

Personal Assistance and Independent Living: article 19 of the UN Convention on the Rights of Persons with Disabilities

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Summary

The paper reviews personal assistance and independent living within the framework of article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD). It concentrates on the issues of independent living and personal assistance (for a full review of the other important issues of article 19 please see European Coalition on Community Living report Focus on Article 19 of the UN Convention on the Rights of Persons with Disabilities at <http://www.enil.eu/elib/articles/ECCL-Focus-Report-2009-final-WEB-1.pdf>)

This paper provides the full text of article 19 and considers the misconceptions and misunderstandings of the terms 'independent living' and 'personal assistance', as well as the history of independent living movement. Explanations are given of the differences between organisations *of* and *for* disabled people. Adolf Ratzka's model of personal assistance is used to demonstrate the ideal model for personal assistance. Recommendations are then given for the EU, for national governments and for disabled peoples' organisations for strengthening the knowledge and active base for personal assistance within the framework of article 19 of the CRPD (see full English version of CRPD at <http://www.enil.eu/elib/app/webroot/files/UNconvoptprot-en.pdf>)

Introduction

The CRPD consists of 50 articles concerning the human rights, dignity and independence of disabled people. Article 19 deals with the right to independent living, community support and personal assistance. This paper reviews personal assistance and independent living according to the philosophy of the independent living movement.

Article 19 of the UN Convention states that disabled people should live where they wish and with whom they wish. That they should enjoy a range of community support services including personal assistance. That they should enjoy community life and its opportunities on an equal basis to non disabled people and they should not be subject to isolation or segregation. Yet how far will the application of article 19 be dependent on the development and extent of independent living supports or barriers currently evident in different countries? How far might the concept of independent living be interpreted differently in Europe and by distinctive groups of stakeholders?

By encapsulating independent living in international law, it becomes not just available but a requirement in widely differing political and cultural settings around the world. Whether or not it achieves its emancipatory potential will depend on many factors, not least the ability of disabled people to retain ownership of its meaning, its interpretation and its application.

(Collingbourne 5-6 2009)

The English version of the full text of article 19 of the CRPD readsⁱ

Article 19 - Living independently and being included in the Community

States Parties to this 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;

(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.

While article 19 is welcomed for the importance placed on the right to personal assistance, the European network on Independent Living (ENIL) and its members recognise that the terms 'independent living' and 'personal assistance' have often been exploited and misused to profit organisations, charities and disability business' which are not run and controlled by disabled people. These organisations do not appear to want to fully understand the concept of independent living as developed by the independent living movements across Europe and internationally.

Such organisations do not work within the framework of the independent living movement to benefit disabled people; rather they use these terms to profit financially and politically. In fact residential institutions can use these terms to claim that their institutions are 'independent living institutions', they and the non-

residential day centres can develop terms like ‘independent living’ skills which may consist of learning tasks which relieve staff of some activities for example doing up buttons on clothing. While residential institutions cannot be called independent living institutions or centres neither can those working in them be claimed to provide ‘personal assistant services’. All examples are a misuse and clear misrepresentation of the concept developed by the independent living movement. It should be clear that each misrepresentation works against the realisation of the human rights of disabled people as outlined in article 19ⁱⁱ.

We foresee this practice increasing over the coming years with the implementation of the CRPD and article 19.

The aims of this paper are to:

1. Clarify what independent living and personal assistance are in line with article 19 of the CRPD, and within the framework of the independent living movement and disabled peoples’ wishes.
2. Briefly identify the existing situation in relation to personal assistance in a selection of European countries.
3. Offer recommendations on the ways disabled people, their organisations, governments and the European Parliament can ensure that article 19 achieves its aims, making personal assistance and independent living a reality for all in Europe.

1. What is independent living and the independent living movement?

It is widely accepted that disabled people have fewer opportunities to participate in the activities of everyday life due to a number of social, access and attitudinal barriers. The social model of disabilityⁱⁱⁱ identifies the philosophy and actions that need to be taken to begin to remove the multiple social disadvantages that exist for disabled people and which continue to prevent us from living with the full choices, self determination, rights and control that non-disabled people take for granted. The philosophy of the social model of disability underpins the aims of the independent living movement. Independent Living requires a number of societal practices to be put in place which do not discriminate the life chances of an individual purely because they have an impairment (or multiple impairments) which may be sensory, physical, intellectual related to mental health or are perceived as learning difficulties.

The aims of independent living can be summed up in the seven needs of independent living for disabled people first developed by the Derbyshire Coalition of Disabled People in England.

◦ Accessible Information

- Peer support
- Accessible Housing
- Access to technical aids and equipment
- The right to personal assistance
- Accessible transport
- Accessible environments

Education and employment were later added to the list.
(Oliver and Barnes 1998)

1.1 Summary of the early independent Living movement and actions

The independent living movement was active in the United States of America in the 1960s and 1970s with the first well known Centre for Independent Living (CIL) established at Berkeley at Boston University in 1972

See <http://www.cilberkeley.org/>

Other examples were Finland establishing the first independent living program in 1973 with 6 Centres for independent living being established in the same year. In 1975 the Union against the Segregation for Physically Impaired (UPIAS) published a manifesto in England relating to institutionalisation and the lack of rights of disabled people. In the same year a group of disabled people living in an institution in Zimbabwe organised themselves for advocacy. In 1978 Japanese disabled people organised radical self- advocacy and Switzerland held one of the first conferences of self-help for disabled people.

In the early 1980s the first Canadian CILs were founded, and the first organisation of disabled people was founded in Nicaragua providing Independent living services and advocacy. In 1981 the British Council of Disabled People was founded (now renamed the UK Disabled People's Council), whilst in Germany a disability rights coalition staged a mock tribunal putting the country on trial for the abuse and segregation of disabled people (Behrendt et al undated). In 1981 in Hampshire, England 'project '81' became one of the earliest forms of what we now recognise as a direct payments system. This brief review shows that neither personal assistance nor independent living are new ideas, yet at the time of writing there are still many European countries without any form of personal assistance or access to independent living available.
(Behrendt, et al undated, Barnes et al 1999)

1.2 Independent Living and organisations of disabled People

The independent living movement is a movement of disabled people that works for the full rights of disabled people and it is the basis on which all Centres for Independent Living, Centres for Integrated Living, Centres for Inclusive Living or CILs are developed and managed.

CILs are run, controlled and organised by disabled people to offer training, peer support and other services to disabled people, they also engage in work with local, national and European governments to raise awareness and challenge issues that relate to the services and rights of disabled people. These organisations work on the philosophy of the social model of disability.

Of course an organisation can be about independent living without being called a CIL, what many groups and organisations share is a commitment to the principles and the aims of independent living, however such organisations must be run and controlled by disabled people.

Such organisations represent organisations **of** disabled people, that is they have staff, boards and management committees who are disabled people and represent cross-disability issues. We suggest that such organisations are comprised of 75% and over of disabled people at decision making levels and work within the model of independent living philosophy as described. This differs from organisations **for** disabled people who may not have any or very few disabled staff, with few or no disabled people making decisions at board or management level^{iv}.

1.3 What is a personal assistance user?

The term personal assistance user refers to a disabled person choosing a personal assistant of their choice to aid them in everyday tasks and in negotiating environmental, transport and other social barriers. However, not all disabled people want or require personal assistance, but all disabled people including those that use or wish to use personal assistance want to exercise choice, control and self-determination over their own lives.

We support the definition of the personal assistance system by Dr Adolf Ratzka (Ratzka 2004) and the European Centre for Excellence in Personal Assistance (ECEPA) which sets key principles in place:

The funding of [personal assistance] services follows the person and not the service provider,

Personal assistance users are free to choose their preferred degree of personal control over service delivery according to their needs, capabilities, current life circumstances, preferences and aspirations.

Their range of options includes the right to custom-design their own services, which requires that the user decides who is to work, with which tasks, at which times, where and how.

Therefore, a policy for “personal assistance”, among other solutions, enables the individual to contract the service of his or her choice from a variety of providers or to hire, train, schedule, supervise, and, if necessary, fire his or her assistants. Simply put, "personal assistance" means the user is customer or boss. (Ratzka 2004: 2-4)

Personal assistance is NOT the assistance of nurses, social workers, charities or medical professionals. It is not a volunteer visiting a disabled person and having tea or coffee with them, nor should it be the assistance of family members as this is less likely to support self-determination and independence than a personal assistant distinct from the family with set tasks organised and overseen by the personal assistance user. The exception would be where a disabled person has a special requirement for a person from their own family due to religious or other cultural criteria which cannot be satisfied by other eligible persons.

Personal assistance is certainly not something offered by staff in residential homes or institutions (including day centres), nor should it be described in article 19 as ‘personal support’ or by any other term. Personal assistance is something controlled and managed by the disabled person to ensure their self-determination and independence on their own terms- anything else contravenes the aims and philosophy of the original concept developed by the independent living movement.

2 What is the European situation on Independent Living and Personal Assistance?

In spite of the earliest recorded evidence of active independent living movements existing in the 1960s the situation in Europe is still mixed. Almost 50 years later many European countries are without any personal assistance schemes.

As noted the personal assistant schemes recognised by disabled people are those in which users have full control. In many countries disabled people are unable to obtain any form of funded personal assistance from their governments, or such funding is restricted to those with physical and sensory impairments denying those with multiple impairments, learning difficulties and mental health issues access to systems. This is a situation, which needs to change (see

resources on different country areas and independent living progress at the end of the paper)

Where there are personal assistance systems in place we are aware that not everything is running as smoothly or completely within the independent living and personal assistance framework as we would like. Selected examples are outlined below:

Some governments are seeking to save money by restricting the tasks that a personal assistant can do, meaning the tasks that they will pay for a personal assistant to do. There are cases in Sweden. For example the municipality of Visby limits personal assistants tasks A person living alone should now only live in a flat/house with two rooms and a kitchen, if living in a larger flat they should move or pay for the cleaning of the rest of the flat. Members of Parliament reacted to the new interpretation of the National Social Insurance Office limiting personal assistance by saying that if you can get the spoon to the mouth or eat by yourself you do not need personal assistance-even if you need help in getting the food to the table. See below (in Swedish)

<http://www.independentliving.org/assistanskoll/20090611-Lena-Lager-Socialdirektor-i-Gotlandskommun-upphandlingen-assistans.html>

Where government departments fund schemes for personal assistance they can refuse to increase the amount of money to an organisation in spite of the organisation showing the need for greater resources and a greater demand for personal assistance. Thus the number of those able to access the schemes is limited and the organisations trying to run such schemes become frustrated having to turn people away. This is the case in Slovenia. (personal communication with YHD activists 17.07.2009).

When a national government declares that they are presenting a personal assistance scheme, but will only fund an unemployed family member to be the personal assistant. This enables them to remove the person from the unemployment figures and at the same time to pay a low amount of salary to the person for being the personal assistant. This is problematic in many respects, one being that self-determination is often better achieved with a personal assistant who is distinct from the family and another being that low cost schemes develop into sub standard alternatives to the real goal of independent living. This is the case in Bulgaria (see Panayotova 2009 ANED Country report)

Where local authorities or municipalities, responsible for administering direct payments through which to pay for personal assistance, increase restrictions on who can access direct payments (or personal budgets). For example, in 2007, over 70% of authorities restricted access to direct payments to all but those considered the most severely disabled (2007 National Centre for Independent Living). At the same time national government announced a totally inadequate

1% increase in overall social 'care' funding for an inclusive three year period (National Centre for Independent Living 2007). This is an example from the UK.

3. Recommendations for EU and national governments on personal assistance

3.1 Ratify the Convention and the Optional Protocol

3.2 Publish guidelines and clear definitions on what independent living and personal assistance are in line with the philosophies of the independent living movement. These guidelines should be published and publicised at European and national levels.

3.3 Ensure proper and authentic translations of article 19 in line with article 50 of the CRPD using direct translations (from official UN languages for example Arabic, Chinese, English, French, Russian and Spanish). The European Commission should monitor translations or appoint a European body to do so to avoid terms like 'personal help' or 'personal support' appearing in place of the term personal assistance. Moreover, they should ensure that government bodies responsible for misleading translations are educated on issues of independent living by organisations of disabled people.

3.4 Develop a stream of European core funding support for organizations dealing with issues of independent living and personal assistance on a cross disability basis. These organisations should be run and controlled by disabled people. This means having at least 75% representation of disabled people with lived experience of independent living in decision making positions.

3.5 Ensure that key organisations are consulted as 'experts'. This means organisations of disabled people running personal assistant schemes and adhering to the illustrated independent living principles.

3.6 Develop a European database of organisations of disabled people with experience of both the practical application and knowledge surrounding independent living with personal assistance.

3.7 Develop European and national policies for the CRPD with the full and equal participation of organisations of disabled people in line with article 4 (section 3) of the CRPD.

3.8 Ensure implementation of the CRPD with full participation of organisations of disabled people in line with article 4 (section 3) of the CRPD.

3.9 Ensure that organisations of disabled people are fully involved in monitoring the implementation of the article 19 at national levels as full and equal partners entering into full dialogue with national governments and decision-making bodies.

The monitoring activities should include a monitoring process of existing national law and policies. The process should include an identification of how such laws are, or are not, implemented effectively in achieving the aims of independent living (as in article 4 1 sections a and b). Monitoring processes should also include an identification of personal assistance opportunities for all disabled people including those with mental health issues, learning difficulties and those with so called complex support needs. If there are no opportunities for people to access personal assistance- this situation needs to change

3.10 There should be an appropriate remuneration system for the active participation and knowledge of disabled people and their organisations in carrying out the processes of implementing and monitoring the CRPD.

3.11 Develop a European directive on article 19 in full consultation with organizations of disabled people. Thereby strengthening the application of European action plans, and strengthening the implementation of article 19. This would secure the path for European citizens in achieving their designated human rights to personal assistance services.

3.12 Putting a penalty system in place for national governments that fail to make progress on article 19 within a specified time period.

4. Recommendations for disabled peoples' organisations and individuals

4.1 For translations of article 19 and other articles refer to one of the 'authentic texts' (English, Spanish, French, Arabic, Russian, or Chinese)

See: <http://www.un.org/disabilities/default.asp?navid=12&pid=150>.

Make complaints to the organization that was responsible for the translation. Lobby your national government for changes in the translation. Circulate template letters among members and publicise suggestions for change on your web sites. Get the media involved.

4.2 Write to and interview your MEPs. Many of us who joined the 2009 Freedom Drive at Strasbourg made good contacts with MEPs use these contacts to continue to lobby for independent living, personal assistance and a directive for article 19.

4.3 Lobby for a directive on article 19 by writing to the disability intergroup care of Richard Howitt's office

Office of Richard Howitt, MEP

Member of the European Parliament for the East of England

Parliamentary Assistant: Mr. Brian Dawson

Parliamentary Stagiaire: Ms. Katharina Fischer

European Parliament, ASP 13G 246, Rue Wiertz, 1047 Brussels, Belgium

Tel: + 32 2 2847477 Fax: + 32 2 2849477

richard.howitt@europarl.europa.eu

www.richardhowittmep.com

Intergroup email is expected to be set up in January 2010

4.4 Write to Laszio Andor the commissioner for Employment, social Affairs and Equal Opportunities at the European Commission calling for a directive on article 19. at: European Commission
DG Employment, Social Affairs and Equal Opportunities
B-1049 Brussels
BELGIUM

4.5 Develop awareness raising campaigns nationally and invite national MPs and MEPs to attend.

4.6 Use internet resources, Blogs, face book, Twitter, My Space, You Tube to spread the message. See excellent example on Personal Assistance by YHD Slovenia who asked parliament candidates to become PA assistants for a day. Films were made and put on You Tube and statements from potential parliamentarians and PA users were then published. See

http://www.enil.eu/enil/index.php?option=com_content&task=view&id=38&Itemid=82

4.7 Monitor and document the changes and shifts happening in existing Personal Assistance systems. In addition, document emerging Personal Assistance schemes.

4.8 Monitor and document abuses of the terms 'personal assistance' and 'independent living' and publicise these through your own national organisations and through ENIL.

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Available at <http://www.independentliving.org/docs6/ratzka200410a.html>
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- National Centre for Independent Living (2007) Spending Review: Cuts in Social Care set to Continue
<http://www.ncil.org.uk/press-releases.asp?action=view&id=59>
Accessed 21.10.09

Additional Resources

Academic Network of European Disability Experts (ANED) Country reports on the Implementation of Policies supporting Independent Living for Disabled people
Available at

<http://www.disability-europe.net/?jsEnabled=1>

Accessed 21.10.09

Direct Payments in the Care. Current Situation in 8 Countries (2009) Expert Centre Independent Living, Van Hauwermeiren Juliska and Decruynaere Elke
Available at

<http://www-en.onafhankelikleven.be/publications/>

Accessed 22.10.09

Research paper Community Living and the Support of Independent Living: costs and Benefits Jolly Debbie
Available at

<http://www.enil.eu/elib/a...nd the support of IL cost and benefits.doc>

Accessed 03.12.09

UN Convention on the Rights of Persons with a Disability full text link

Available at

<http://www.enil.eu/elib/app/webroot/files/UNconvoptprot-en.pdf>

Accessed 22.10.09

UN Convention on the Rights of Persons with a Disability Link to Easy Read version

Available at

<http://www.enil.eu/elib/a...ional-agreement-rights-disabled-people.pdf>

Accessed 22.10.09

Endnotes

ⁱ We are aware that in some countries versions of the UN Convention do not include the term 'personal assistance' in article 19. In these situations ENIL advises disability organisations to write up a list of definitions and guidelines for article 19, to contact the office responsible for transcription and to urge their MPs

and MEPs to lobby for a translation that mirrors authentic texts of the CRPD see recommendation 4.1

ii See ENIL members YHD leaflet on Independent Living available at [http://www.enil.eu/elib/a...et\[1\]Kdefinition of Independent Living.doc](http://www.enil.eu/elib/a...et[1]Kdefinition%20of%20Independent%20Living.doc)

iii See ENIL web-site for an outline of the social model of disability http://www.enil.eu/enil/index.php?option=com_content&task=view&id=2&Itemid=84

iv The recommended percentage of disabled people in an organisation to count as an organisation **of** disabled people from the Office of Disability Issues (England) is 75% and over.

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