



FACT SHEET: Independent Living

1. What is Independent Living?

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

2. How do Independent Living pioneers define Independent Living?

“Independent Living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect. [...] Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbours and friends take for granted. We want to grow up in our families, go to the neighbourhood school, use the same bus as our neighbours and work in jobs that are in line with our education and interests, and start families of our own. Since we are the best experts on our needs, we need to show the solutions we want, need to be in charge of our lives, think and speak for ourselves - just as everybody else. To this end we must support and learn from each other, organize ourselves and work for political changes that lead to the legal protection of our human and civil rights. We are profoundly ordinary people sharing the same need to feel included, recognized and loved. As long as we regard our disabilities as tragedies, we will be pitied. As long as we feel ashamed of whom we are, our lives will be regarded as useless. As long as we remain silent, we will be told by others what to do.” (Adolf Ratzka, Sweden)

“What does independent living mean to me? I think that is a very deep, life changing question and it means a lot of things. I suppose I could say it has changed my life and I know it has changed the lives of many other disabled people whom I have come into contact with [...] It is very hard I think to get that message across to people who perhaps are not dependent on others to support them in their day-to-day living. But it has provided me with a life, my work – I have worked widely – and the opportunities and the choices to do the things I want, like you do. I think with the restrictions somebody like myself has,





with the kind of severe impairment I have, it is freedom. It is the freedom for me to be able to do what I want to do, when I want to do it, in a way, because I have people around me who can support me to do that.” (John Evans, UK)

3. What is the brief history of the Independent Living movement in Europe?

The idea of the Independent Living movement spread to Europe from the United States of America in the late 1960s, whereas the European Network on Independent Living (ENIL) was established in 1989 (see: Fact sheet on ENIL). One of the pioneers of the movement in Europe was Adolf Ratzka. At the age of 22, he won a scholarship to study in California. There, he experienced personal assistance and other accessible facilities. In 1973, he moved to Sweden, where he found that attitudes towards disabled people were much different. In 1984, he founded STIL – the Stockholm Cooperative for Independent Living. The idea was to reverse the situation of disabled people, where they are perceived as service users, not patients or objects of care. In the UK, John Evans and several other disabled people living in the same institution – together known as Project 81 - managed to break free by persuading relevant authorities to redirect the funding away from the institution, so that disabled people themselves can choose their own housing and support. Although the Independent Living movement has spread to many countries, personal assistance is still not widely available and large numbers of disabled people are still segregated in institutions.

4. What does Independent Living mean for disabled people?

The key principles of Independent Living are: choice, control, freedom, equality. The main objective of the Independent Living movement is to change the status of disabled people - from patients and objects of care and charity to equal citizens and rights holders. Independent Living focuses on empowerment and demands the same degree of self-determination, freedom of choice and control over everyday life for disabled people, as expected by any other citizen.

5. Does independent living mean being on one's own?

“Living independently” does not mean that disabled people have to be independent in the sense of living a highly individualised and self-sufficient life, at a distance from other people. It is, rather, based on a social model of disability, which recognises that people are not limited in their choices because of any inherent feature or condition of the person themselves, but by the social and physical environment in which they live. In enabling environments, things are not done *to* a person, but rather disabled people are





supported, just like anyone else, to make independent and autonomous, and when needed, supported decisions.

6. Can all disabled people live independently?

Article 19 of UN Convention on Rights of Persons with Disabilities recognises “**the equal right of all persons with disabilities to live in the community, with choices equal to others**”, and requires that States take “**effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community**”. Article 19 does not differentiate between people with different impairments and applies equally to all disabled people. This means that everyone should have the right to live independently, regardless of the “severity” of their impairment, their age, gender, ethnicity, material status or any other characteristic.

7. Can everyone live in their own apartment or do some people have to live in group homes?

According to Article 19(a) of UN Convention on Rights of Persons with Disabilities, disabled people should “**have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others**” and should not be “**obliged to live in a particular living arrangement**”. Crucially, according to Article 19(b), community support services for disabled people, including residential services, should “**prevent isolation or segregation from the community**”. Isolation and segregation of disabled people can persist even after the closure of large institutions. Isolation and segregation can occur within one’s home in the community, if the disabled person does not receive adequate support or if the outside environment and services are inaccessible. Segregation may occur in group homes when a smaller group of disabled people receive care, rather than support, and if they have not been able to decide for themselves where and with whom they would live. Although located in the community, group homes can easily become a smaller version of institutions. **Disabled people do not require special housing stock; they require supports which they can take into the housing market to access rental or other housing tenure just like other people.**

8. What is the definition of an institution?

The European Coalition for Community Living defines an institution as “... any place in which people who have been labelled as having a disability are isolated, segregated





and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size.”

The concept of a “total institution” was defined by Erving Goffman, who said that: “the feature of total institution is a system in which people are grouped together and their lives are regulated by the rules of that one system. [...] All aspects of life are conducted in the same place and under the same central authority. [...] Each phase of the member’s daily activity is carried on in the immediate company of a large batch of others, all of whom are treated alike and required to do the same thing together. [...] All phases of the day’s activities are tightly scheduled, with one activity leading at prearranged time into the next, the whole sequence of activities being imposed from above by a system of explicit formal rulings and a body of officials.”

9. What is the definition of community living?

Community living refers to disabled people being able to live in their local communities as equal citizens, with the support that they need to participate in every-day life. This includes living in their own homes or with their families, going to work, going to school and taking part in community activities. To ensure that disabled people have the same choice, control and freedom as any other citizen, any practical assistance provided to them should be based on their own choices and aspirations.

10. Is sheltered employment better for disabled people than having a job in the open labour market?

One key element of disabled people’s integration in the society is their participation in the labour market. Article 27 of the UN Convention on the Rights of Persons with Disabilities sets out “the right [...] to gain a living by work freely chosen or accepted in a labour market and work environment **that is open, inclusive and accessible** to persons with disabilities.” As opposed to the open labour market, in sheltered employment disabled people work together in a segregated setting and they can be trained and supervised by other disabled people. Their salaries are commonly lower than in regular employment. Sheltered employment creates a “closed circle”, because it perpetuates the isolation and segregation of disabled people from the society, and in the long term negatively impacts the productivity and community integration of people with disabilities. Segregation of disabled people in sheltered employment decreases expectations and enhances negative public attitudes. Very few people progress into competitive employment. The sheltered employment model assumes that disabled





people are less productive, and “protects” them against the open labour market. For the right to work to become a reality, disabled people should be offered different employment options, in order to be able to choose the type (and amount) of work that best suits their needs.

11. Is inclusive education important for Independent Living?

Being included in mainstream education is a first and a very important step towards Independent Living for disabled children, and their families. The right to education is set out in Article 24 of the UN Convention on the Rights of Persons with Disabilities, which requires States to ensure that disabled people “**are not excluded from the general education system on the basis of disability**, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability.” Disabled people have a right to access “an inclusive, quality and free primary education” in their local communities.

Inclusive education is defined as having the “training and resources aimed at fostering every student’s equality and participation in all aspects of the life of the learning community. Inclusive education aims to equip all people with the skills needed to build inclusive communities”. Inclusive education should not be confused with integrated education, and it should replace special education (provided in special schools and institutions), in countries where such segregated forms of education still exist.





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