

Freedom Drive Conference 2019:
Defending the Right to Independent Living 30 Years After

October 3 18:15 – 20:15 Mundo, Rue de l'industrie 10

Intervention: Personal Assistance – Adolf Ratzka 5'

Independent Living means to feel that you can affect the quality of your life, to take responsibility for your life. Only at the level of the individual can we understand and learn this. Only at the level of the individual can we transform ourselves. When we build yet another global superstructure, keep asking the question: what is it that the Independent Living Movement is best at, that other organizations are not doing, what is our niche? And how could a new global umbrella organization be useful?

True Personal assistance means having enough hours for living a life like your non-disabled brothers and sisters, and friends. Where you are in control over who works, at what hours, where and with what tasks. Everything else is fake personal assistance.

True personal assistance is labor intensive and expensive. True personal assistance exists only in very few countries. And where it exists we cannot be sure it will last. In Sweden, we have had it but an increasing number of people are losing it. The government, most political parties, the public – everybody says: "personal assistance is nice but too expensive. Before 1994, when direct payments for personal assistance started, everybody was happy and content. They got help from their families or lived in institutions. Now, these people want more and more assistance hours for work and for raising families. Why now? We can't afford that." Nobody wants to listen when we talk about the costs of alternatives to personal assistance, the costs of institutionalization, the invisible costs of our and our family members' missed life opportunities. That's too complicated for most people.

What can we learn from the Swedish example? Any reform that is to grant true personal assistance needs long preparations, lots of research and statistics about the living conditions of people living with assistance from their families or living in institutions. Even in a small country like Sweden, it takes hundreds of lectures, conferences, TV reports, newspaper articles, books and movies – not only to get the legislation passed but also afterwards. Forever. Because taxpayers and voters have short memories. They need to be constantly reminded of the benefits of personal assistance. Otherwise, they only see the costs.

My point is: the whole population needs to be convinced that we are ordinary human beings with the same needs, dreams about life like everybody else; that we deserve the same life opportunities that other people take for granted. If the voters and taxpayers cannot identify themselves with us, if they cannot picture themselves in our living conditions, we cannot feel safe.