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**BACK TO THE
FUTURE** 2024

 **NCIL ANNUAL CONFERENCE ON INDEPENDENT LIVING**

2024 Annual Conference on Independent Living

BACK TO THE FUTURE

Presented by the National Council on Independent Living

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Revisiting the 12 Independent Living Pillars through a global and intersectional lens

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The European Network on Independent Living (ENIL)

- a membership organisation led and controlled by disabled people
- established in 1989
- with a mission:
 - to advocate and lobby for Independent Living values, principles and practices, namely for a barrier-free environment, provision of personal assistance support and adequate technical aids, together making full citizenship of disabled people possible (ENIL, n.d.)

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Key principles of ENIL's work

- solidarity
- peer support
- self-representation
- cross-impairment
- self-determination

(ENIL, n.d.)

Original 'core services' at the Physically Disabled Students' Program (PDSP) in 1970-72

- **personal assistance** (support with finding assistants/attendants)
- **housing** (support with finding accessible housing)
- **technical aids** (wheelchair repair and redesign)
- **advocacy** (support with accessing benefits and services)

(Evans, 2002; Shapiro, 1993; Zukas, 1975)

Key principles:

- disability is a **social problem** not a medical one
- disabled people should be **in control** of their support
- the support provided should be **comprehensive** (holistic, integrated approach)
- full **community integration**
- **cross-disability** coverage

(based on Zukas, 1975; see also Evans, 2002: 6)

Services at CIL Berkeley in late 1970s

- **personal assistance**
- **housing**
- **technical aids**
- **advocacy** (including organising campaigns and protests)

- **legal advice and litigation**
- **employment / job development** (job search, awareness raising among employers)
- **peer counselling/support** (psychological support, empowerment towards self-determination)
- **transport** (including own service – an adapted van)
- **deaf services, blind services** (communication support: sign language interpreters, readers)

(Kleinfield, 1979; Heumann, 2004: 364-365)

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Services at CIL Berkeley in late 1980s

New trends, as reported by Racino (1989):

- IL skills training for **people with intellectual disabilities**
- **youth services** (peer support, mentoring, job search)

Individual advocacy (counselling for benefits) increasingly substitutes systemic advocacy (campaigning work):

‘CIL continues to be actively involved in both individual advocacy and systemic advocacy, though many of the staff members report 80-99 % of their time is now spent on supportive services.’ (Racino, 1989: n.p.)

The 7 Needs of Derbyshire CIL (DCIL) – early 1980s

- **information** (about entitlements, available supports)
- **peer counselling**
- **housing** (accessible and affordable)
- **technical aids**
- **personal assistance**
- **transport** (accessible and affordable)
- **access** (to the built environment)

(Davies, 1990: 7; Hunt, 2019: 156)

The 12 Pillars of IL

In 1989, the 7 Needs evolved into 11 Needs, adding:

- **employment**
- **education**
- **income support** (benefits)
- **advocacy**

(Evans, 2002: 7; Hunt, 2019: 157)

Later, the 11 Needs evolved into the 12 Pillars of IL, adding:

- **healthcare**

(Disability Rights UK, n.d.; ENIL, 2023; Spectrum CIL, n.d.)

The 12 Pillars of IL at a glance

Accessibility: Full access to our environment

Transport: A fully accessible transport system

Technical aids: Appropriate technical aids/equipment

Housing: Accessible / adapted housing

Personal assistance: Personal assistance to enable an independent lifestyle

Education: Inclusive education and training

Income: An adequate income

Employment: Equal opportunities for employment

Information: Appropriate and accessible information

Advocacy: Advocacy (towards self-advocacy)

Peer support / counselling: Empowering counselling services

Healthcare: Appropriate and accessible healthcare provision

(based on Spectrum CIL, n.d.: n.p.)

The UN Convention on the Rights of Persons with Disabilities (CRPD)

Core elements of Article 19, according to General Comment No 5 (para. 38):

- **legal capacity**

‘To ensure the right to legal capacity, in line with the Committee’s general comment No. 1, to decide where, with whom and how to live for all persons with disabilities, irrespective of impairment)’

- **housing**

- **accessible mainstream services** (including information and communication technologies)

- **personalised disability-specific support services** (e.g., personal assistance)

- **data collection**

- ‘To collect consistent quantitative and qualitative data on people with disabilities, including those still living in institutions’

The UN Convention on the Rights of Persons with Disabilities (CRPD)

Global application of Article 19 (paras 7 and 22, General Comment 5):

- Reflects the **diversity of approaches to human living** and its content is **not biased towards certain cultural norms or values**
- Living independently and being included in the community is a **basic concept of human living**
 - ‘It means exercising **freedom of choice and control over decisions affecting one’s life** with the **maximum level of self—determination and interdependence within society**. This right must be effectively realised in different economic, social, cultural and political contexts.
- All persons should be free to choose to be active and **belong to a culture of their own choice**, with the **same degree of choice and control** over their life as other members of the community
- Independent living is not **compatible with the promotion of a ‘predefined’ individual lifestyle**

ENIL's proposal for additional pillars

- access to **supported decision-making**
- knowledge about **IL history, philosophy, and organising**
- support for **sexual and reproductive rights**
- access to **internet and digital technology**
- access to **legal aid**
- support for **transitions**
to adulthood, higher education, employment, from parental home,
and from institutional care

ENIL's proposal for additional principles

- adopt an **intersectional perspective**

consider overlaps between disability and older age, gender, sexuality, poverty, climate change, and locality

- ensure IL in **emergency situations**

armed conflicts, natural disasters, pandemics)

- co-produce **disability research**

- **decolonise IL**

- engage with – and promote – local knowledges and practices regarding self-determination ('choice and control')
- develop culturally sensitive, locally appropriate Independent Living ideas and practices

Discussion questions

- What are the current priority pillars in your state or country?
- How to make the IL Pillars framework more inclusive?
diversity of impairments, ages, genders, ethnicities; culturally sensitive / decolonial; appropriate for both high-income and low-income contexts
- Are there additional pillars or principles that need to be considered?

References

Davies, K. (1990) 'A social barriers model of disability: theory into practice. The emergence of the "seven needs"', paper prepared for the Derbyshire Coalition of Disabled People.

<https://web.archive.org/web/20240324073420/https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/DavisK-davis-social-barriers.pdf>

Disability Rights UK (n.d.) 'Independent Living. Disability Rights UK Factsheet F38', online publication. London: Disability Rights UK.

<https://web.archive.org/web/20231108170115/https://www.disabilityrightsuk.org/resources/independent-living>

ENIL (n.d.) 'About ENIL', online publication. Brussels: European Network on Independent Living.

<https://web.archive.org/web/2023110111447/https://enil.eu/about-enil/>

Evans, J. (2002) 'Independent Living Movement in the UK', online publication. Leeds: The Disability Archive UK. Available online at:

<https://web.archive.org/web/2023110120434/https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/evans-Version-2-Independent-Living-Movement-in-the-UK.pdf>

Heumann, J. (2004) *Judith Heumann, Pioneering Disability Rights Advocate and Leader in Disabled in Action, New York: Center for Independent Living, Berkeley; World Institute on Disability; and the US Department of Education 1960s-2000*. An oral history conducted by Susan Brown, David Landes, Jonathan Young in 1998-2001. Berkeley, CA: Regional Oral History Office, The Bancroft Library, University of California, Berkeley.

<https://oac.cdlib.org/view?docId=hb9v19p0k9&brand=oac4>

Hunt, J. (2019) *No Limits. The Disabled People's Movement – A Radical History*. Manchester: TBR Imprint.

Kleinfield, S. (1979) 'Declaring independence in Berkeley', *Psychology Today*, Vol. 13, No. 3, pp. 67–78. Reprinted and posted at:

<http://www.independentliving.org/toolsforpower/tools2.html>

Racino, J. A. (1991) 'Center for Independent Living (CIL): Disabled People Take the Lead for Full Community Lives'. Syracuse, NY: Research and Training Center on Community Integration, Syracuse University. <https://www.independentliving.org/docs4/racino91.html>

Spectrum CIL (n.d.) "'Rights not Charity' – 12 Basic Rights', online publication. Southampton: Spectrum CIL.

<https://web.archive.org/web/2023110172314/https://spectrumcil.co.uk/wp-content/uploads/2015/04/SPECTRUM-12-Basic-Rights-2013>

Zukas, H. (1975) *CIL History. Report of the State of the Art Conference*. Berkeley, CA: Center for Independent Living – Berkeley.

<https://web.archive.org/web/2023110174358/https://www.independentliving.org/docs3/zukas.html>