

## **Personal assistance means the difference between surviving and having a real life**

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On YouTube in Slovak audio [at](https://www.youtube.com/watch?v=FryVeyswges)  
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I am working in the international Independent Living Movement. The goals of this civil rights movement are getting people with disabilities more personal and political power.

### **Independent Living**

Independent living means that persons with disabilities live included in the community, with a full social life, access to all services offered to the public, and participate in all spheres of life, with the same range of options, the same degree of choice, self-determination and interdependence on other persons that our non-disabled brothers and sisters, friends and neighbors take for granted.

Those of us who depend on other persons for the activities of daily living can use personal assistance to achieve this degree of choice, self-determination and interdependence. Though we might not be able to do much or anything by ourselves, due to our physical or cognitive limitations, we still can get things done by delegating the task to another person, in the way **we** decide, according to **our** individual requirements, circumstances and preferences.

### **In my own case, my entire adult life has been based on personal assistance**

I was hospitalized with polio at age 17. At age 22, I was able to leave the residential institution to attend university with the help of personal assistants. They got me up in the morning, helped me with bathing, toileting and dressing, shopping, cooking, cleaning and other household work. They helped me with my ventilator and carried my books. I hired fellow students who needed some income as my personal assistants, I trained them, paid their wages and supervised them. I was their boss. I could afford to hire them because I received monthly payments from the state for this purpose.

When I started to work, my personal assistants helped with everything I needed to concentrate on my job. They drove me to work, helped me at my workplace, accompanied me when I went out to meet friends, enabled me to travel to other countries.

When I met my wife, we decided to get married after much thinking. We had seen many couples where one of them was the sole caregiver of the other; where both lived in extreme mutual dependence; where none could take a step without the other, tied together like Siamese twins. My wife and I wanted to live together but also wanted to feel free in a relationship where both, independently from each other, could develop and grow as human beings. With the help of my assistants I would continue to take care of myself, and, with the help of my assistants, I would do my part of the household chores.

Our decision to have a child was also based on personal assistance. I wanted an active part in raising our child, wanted to be close to my child. I would do my share of the physical work in child raising with the help of my personal assistants. I took our daughter to the kindergarten in the morning, my wife picked her up after work. My daughter and I went shopping every Saturday, visited museums, went fishing. I instructed my assistants to stay behind us and only interfere when I'd ask them or to prevent an accident.

### **What are the alternatives to personal assistance?**

Can we have the same quality of life as others while living in a residential institution: with studies, friends and travel, with interesting work, hobbies, and a family of our own? And let's not forget residential institutions can have different names, can have 200 beds or just two. What matters is that institutions do not give us the same choices that non-disabled persons have as to: where to live, with

whom and for how long. In institutions, we cannot decide who works for us, when, with what tasks, where and how. In institutions, we have to adapt our needs to the needs of the institution. We get up, go to bed, go out and meet people – not when **we** want but when the **staff** has time.

The family as caregiver for adults with disabilities might be a necessity in many countries, but it is not a solution. Dependence on the family forces us to adapt our needs to their needs, causes guilt feelings on both parts, limits our growth as human beings. When you are a teenager it cannot feel good to ask mum or dad for help to go to the toilet. When you are 50, mum and dad might need lots of help themselves. The family is not a sustainable solution; it is a ticking time bomb.

Your country has personal assistance services, I understand. How many hours of services can you get? Is it enough for somebody to leave the parental home or an institution and to live by oneself? Or is it just a few hours which gives your parents an evening off? Who is in charge? Can the user recruit, employ, train, pay and supervise the assistants or is it somebody else? Who decides at what time the personal assistant is to come tomorrow morning? Who decides what the assistant is supposed to do? Who fires an assistant who hasn't worked well? What is your role as the user: are you the object or are you the boss? If you are not the boss, I would not call it "personal assistance".

### **Not your diagnosis but the politics of your country make you disabled**

I have been very fortunate to have had personal assistance for the last 50 years. In most countries I would not have been able to have such a good life. Without personal assistance I would have been much more disabled. Without personal assistance I probably would have died a long time ago. It is not your medical diagnosis that determines the quality of your life. It is the politics of your country.