

FACT SHEET

DISABLED CHILDREN AND INDEPENDENT LIVING



WHAT DO WE MEAN BY DISABLED CHILDREN?

The United Nations Convention on the Rights of the Child (UNCRC) defines 'children' as those under 18 years of age.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) defines 'persons with disabilities' as those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

The CRPD has an article specifically focused on 'children with disabilities' (Article 7), which makes it clear that disabled children have the same human rights as all children and that the best interests of the child should always come first.

Article 7 of the CRPD also makes it clear that disabled children should be supported both on age and impairment grounds to have a say on issues affecting them.

HOW DOES INDEPENDENT LIVING APPLY TO DISABLED CHILDREN?

Disabled children have all the rights outlined in the CRPD, and this includes Article 19 on independent living.

Article 19 CRPD notes that State Parties to the Convention "recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall 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". This includes ensuring that disabled people have the opportunity to choose where and with whom to live and are not obliged to live in a particular living arrangement (i.e. in institutional settings). It also includes ensuring access to in-home, residential and other community-based support services, particularly to personal assistance.

On a daily basis, disabled children should be allowed to exercise the same extent of choice, control, freedom and equality, and decision-making regarding their lives, as non-disabled children. This could include deciding what afterschool activities a disabled child would like to be involved in, be it sports or cultural activities, what hobbies they could have, how they wish to spend their free time, and decisions regarding choice of clothes, for example.

Equality means having the same opportunities when it comes to getting educated, being involved in cultural, sports and social activities, and all the other options available to non-disabled children. In all these processes, the role of parents or legal guardians is, of course, essential; therefore, it should be made clear that independence is not absolute when we talk about independent living for disabled children, as it is not in the case of non-disabled children.

The CRPD also sets out the right of disabled children to live in their families and obliges States Parties to ensure access to this right. Article 23 notes:

“States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.” (para 4)

“States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.” (para 5)

It is necessary to point out that independent living is for all disabled persons, regardless of their gender, age or level of support needs. When the discussion involves disabled children, the extent of choice and decision-making is often the question, as in case of non-disabled children. Independent living for disabled children means a disabled child should have the same opportunities that are available to their non-disabled peers. This includes, as above, the right to grow up in their families, access to mainstream education, and interaction with other children irrespective of background and support needs, as opposed to institutional segregation. Importantly, the voices and wishes of disabled children, as of all children, should be taken into account when decisions concerning their lives are being made.

WHY ARE INSTITUTIONS ESPECIALLY HARMFUL FOR CHILDREN?

There is a substantial amount of academic research demonstrating that institutions are harmful for the emotional and developmental well-being of children. Institutionalisation and segregation have a long term and permanent negative impact on disabled children's life chances, with those who are segregated as children less likely to have educational qualifications, less likely to get into paid employment, and more likely to experience isolation as adults. Segregation of disabled children also has long term negative economic consequences for the individual and society as a whole.

WHAT SUPPORT DO CHILDREN AND THEIR FAMILIES NEED TO LIVE INDEPENDENTLY?

As noted, independent living for disabled people can be realized if the necessary conditions and services are provided. This is also true for disabled children, who, in order to live a full, ordinary life of a child, require the provision of community-based services, including inclusive education.

For disabled children and their families, to have full access to independent living, mainstream services such as education, health and leisure should be accessible. There should be readily available information about services and support available to children and disabled children.

Disabled children and their families need a full range of options of support, so that they can choose what works best for them and their family's needs. Support should not negatively affect a family's functioning, but support a disabled child to access family life.

Personal assistance does not and should not replace parents; therefore, personal assistance should have clear boundaries and guidance from parents and guardians.

Families should have access to technical aids and equipment such as wheelchairs, hearing aids, communication aids. Families should also have access to communication support, such as training in sign-language, so that disabled children can be fully included in the family.

Accessible housing is a key element, in order to maintain independent living for disabled children. Accessible housing makes it easier for families to stay together and therefore enables disabled children to be part of their communities.

While timely support and continuity in support are key for all disabled people, they are particularly important for disabled children. Given how quickly things change in the life of a child, and how key being able to have access to services such as education can be to a child's development, continuity in support is essential. No child's potential should be stunted by not getting the support they need to access the same opportunities as their non-disabled peers.

HOW DOES INCLUSIVE EDUCATION SUPPORT INDEPENDENT LIVING?

Inclusive education is one of the 12 pillars of independent living - it is key to disabled people having choice and control over their lives and opens up many opportunities. Education is not just an important stepping stone for disabled people, but a great way for disabled children to be active and integral in their local communities. Inclusive education provides spaces to foster friendships and social networks, and inclusion from a young age also challenges stereotypes and prejudices.

Article 24 of the CRPD obliges States Parties to ensure that disabled children have access to mainstream education, including compulsory primary education and secondary education. Education should be available to disabled children on an equal basis with others, in the communities in which they live.

HOW CAN ORGANISATIONS PROMOTING INDEPENDENT LIVING INVOLVE CHILDREN IN THEIR WORK?

Disabled people's organisations (DPOs) can carry out the following activities, among other:

- Provide information about independent living in formats accessible to disabled children and their families;
- Provide case studies showcasing what independent living can look like for disabled children;
- Approach social, health and education services to look at how independent living tools such as personal assistance could enhance opportunities for disabled children;
- Set up peer support spaces for disabled young people and their families;
- Run training for disabled children and their families on independent living.

HOW DOES ENIL PROMOTE INDEPENDENT LIVING FOR DISABLED CHILDREN?

For ENIL, it is key that all disabled people, regardless of age, have access to independent living. We know from experience that having access to independent living helps disabled people access other human rights. We work towards a Europe where no disabled child is institutionalized.

We do this through our work of deinstitutionalisation and our involvement in the European Expert Group on the Transition from Institutional to Community-based Care (where we work together with children's organisations). We have made disabled children's access to independent living a key theme of the 2017 Freedom Drive and we have contributed to a number of projects looking at disabled children's experiences.

REFERENCES AND FURTHER READING

UN Convention on the Rights of Persons with Disabilities:

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

General Comment No. 4 on Inclusive Education:

http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/4&Lang=en

General Comment No. 5 on Independent Living:

http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en

UN Convention on the Rights of the Child:

<http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx>

ENIL Fact sheet on Personal Assistance: http://enil.eu/wp-content/uploads/2016/06/FAQ_Personal_Assistance.pdf

ENIL Fact sheet on Independent Living: http://enil.eu/wp-content/uploads/2016/06/FAQ_Independent_Living.pdf

Hasler, Frances (2003) Philosophy of Independent Living, available at:

<http://www.independentliving.org/docs6/hasler2003.html%232>

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Brown, Kevin (2009) The Risk of Harm to Young Children in Institutional Care,

available at: https://www.crin.org/en/docs/The_Risk_of_Harm.pdf

Council of Europe, Commissioner for Human Rights (2017) Position Paper: School segregation still deprives many children of quality education, available at:

https://www.coe.int/en/web/commissioner/-/school-segregation-still-deprives-many-children-of-quality-education?utm_source=email&utm_campaign=eNB_September&utm_medium=email

World Health Organisation (2010) Better health, better lives: children and young people with intellectual disabilities and their families, available at:

<http://www.challengingbehaviour.org.uk/learning-disability-files/Betterhealthbetterlives.pdf>

Eurochild (2014) Deinstitutionalisation Myth Buster, available at:

<http://eurochild.eu/fr/examples/library-details/article/deinstitutionalisation-myth-buster/?>

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Eurochild, Opening Doors for Children Campaign: <http://www.openingdoors.eu>

Lumos Foundation: <https://www.wearelumos.org>

Note on terminology: ENIL prefers the term 'disabled people' over 'persons with disabilities' or 'people with disabilities', in order to reflect the fact that people are disabled by the environmental, systemic and attitudinal barriers in society, rather than by their impairment. This is in line with the social model of disability.

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