



# **Kränker Sverige Rätten till ett självständigt liv?**

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**Rannveig Traustadóttir, Professor  
University of Iceland  
Center for Disability studies**





# Independent Living and Personhood

## Overview

- Independent living and being included in the community, Article 19 of the UN CRPD
- General Comment no. 5 on Art. 19
- What is independent living?
- Research on the implementation of Art. 19 in the Nordic Countries





## **Article 19. Living independently and being included in the community**

“States Parties to the present 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, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;





## **Article 19. Living independently and being included in the community**

(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”





## The right to live independently and be included in the community

- The right to live independently and be included in the community is recognised as particular right under Art. 19
- The rights in Art. 19 apply to ALL disabled people, regardless of the severity of their impairment and need for support
- The provisions of Art. 19 do not only refer to residential services, but also to services and supports in people's homes, social services, support for community inclusion, support for employment, access to minstream community services such as health services, etc.





## The right to live independently and be included in the community

- **Many experts on the CRPD view Art. 19 as at the core of the treaty. It:**
    - emphasises disabled people's rights – as right bearing individuals and not recipients of welfare or charity,
    - aims to prevent social exclusion, segregation and institutionalisation,
    - encourages inclusive environments and participation in all aspects of life,
    - rejects laws and policies that deprive people of autonomy and choice,
- Implementing Art. 19 should encourage and empower personal competence, identity and disabled people's possibilities





## Key elements of article 19

- **choice of residence,**
- **where and with whom people live,**
- **access to a range of community support services and**
- **equal access to mainstream community services**





## Article 19 requires States to:

- recognize the right of disabled people to live in the community,
  - take effective and appropriate measures to facilitate their full enjoyment of that right, with choices equal to others, and
  - take effective and appropriate measures to facilitate disabled people’s full participation and inclusion in the community.
- This includes choice of residence, where and with whom people live, access to a range of community support services and equal access to mainstream community services (the key elements of Art. 19)







## Article 19 is interrelated to many other articles in the Convention

- The right to live in the community and be fully included in society is one of the themes that goes through the entire text of the Convention.
- **Examples:**
  - One of the general principles in **Art. 3(c)** is “Full and effective participation and inclusion in society”
  - Article 26 (rehabilitation) in order to “support participation and inclusion in the community and all aspects of society”
  - Art 5 (non-discrimination) and Art. 9. (accessibility) are key to ensure disabled people equal access to mainstream services and society in general





## Article 19 is interrelated to many other articles in the Convention

- **More examples:**
  - Measures to combat multiple discrimination of disabled women (Art.6) and specific barriers for disabled children (Art. 7) are important provisions that need to be considered when implementing Art. 19
  - **Article 12** on equal recognition before the law is a key to self-determination, autonomy and choice which are key rights to be able to enjoy the rights under Art. 19 about choice and control of your everyday life.
  - And many more...





## General Comment no. 5 on Article 19

- The CRPD Committee published this GC in August 2017:
  - It is comprehensive and detailed
  - Includes definitions of key terms in Art. 19 (independent living, community living, personal assistance)
  - Outlines the Core Elements of Art. 19
  - Outlines obligations of State Parties under Art. 19
  - Outlines the relationships of Art. 19 with other provisions in the Convention
  - Addresses implementation at national level





# Ideology of Independent Living

## Has a long history –

- Often unclear what people mean by “independent living“, “independent life” and “independence”
- **At least two ways of understanding** the ideology of independent living and what it means in practice





# Two main ways of understanding Independent Living

## 1. Ideology based on an international movement – the Independent Living Movement

- Has its roots in Berkeley, California (50 years ago)
- Key aspect is Personal Assistance
- Has set principles and a specific understanding of IL

## 2. More general understanding of independent living

- Refers in general to disabled people having access to the support needed to be able to lead an independent life and participate in society/ community on an equal basis with others





# 1. Ideology based on an international movement: The Independent Living Movement

- **An international movement**
  - Roots in the disabled people's movement – Berkeley California in late 60s and early 70s
  - Has grown stronger and gained more support and attention over the years
  - Conceptualized and carried out by and for disabled people
  - Independent living co-operatives and others providing PA services exist in most countries
  - Has a strong European component, ENIL, European Network on Independent Living ([www.enil.eu](http://www.enil.eu))

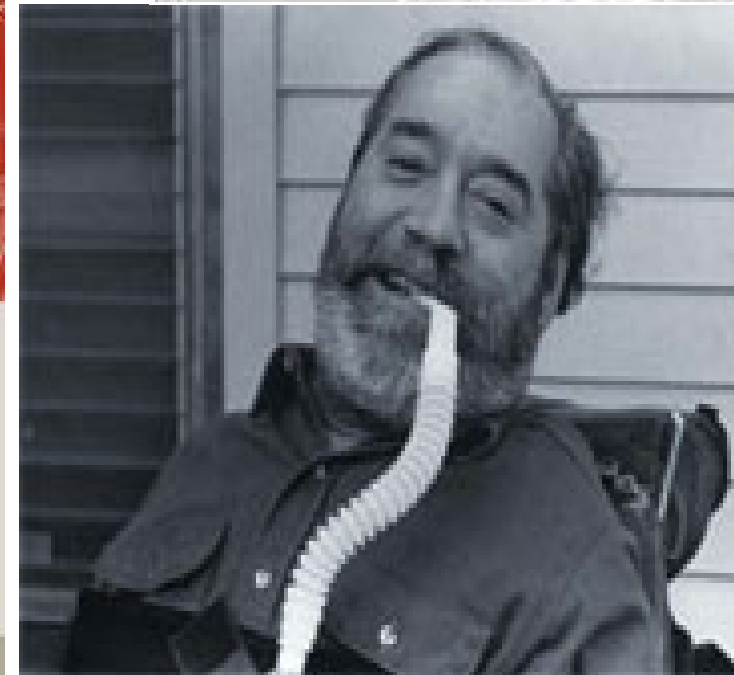
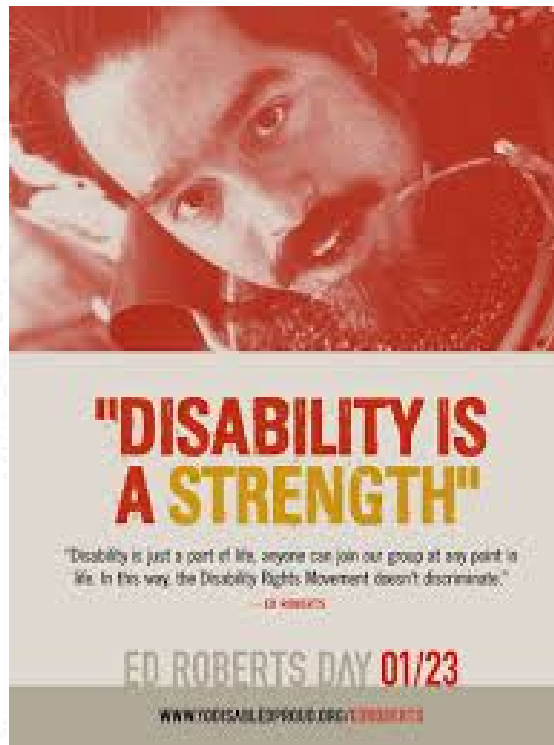




# Ed Roberts (1939-1995)

## The father of Independent Living

- **More about Ed Roberts at**  
[http://www.ilusa.com/links/022301ed\\_roberts.htm](http://www.ilusa.com/links/022301ed_roberts.htm)





# What is “independence” and “independent living”?

- **The independent living movement challenges the traditional understanding of “independence“**
  - Independence is not the physical or intellectual capacity to look after yourself on your own and do everything without assistance
  - Independence means having access to the assistance and supports you need to take part in everyday community life on an equal basis with others







## User-led Personal Assistance

- Is a service model disabled people have conceptualized, fought for and developed
- User-led Personal Assistance is implemented in various ways – and under various terms – but the key is that the control of the service is with the user, who decides:
  - who is hired
  - what task they carry out
  - when, where and how





## 2. More general understanding of independent living

- Refers in general to disabled people having access to the support needed to be able to lead an independent life and participate in society/ community on an equal basis with others
- **Is a part of disability policy in most western countries**





## General Comment no. 5 on Article 19

- Includes definitions of key terms in Art. 19 (independent living, community living, personal assistance)
- The GC provides a broad definition of independent living which includes the two understandings outlined above
- The GC outlines a wide range of obligations of State Parties to implement Art. 19 (Chapter III of the GC)





# Research on the implementation of Art. 19

- Most research has identified various barriers to the implementation of Art. 19 – this is also true of implementation in the Nordic Welfare states
- Research indicates that there is still a long way to go before the requirements and rights of Art. 19 have been implemented
- The research is an important tool to identify barriers and violations under Art. 19 as well as identifying “best” or “promising” practices - and help develop ways for its implementation





## Nordic Research on Implementing art. 19 – focus on PA

- Brennan, C., Traustadóttir, R., Anderberg, P., & Rice, J. (2016a). **Are Cutbacks to Personal Assistance Violating Sweden’s Obligations under the UN Convention on the Rights of Persons with Disabilities?** *Laws, Special Issue on Disability Human Rights*, 5(2), 23; doi:10.3390/laws5020023
- Brennan, C., Traustadóttir, R., Anderberg, P., & Rice, J. (2016b). **Negotiating independence, choice and autonomy: Experiences of parents who coordinate personal assistance on behalf of their adult son or daughter.** *Disability & Society*, 31:5, 604-621, DOI: 10.1080/09687599.2016.1188768
- Brennan, C., Rice, J., Traustadóttir, R., & Anderberg, P. (2017). **How can states ensure access to personal assistance when service delivery is decentralized? A multi-level analysis of Iceland, Norway and Sweden.** *Scandinavian Journal of Disability Research*, 19:4, 334-346, DOI: 10.1080/15017419.2016.1261737
- Brennan, C., Traustadóttir, R., Rice, J., & Anderberg, P. (accepted for publication 2018). **“Being Number One is the Biggest Obstacle”:** Implementing the UN Convention on the Rights of Persons with Disabilities within Nordic Welfare Services. *Nordisk Velfärdsforskning/ Nordic Welfare Research*





## Nordic Research on Implementing art. 19 Including a focus on the participation of DPOs

- Löve, L., Traustadóttir, R., Rice, J. & Quinn, G. (2017). **The inclusion of the lived experience disability in policymaking**, *Laws, Special Issue on Human Rights Law*, 6(4), 33; doi:10.3390/laws6040033
- Löve, L., Traustadóttir, R., & Rice, J. (2018). **Achieving disability equality: Empowering disabled people to take the lead**. *Social Inclusion. Special Issue on Disability Equality*, 6(1), DOI:10.17645/si.v6i1.118.
- Löve, L., Traustadóttir, R., & Rice, J. (accepted for publication, 2018). **Trading autonomy for services: Perceptions of users and providers of services for disabled people in Iceland**. *ALTER European Journal for Disability Research*.





Rannveig Traustadóttir, Professor and Director  
Centre for Disability Studies  
School of Social Science  
University of Iceland  
[rannvt@hi.is](mailto:rannvt@hi.is)

