourg, several themes emerged that would form the key demands, and activity areas of ENIL to this day. They were: anti-discrimination, de-medicalisation, de-institutionalisation, de-professionalisation, taking control over disabled people's organisations, self-management of services, peer counselling, personal assistance and empowerment.

Personal assistance, as a key tool for Independent Living, was being discussed and defined, and this would form the basis of the Strasbourg Resolutions. It was largely based on what should not be considered as personal assistance, such as different forms of care and home help, as well as the challenges of using family members and worse, volunteers, to provide personal assistance.

Institutionalisation of disabled people in special services, hospitals, care homes and other settings emerged as a key theme of the first conference and remains one of ENIL's priority areas for action. In his speech, Adolf spoke about the continued segregation of disabled people and the need to fight it:

“Since we are often considered sick, many of us get shut away in hospitals and hospital-like institutions. There, it is claimed, we can be better "cared for". With this argument we are put into special kindergartens, special schools, special workshops, special housing and special transportation. The only places that are still not segregated are the cemeteries! We have to shut down these special, dehumanizing and degrading Apartheid solutions and force our way into the mainstream of society.”

A definition of an ‘institution’ proposed during this keynote speech has lived to this day, and is reflected in the definition included in the General Comment 5 on Article 19 of the UN Convention on the Rights of Persons with Disabilities. It includes the obligatory sharing of assistance, no choice over who assists you and when, having to adapt to a set of rules or regime, being limited to a specific setting as the only way of getting support, and being at the bottom of the pyramid in terms of power relations.

Thus, what emerged out of that Strasbourg conference was the first set of demands aimed at European and national politicians, based on the Independent Living ideology.

1. Access to personal assistance service is a human and civil right. These services shall serve people with all types of disabilities, of all ages, on the basis of functional need irrespective of personal wealth, income or marital and family status.
2. Personal assistance users shall be able to choose from a variety of personal assistance service models which together offer the choice of various degrees of user control. User control, in our view, can be exercised by all persons, regardless of their ability to give legally informed consent.
3. Services shall enable the user to participate in every aspect of life such as home, work, school, leisure and travel and political life. These services shall enable disabled people to build up a family and fulfil all their responsibilities connected with this.
4. These services must be available long term for anything up to 24 hours a day, 7 days a week, and as a short term, or emergency basis. These services shall include assistance with personal, communicative, household, mobility and other related services.
5. The funding authority shall ensure that sufficient funds are available to the user for adequate training of the user and the assistant, if deemed necessary by the user.
6. Funding must include assistants' competitive wages and employment benefits, and all legal and union required benefits, plus the administrative costs.
7. Funding shall come from one guaranteed source, and to be paid to the individual wherever he/she chooses. Funding shall not be treated as disposable taxable income, and shall not make the user ineligible to other statutory benefits of services.
8. The user should be free to appoint all personal assistants, whoever he/she chooses, including family members.
9. Lack of resources, high costs, substantial or nonexistent services shall not be used as a rationale for placing an individual in an institutionalized setting.

10. There shall be a uniform judicial appeals procedure which works independently of the funders, providers or assessors, and is effected within a reasonable amount of time and enables the claimant to receive legal aid at the expense of the statutory authority.

11. In furtherance of all the above disabled people and their organizations must be decisively involved at all levels of policy making including planning, implementation and development.

Independent Living principles (1990) and other key declarations

Although the first ENIL Secretariat would be established in Bray 9 years after the Strasbourg conference, in 1998, there was a flurry of activity and cooperation during this time among Europe's Independent Living activists. A key document that emerged were the Independent Living Principles, adopted at the ENIL meeting “Het Timmerholt”, held between 31 August – 3 September 1990 in the Netherlands. These principles are referred to in the current ENIL Constitution, 30 years on. During the same meeting, the founders of ENIL agreed on the purpose and mandate of ENIL, which read as follows:

1. To contribute towards the situation of disabled people through individual empowerment.
2. To work on building a European Network on Independent Living.
3. To carry out educational events on Independent Living, e.g. seminars, workshops and development of resource materials.
4. To work on developing European concepts, principles and definitions related to Independent Living.
5. To promote the philosophy and concept of Independent Living among political parties, governments and other European bodies.
6. To seek funding for ENIL to carry out its activities.
7. To promote an understanding of Independent Living in Europe.
8. To facilitate information sharing on Independent Living.

The year after, in 1999, the first global meeting on Independent Living was organised in Washington DC. Between 21 - 25 September, over 100 leaders evaluated the movement's 30-year old history and set the agenda for the future. The Washington Declaration, adopted during this meeting, set out to “celebrate the achievements of the Independent Living Movement around the world; accept the responsibility for our own actions and lives; and reaffirm the global philosophy and principles of Independent Living.”

Another event worth mentioning, from the early years of ENIL, was the 1st European Congress on Independent Living in Tenerife, which again brought together many of the leaders. Held from 24 – 26 April 2003 – the first European Year of People with Disabilities - this was one of the biggest conferences on Independent Living ever held in Europe, and the first of its kind in Spain. Over four hundred participants from many European countries as well as delegates from the USA, Mexico and Argentina attended this two-day congress. Long-awaited in Spain, one of the aims of the Congress was to spread Independent Living throughout the rest of Southern Europe.

The main outcome from the congress was the Tenerife Declaration, which was a comprehensive statement outlining the importance of Independent Living, and calling upon the EU Governments, the European Commission and EU institutions to support its further development throughout Europe. The declaration, titled “Promote Independent Living – End Discrimination against Disabled People” was the culmination and work of many of the delegates present at the Congress. Later in the year, ENIL's first Freedom Drive was held in Strasbourg, at the initiative of the late Martin Naughton. Three years after the Congress, in

2006, ENIL's Secretariat in Valencia opened, with the financial support of the Valencia regional Government.

Independent Living as a right for all disabled people

The last 15 years have seen many changes, the most significant one being the adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD) and its ratification by the EU and all 28 Member States. The right to live independently and being included in the community is set out in Article 19, with the General Comment No 5 serving as a blueprint for implementation of this right. That the Independent Living movement had a key role in drafting of the CRPD and the General Comment is visible in the extent to which they reflect the Independent Living philosophy and the principles set out in the various declarations, speeches and policy documents adopted over the years.

As defined by John Evans, one of the founders of ENIL -

“[...] Independent Living is all about the disabled person taking control of their lives and being involved in all decisions that affect one's life. It is deciding what you want to do, when and how, and how you go about doing it. It prescribes that the disabled person is in the position of self-direction and self-determination about what affects their lives. It is about Disabled People becoming empowered and being in power. The main principles are being in control and having a series of choices and opportunities in one's life in order to enable the disabled person to live the life they want. It is also about equality of opportunity and equality of citizenship.”

Finally, the world-wide Independent Living network, called for in Strasbourg in 1989 came to life in 2017, when the World Network of Centers of Independent Living (WIN) was established in Washington DC. This provides us with an opportunity to work more closely together with the CILs around the world and to join forces in fighting for Independent Living globally, while bringing new generations of Independent Living leaders and activists on board. The timeline is to be continued.

In memory of the many Independent Living leaders who are no longer with us, but whose legacy remains: Manuel Lobato, Bente Skansgard, Martin Naughton, Nick Danagher, Peter Lambrechts, Debbie Jolly, Kalle Konkola, and others. We are grateful to John Evans for keeping ENIL's archives over the years and to Tony Baldwinson for digitalising them. Selected documents from these archives will be made available on ENIL's website www.enil.eu by the end of 2019.

Sources and further reading on the history of ENIL:

Keynote speech by Adolf Ratzka, 1989: <https://www.independentliving.org/docs2/enilpakeytoil.html>
Strasbourg Resolutions: <https://www.independentliving.org/docs2/enilstrasbourgresolutions.html>
Independent Living Principles: <https://enil.eu/wp-content/uploads/2019/02/Principles-of-Independent-Living.pdf>
From Le Court to Strasbourg: Fighting for Independent Living for 30 Years - <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/2-From-Le-Court-to-Strasbourg.pdf>
Independent Living Institute Library: <https://www.independentliving.org/library.html>