

Independent Living (IL) – a political decision

By Jamie Bolling

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Independent Living

First of all, I would like to thank the network of The Future of the Welfare State in the Western Balkans for the invitation to come and address this conference and speak about Independent Living.

Martin Luther King had a dream.

Thanks to Martin Luther King I also have a dream. I have many dreams!

I have a dream for each and every person living in an institution – for their life to be free, that they won’t suffer from violence, and could gain back a will to life if they have lost it.

I have a dream for the people I meet – those with down syndrome who ask me if they can come to work with me as they are tired of only meeting other people with down Syndrome at their sheltered workshop.

I have a dream for children who are being put into institutions, larger or small group homes; when I know they would fare better, develop better if they were living in their own home or as a last resort in a foster home.

I have a dream that people will recognize the prejudice they carry within and that they would deal with this prejudice. Whether it is prejudice towards Roma, Jews, people with black skin, an Arabic name, a Muslim, a Christian or towards me and my brothers and sisters that have some kind of an impairment.

Am I only a dreamer?

No, I know what it is to have prejudice. I know what it entails to deal with prejudice.

I remember the first time after my accident in 1991 when I was to be transported from the hospital to visit my home in Stockholm. I saw the van that waited. It was big. I was thinking that

is the kind of bus they picked up the disabled people in my town back in Ohio, USA to take them to their sheltered workshops. I found myself crouching as low as I could in my wheelchair. I was trying to hide so no one could see me through the windows. Then I realized what I was doing. I asked myself "What the hell are you doing?" Am I better than those others picked up by vans to be transported to the sheltered workshops?

I usually start a speech by saying –
I have three passports
Two daughters
And one passionate drive.

I was born in the USA and lived there until I was 19 years old. I lived 14 years of my employment experience in Switzerland and I was lucky to fall off a horse in Sweden. Sweden is a country with good social policy. I accessed good rehabilitation. I was able through personal assistance to go back to the university and become a doctorate student. I could and can accept jobs including becoming the director of the European Network of Independent Living – ENIL. Today I am able to be the director for the Independent Living Institute and co-president of ENIL.

My daughters are today 37 and 34 years old but in 1991 they were then 6 and 9 years old. Two weeks after my accident my oldest daughter came into my room at the hospital and yelled, "Get out of that bed and come home and take care of us." She was diabetic since the age of 3. She was missing me. I quietly explained that I would first need to get into a wheelchair and then I could come home. She interrupted me "You are not allowed to sit in a wheelchair." With her prejudice at the age of 9 she found the wheelchair would be the Worse. I had not taught her this at home – but the norms of our societies taught her as they had taught me about the prejudice I had on the vans. The norms impregnate the prejudice towards others that are different into our minds. Then we build social structures that empower some and marginalize others.

When we would go to town my girls and I – they would say – "Mom you can stay in the car."
"No I am not going to stay in the car" I would say.
They tried to hide me, but it did not work.
They worked through their prejudice as I worked through mine. And today we are different people.

I found a home in the Independent Living movement after my accident. I met an ideology in which I believe and for which I have been passionately involved since 1993. It is built on:

Self-determination

Choice

Control

Participation

Inclusion

These are the pillars, the foundation of Independent Living.

I have a dream that people in my country and in the countries of this network will receive the support they need based on their individual needs. Individual assessment for support services is another foundation of Independent Living.

I have a dream that those who need personal assistance (PA) will access personal assistance. I have too many friends in the Balkans whose parents are over 70 and still carry their child – now of 50 years of age. How long will they survive? Once Vanja's mother can no longer support Vanja, will she have to go to the home for the elderly with her mother like Miroslav had to do in Bulgaria?

In my work as the director of ENIL I met a leader of the Council of Europe who asked me "At least some people need to live in **institutions** don't you think?"

No was my response. I knew this person was referring to people with intellectual impairment. I told the person how in Sweden with the example of personal assistance it has been shown that people needing 24/7 service, with high level needs, wheelchair users in need of supported decision making, can live in their own home with personal assistance. Through what we call the **JAG model** there is a guarantee that the assistants are at the job, working at all times, through a **service garant**.

If I get a call at 6:50 in the morning from a personal assistant who is to start at 7:00, with them saying they are sick I need to start calling to find someone to replace the person. I need the person to come and get me out of my bed. Not a great situation and luckily does not happen so often. A person not understanding this situation would not know finding a replacement is necessary. But a **service garant** would start the calling.

In Sweden since 1994 disabled people with certain needs can access personal assistance as a right. Not all disabled people but those with certain needs who qualify under the legislation. The legislation that made this possible is the legislation LSS. This law guarantees 10 types of services as a right, one of which is personal assistance.

The adoption of LSS was an important step in closing the larger institutions in Sweden on January 1, 2000. At the time when the decision was made to close institutions there were 85% against the decision. It was a political decision that was taken due to breaches of human rights, the reporting of violence in institutions and of the devastating conditions in institutions. Those who were against were politicians who doubted the decision, parents who wondered what would happen to their children with impairments, people themselves living in the institutions afraid to move and the people working in the institutions. The employees did not want to lose their jobs. I am often met with the view that there are the rights of the workers and closing institutions is a threat to these rights. My reply is that there are the rights of those living in the institutions and the workers. It is important to put the rights of people who are living in the institutions first as they are those living there everyday. The services will have to be rendered but maybe under a different roof.

The deadline to close the institutions in Sweden was January 1, 2000 – soon 20 years ago. Not so long ago. And yet long enough that new politicians do not remember why the institutions were closed.

People who had never had a home, had their name on the door of their own flat and had their own key. Some were moved out against their will but with training and good personnel, they learn to appreciate their new homes. Small group homes with 3 – 5 persons along with personal assistance were the main services used for the closure. But also, the other 9 services in LSS:

1. Advice and other personal support from experts who with special knowledge about what it is like to live with serious functional impairments. A social worker, psychologist, physical therapist, preschool adviser, speech therapist, occupational therapist, or dietitian can provide such support. Advice and support shall be a complement to and not a replacement for measures such as rehabilitation and social services.

2. Personal assistance – Individuals with serious physical impairments who have not reached the age of 65 may be entitled to assistance from one or more personal assistants.

To be entitled to personal assistance, the individual must need help with meals, personal hygiene, dressing and undressing, communicating with others, or need some other assistance that requires extensive knowledge of people with functional impairments. The municipality may provide assistance directly or the individual may obtain financial aid, in which case the individual acts as an employer and hires someone to provide assistance.

3. Companion Service – Individuals who do not have personal assistance may be entitled to companion service. Companion service shall be personalized, tailored to meet the needs of the individual to have an active social life.

4. Contact Person – In order to reduce social isolation, assist in participation in leisure activities, and provide advice in daily situations, individuals may sometimes need help from a contact person, who can make it easier for the individual to live independently. Sometimes a family, known as a support family, can provide support.

5. Relief service in the home – Relief service is available both as a regular service and for unexpected situations.

6. Short stay away from home – The purpose of a short stay away from home is to provide the individual with the opportunity for recreation and a change of environment while providing relief for relatives. A short stay can be arranged in a short-term home, with another family, or in some other way, such as at a camp.

7. Short period of supervision for schoolchildren over the age of 12 – Schoolchildren over the age of 12 are entitled to supervision before and after school and during holidays.

8. Living arrangements in a family home or in a residence with special services for children and adolescents – Children and young people who cannot live with their parents may be entitled to live with another family or in a residence that provides special services. This should be a complement to the parental home both for the children who can live with their parents, part of the time, and for those who cannot live at home at all.

9. Residence with special services for adults or other specially adapted housing – Residential arrangements may vary, but the most common forms are group housing and service housing. The individual may also be entitled to a specially adapted home that is assigned by the municipality.

10. Daily activities – Working age individuals who are not gainfully employed or studying are entitled to assistance participating in daily activities if they qualify for LSS pursuant to criteria 1 and 2.

It is important to note the maximum size of a small group home which in Sweden was to be at most 5 persons. But as we have learned through the General Comment 5 on article 19 of the UN Convention for the Rights of People with disabilities -

It is not the size that makes an institution but the lack of self-determination.

The Definition from the GC5 is: Independent Living arrangements – Neither large-scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals, nor even individual homes can be called independent living arrangements if they have other defining elements of institutions or institutionalization. If they are about losing personal autonomy and choice or self-determination; they are institutions.

The Definition from the GC5 for Independent Living: Independent living/living independently means that individuals with disabilities are provided with all necessary means enabling them to exercise choice and control over their lives and make all decisions concerning their lives. Personal autonomy and self-determination are fundamental to independent living, including access to transport, information, communication and personal assistance, place of residence, daily routine, habits, decent employment, personal relationships, clothing, nutrition, hygiene and health care, religious, cultural and sexual and reproductive rights. These activities are linked to the development of a person's identity and personality: where we live, with whom, what we eat, whether we like to sleep in or go to bed late at night, be inside or outdoors, have a tablecloth and candles on the table, have pets or listen to music. Such actions and decisions constitute who we are. Independent living is an essential part of the individual's autonomy and freedom and does not necessarily mean living alone. It should also not be interpreted solely as the ability of carrying out daily activities by oneself. Rather, it should be regarded as the freedom to choice and control, in line with the respect for inherent dignity and individual autonomy, as enshrined in article 3 (a) of the Convention. Independence as a form of personal autonomy means that the person with disability is not deprived of the opportunity of choice and control regarding personal lifestyle and daily activities.

LSS is a law that is to ensure:
Self-determination, choice, control.
Dignity and equal opportunity

It is a law with Independent Living Values.

We think this is because there was an Independent Living pilot project on personal assistance that became a base for the legislation. It is the same for Article 19 of the Convention for the Rights with Persons with Disability, we think there were many good activists that were able to get the message across on how important Independent Living and self-determination are.

Independent Living started in the late 60s in the USA. Our leaders Ed Roberts and Judith Heumann had to fight for the right to Education. They met poor attitudes and needed the media to fight for their cases. They started the movement with other disabled people meeting inaccessibility and exclusion and joined together as a force for Independent Living.

Many disabled Europeans wanting a university degree found it better to go the USA where universities are more accessible. They then brought back the Independent Living ideology to the various countries in Europe. For example, there was: Adolf Ratzka to Sweden, Kapka Panayotova to Bulgaria, John Evans to the UK and Bente Skansgård to Norway.

Independent Living is about self-determination and the right to services, the right to personal assistance, the right to inclusive education, the right to supported employment when needed, the right to accessible transport and the right to family life.

Independent Living is a cross disability movement. It is about rights, assessment for services based on individual needs with the recognition that it is we the disabled who are the experts of our needs. We are rights based and diagnose based.

Our main tool for lobby is the UN CRPD and article 19 – living independently and being included in the society.

I have been asked to talk about – **What is needed to move towards Independent Living for all in the Western Balkans?**

Real processes of de-institutionalisation are needed and not copies of what has happened in for example Estonia with the building of the care villages – that house 60 persons. With one community building in the center and satellites for ten persons each, or ten persons in each house. With rules on the wall of what people are expected to do not allowing for self-determination.

The provision of other community-based services are needed to close institutions. To consider a few within different areas:

Early intervention and Childhood – habilitation is important, family support so children can live at home and in the last resort foster homes;

Employment – access to jobs and support for companies for reasonable accommodation; supported employment for those who need it.
Housing – adaptations or access to social housing;
Education – integrated education, classes within the public-school campus for those needing complementary support;
Provision of health care for all people through the mainstream services – so mainstream services need to be accessible;
Advocacy services – the spreading of knowledge on services provided – so people know and understand the system;
Access to peer support – for empowerment;
Access to family life – living at home or starting a family; (not an institution half the week as for a young girl in Norway);
Personal assistance but real personal assistance; this is not service in a hospital where the person has not chosen the person supporting.
IL is not only services for the less marginalized disabled people. It is about services as rights – as per article 19 of the UN CRPD.

To summarize:

Key services are:

peer support;

advocacy services;

personal assistance;

early intervention for children – habilitation and family support.

When I had my accident:

I needed accessible transport;

Access to rehabilitation;

Housing adaptations: kitchen, bath, elevator

Personal assistance – to allow me to access self-determination. Being helped out of my bed when I want to get up. It allowed me to continue my education and employment, allows me to be active in the church, in politics – life is long – my interests change!

What is personal assistance? There are definitions in the GC5 or on the ENIL website www.enil.eu.

Personal Assistance is a **tool which allows for independent living**.

Personal assistance is purchased through **earmarked cash allocations** for disabled people, the purpose of which is to pay for any assistance needed.

Personal assistance should be provided on the basis of an **individual needs assessment** and depending on the life situation of each individual.

The allocation should allow for a good standard for salary - The rates allocated for personal assistance to disabled people need to be in line with the current salary rates in each country.

I recruit, train and manage my assistance – not someone else. As disabled people, we must have the right to recruit, train and manage our assistants with adequate support if we choose.

There should be choice of the employment model - and we disabled people should be the ones that choose the employment model which is most suitable for our needs. In Sweden one can choose between the municipality, a private company, a cooperative or public company that administers the service.

Personal assistance allocations must cover the salaries of personal assistants and **other performance costs**, such as all contributions due by the employer, administration costs and peer support for the person who needs assistance.

According to the GC5 -

Personal assistance: Personal assistance refers to person-directed/“**user**”-led human support available to a person with disability and it is a tool for independent living. Although modes of personal assistance may vary, there are certain elements, which distinguish it from other types of personal assistance, namely:

(i) **Funding** for personal assistance must be provided on the basis of personalized criteria and take into account human rights standards for decent employment. The funding is to be controlled by and allocated to the person with disability with the purpose of paying for any assistance required. It is based on an individual needs assessment and upon the individual life circumstances. Individualised services must not result in reduced budget and/or higher personal payment;

(ii) **The service is controlled by the person with disability**, meaning that he or she can either contract the service from a variety of providers or act as an employer. Persons with disabilities have the option to custom-design his or her own service, i.e. design the service and decide by whom, how, when, where and in what way the service is delivered and to instruct and direct service providers;

(iii) **Personal assistance is a one-to-one relationship.** Personal assistants must be recruited, trained and supervised by the person granted personal assistance. Personal assistants should not be “shared” without full and free consent by the person granted personal assistance. Sharing of personal assistants will potentially limit and hinder the self-determined and spontaneous participation in the community; and

(iv) **Self-management of service delivery.** Persons with disabilities who require personal assistance can freely choose their degree of personal control over service delivery according to

their life circumstances and preferences. Even if the responsibilities of “the employer” are contracted out, the person with disability always remains at the center of the decisions concerning the assistance, who must be enquired about and respected upon individual preferences. The control of personal assistance can be through supported decision-making.

I would like to conclude by emphasizing a few points.

Every person has a unique life style – people should receive support based on an Individual assessment of needs. Services should depend on the person and their need.

Choice – people should have the choice to live a life as they decide. To build a family, work, engaged in cultural activity and politics etc.

The society needs to have mainstreamed services that are accessible through Universal design. This means physical accessibility but also knowledge with the professionals (doctors etc) understanding disability and needs so that they make the right decisions for someone’s life.

There should be coproduction of services – too many services have been formed by professionals without asking us what we need, how we see things being done. We are the experts of our needs. Services will be better if they are co-produced.

There are challenges. The **Trend back towards** Médicalisation in some countries. There is the balance between support from the family vs state. There is a threat of re institutionalization with the cuts of services in countries where institutions were once closed.

Memory is too short sometimes. It has been 25 years since LSS came into effect. There are new politicians who were not around when the institutions were closed, and they now think institutions would be cheaper. So, I have learned rights are not forever. It is a constant battle for rights and humane societies as well as to keep the rights that we have.

The Swedish legislation is not ideal. In LSS there is a shared responsibility for the service between the state and municipalities. There are three categories of disabled people included in the legislation: those with autism or from the autism spectrum, brain damage due to injury and then physical or intellectual impairment that leave someone needing assistance in daily life. Someone who is blind does not have personal assistance but companion service which does not allow the same self-determination and choice. This puts groups against one another. The same for the deal blind a case was taken to the high court but lost. Personal assistance is based on basic needs and there is an ever-changing interpretation of needs due to court cases and reinterpretation of the legislation that is 25 years old.

Many municipalities have always been against the legislation as it is the state that then dictates to the city for the support. Municipalities are sovereign in Sweden. There is a change in the debate and some do think that the State should carry the whole responsibility which would allow for the Freedom of Movement between one municipality to another.

What are age limits is a question that is always asked. If you have acquired your personal assistance before the age of 65 you keep it after the age of 65. But if you have a stroke with a paralysis the day after 65 – it is tough luck. When it comes to children there is shared support between families and the school system. Some children may access personal assistance for hours outside of the school. It is determined individually.

Which people to include in the coverage of personal assistance is another issue. I think it was Finland that excluded people with intellectual impairment the first time around but made changes. Having Independent Living as our ideology we feel that all people with disabilities should be covered by the legislations. Then it is the needs of each person that will determine the services needed. We disabled are not a homogenous group and do not all have the same needs. But we do all have the right to Independent Living with self-determination.

In Sweden there is the right to appeal decisions. This has led to court cases that have not been necessarily beneficial for the service as per the persons using the service.

To conclude:

I called this speech for Independent Living – a political decision. I told of how Sweden closed the large institutions in 2000 as per such a decision. According to Independent Living, legislations should provide for support for disabled people where the disabled person can have a say in the service they are to receive. Services should allow for self-determination and give the individual the choice on where they want to live, with whom they want to live and how they want to live their life. This is according to article 19 of the UN CRPD. Most of our countries have signed the UN CRPD and have already in doing so agreed to promote Independent Living. Now we need to measure the implementation and hope that countries respect this political decision already taken.

I thank again the organisers for asking me to speak with you today. I wish you good luck in your endeavour to better the welfare systems here in this region of the Western Balkans.

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Bečići, Montenegro