



**YHD – Ass. for Theory and Culture of Handicap**

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## **Personal Assistance as a condition of freedom**

When we were at the beginning of our struggle for our right to personal assistance and we started looking for role models we began by reading up on the history of the independent living movement. We were very surprised to find out how similar the struggle these pioneers faced was to our humble beginnings. The only difference was that 30 years had passed since their effort had been embarked upon and that socio-economical situation and historical and cultural contexts are now vastly different.

Not only did we have to fight for our right to independent living outside of institutions and to close those institutions down, we were also forced to fight against the experts who would not let us go out of their clench of treatment. For them, medical model was the ultimate solution and the safest way of maintaining and supporting their illusion of professionalism. We also had to convince politicians that we wanted to live, not merely passively languish, dragging ourselves through life. It was difficult to hammer into their heads why we did not want to live in institutions that they built just for us, so that people can provide care for us and that we are safe from the outside environment. Last but not least, we slowly worked our way to make the public aware that we are nothing special, we don't demand nothing special and that we just want to live normal lives with all the rights and responsibilities that other people have and that we indeed can take responsibility for our decisions, even though they may seem wrong to them. We are addressing these events in past tense, but the truth is, these issues are still as current today as they were then.

We still have not managed to root out old prejudices on our (in) ability to work and live independently. We have not managed to root out the practice of putting people into institutions and building new ones, which are seemingly pleasant, nice, collared but they are still nothing more but institutions. Systemic discriminations which are deeply rooted in people's convictions and intertwined with Law are still very much present in Slovenian society. This is especially true in the areas of employment, accessibility and assistance to those who need help with their daily activities. Excuses of economic nature are still offered when we ask why no measures are taken and why the legislature and legal practice are not being modified. We are in a time of economic crises, it costs too much, our country is not yet able to make such an advanced transition are all too common excuses that we still have to face.

How is it possible that they do not understand that we demand our human and civil rights to be respected? That we wish to have equal opportunities? That we not only have a lot to give and contribute, we are also fully capable of keeping that promise? We wish to contribute and not to be reduced to mere receivers of help and aid. The question is, why does no one want to hear and accept this?

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***Handicap is a symptom of the world!***

For more than a decade YHD is trying that Personal Assistance would become a systematic right of individuals, despite all our efforts, we still haven't reached our goal. We have been implementing the programme of Independent Living for more than 14 years, the programme now provides P. A. for 98 disabled people. The programme is financed from different sources and from some short term period contracts that is why our association constantly has to search for new solutions and ways of financing the programme. Because we are in constant uncertainty, we have to be very innovative, visible and loud enough to manage the programme, which provides us with equal opportunities and I. L.

Law on Personal Assistance was put to public debate in May 2010. YHD was included in the working group that was preparing the text together with other organizations from the field of disability, but unfortunately most of our proposals were rejected or ignored without any explanation or justification.

Current draft of the law does not include a clear definition of P. A.; the law itself is based on the Law on Insurance for Long-Term Care. In practice this would create confusion in the exercise of the right to P. A. Also temporal incompleteness would create problems because the Law on Insurance for Long-Term Care is very complex. Therefore it is inadmissible that the proposal is bound to the concept that binds to 'care and help'.

Law on personal assistance must constitute a clear deviation from traditional forms of care and help in addition it must be founded on the principles of the movement for independent living and according to the concepts provided by ENIL. At this point we have to stress out the fact that disabled persons are the experts on their needs and they must take initiative individually and collectively in designing and promoting better solutions.

We are just a hair's length away of adopting the Personal Assistance Act. We should be satisfied, yet we are deeply concerned. We do not know actually what it is to come; we have no concrete conception as to how things are going to play out in practice. Will we finally receive the things that we have so persistently fought for all these years? Based on current project description, will we lose the individualised personal assistance as it is currently implemented? We have no guarantees that the Act will respect ENIL's principles. One positive side of all this is certainly the fact that the Personal Assistance Act will extend the list of users that will be able to receive the services of personal assistance. We can confirm that we were successful regarding our demand that persons with intellectual disability should also be included into the Law and by that to have the right to PA. The list of users has indeed grown considerably longer, thanks to, especially, all the letters from ENIL members to the Ministry of Labour, Family and Social Affairs of Slovenia. In the first draft of the Act individuals with intellectual disability were excluded. We were adamant that such discrimination is completely unacceptable. For that we wish to thank you sincerely and put forward this is a positive example of mutual assistance.

Our criteria of what personal assistance is or should be have been clearly defined from the very beginning, since we are not satisfied with covering only the basic

needs. The final draft of the Act is very unclear and refers in many articles to other regulations. The Long-term Care Act is an act that is based on the medical model and designed to provide care for users among which are also disabled persons. Many articles in the Personal Assistance Act refer to the Long-term Care Act, which shows great co-dependence and conditionality of the two acts. The following text is included in the Personal Assistance Act: "Ministry has no intention to codify all the areas and rights of the disabled persons concerning their care. Implementation of rights of disabled persons to long-term care is regulated by the Long-term Care and Long-term Care Insurance Act. The two acts complement each other." Ministry defend such co-dependence on the fact that the two services are largely financed from the same source (60% of the resources are provided from the long-term care insurance and its medical insurance fund). We think that this is a useless assertion because these funds could easily be moved to a separate fund, e.g. Personal Assistance Fund where the resources of all other financiers would converge. The article talks about the services of personal assistance, it mentions that same services are listed in the Long-term Act and other are in the Personal Assistance Act, such as escort, assistance at work or educational institutions or any other activity. This is a sure sign that the petitioner thinks of personal assistance in terms of a mere extension to care as defined by the medical model. What is more, personal assistance is understood as "above standard". Such understanding is completely incorrect as it presupposes that personal assistance is just an upgrade of old principles of care. The principle of independent living remains hidden in the articles, as does personal assistance as a human right.

We insist that the Personal Assistance Act must be independent of the Long-term Care Act. It is very probable that the implementation of personal assistance will be based on old notions of patronized care. In fact personal assistance is a decisive shift away from all the traditional practices that are based on the medical model. It is an act of rebellion and resistance against patronized ways of care that put individuals into a subordinate position where individuals are cared for and dependent upon, where one has no power to make decisions about one's own life nor a choice to live differently. Personal assistance must provide not only every day aid, it must also give an individual the power of making decision about his or her life. Personal assistance gives us autonomy and the possibility of self-determination, active life, equality, possibility of choice, dignity and the possibility to be free in our decisions.

There is still a lot of prejudices within the society also ignorance and unwillingness of policy makers, towards changing of old care practices and implementing system solutions, which is ensuring human rights to support range of services within the community. For many the easiest solution still represents the need for building special institutions, they also believe that this is also the most economical and reasonable solutions. However the medical model still dominates so strongly within the profession as well as in many disability organizations, this is mostly the case for practical reasons, benefits and different interests to hold persons with disability in dependence, subordination and under supervision. YHD is constantly trying to stand up to this way of thinking with decisive ideas and requirements for equal citizenship and decent life.

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***Handicap is a symptom of the world!***

YHD has always been a lone warrior in the fight for the right to personal assistance and independent living. We have no strong allies to lean on to in other disability organisations. We were united by our conviction and desire that we can and must create an opportunity for ourselves to live outside of institutions, independent of our parents and relatives, to live a normal life and to demand that our human rights be respected. The so-called traditional disability organisations based on common diagnosis do not put the goal of independent living and personal assistance onto their priority list. They have special projects for health preservation, rehabilitation and so-called day care. Some, exactly three, implement projects named personal assistance; however, none of them are in accordance with the principles of ENIL. These organisations base their policies hand in hand with key medical institutions. For this alone our struggle in all those years has been twofold. We have not only had persuade the experts and policy makers, we also had to bring about a change inside other disability organisations through public awareness programmes and various actions. The change involved both how disabled persons perceive themselves and how the society perceives disabled persons.

There is no common legislature in the area of social care at the EU level; there are only a few directives on discrimination ban, which has unfortunately not been implemented yet in many EU members and there certainly is very little legal practice to be found on the subject.

I believe that this does not pertain only to Slovenia; it is most likely a common denominator of most South - East European countries, which is why we need to work together, is even more important. It is also important to support each other at various events and functions. It is important to seek out new common strategies for combating obstacles and to reach common goals.

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