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## **10h15**

The Independent Living philosophy:  
implications for the individual, our  
organizations and society

## **10h45**

Coffee break

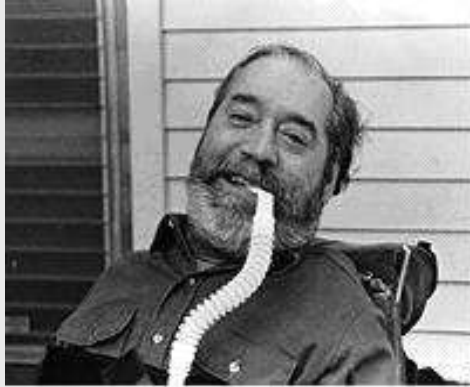
## **11h30**

Personal assistance: key to Independent  
Living The Swedish example of personal  
assistance policy



# History, philosophy and aims of the Independent Living Movement

# The Independent Living philosophy



In 1972, the first Center for Independent Living was founded by disability activists, led by Ed Roberts, in Berkeley, California.



## **Corner stones of the IL philosophy**

- Anti-discrimination
- De-medicalization
- De-institutionalization
- De-professionalization



## **Important concepts in the IL philosophy**

- Control over our organizations
- Self-management of our services
- Peer counseling
- False independence
- Personal Assistance

The Independent Living philosophy

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**Personal Assistance  
is the key to  
independent living**



## **Personal Assistance**

is not

- Volunteers
- Family as assistance providers
- Stationary Institutions
- Mobile Institutions



## **An institution is where**

- other people determine who is to assist us with what functions,
- the user has to adapt his needs to the needs of the whole scheme,
- there are written and unwritten rules regulating the assistance,
- rule over which the user has no control,
- the assistance is limited to certain hours, activities, locations (that is you have to live in certain houses as opposed to anywhere),
- the staff providing assistance is shared by several persons,
- there is a hierarchy with the individual user at the bottom of the pyramid.



## Thus Personal Assistance is when

- **we compensate** our disabilities by delegating tasks to other persons. These tasks involve activities which we cannot carry out ourselves or which we are not good at.
- **we delegate** in order to have the time and energy to specialize in those activities which we can perform well. "Personal" connotes that the assistance has to be customized to my individual needs
- **we decide** what activities are to be delegated, to whom and when and how the tasks are to be carried out.



## The most important concept in the IL philosophy is **EMPOWERMENT**

**Empowerment** means that we can customize individual solutions according to our individual needs which may change over time.

**Empowerment** means to have access to several different solutions at the same time.

**Empowerment** means to take individual control over the funds for paying wages and administrative costs.

**Empowerment** means to organize personal assistance users into a pressure group which negotiates with governmental bodies. Together we have political power, individually we have none.

**Empowerment** means to help and teach each other through peer counseling the skills it takes to run one's own personal assistance scheme and get the most use out of it.

**Empowerment** means to devise ways to allow all of us, regardless of physical or mental disability, to take more responsibility over our lives

# Empowerment





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## The history of Personal Assistance in Sweden

- 1984 First scandinavian conference on IL
- 1987 STIL pilot project
- 1989 STIL becomes permanent
- 1994 Legislation on Personal Assistance



## Personal Assistance in Sweden

- Direct Payment
- Full coverage of assessed needs including assistance at work, household chores and parenting
- Absence of means tests
- Coverage of administrative costs



## Personal Assistance in Sweden

237 SKR (approx. 25.5 €) per hour

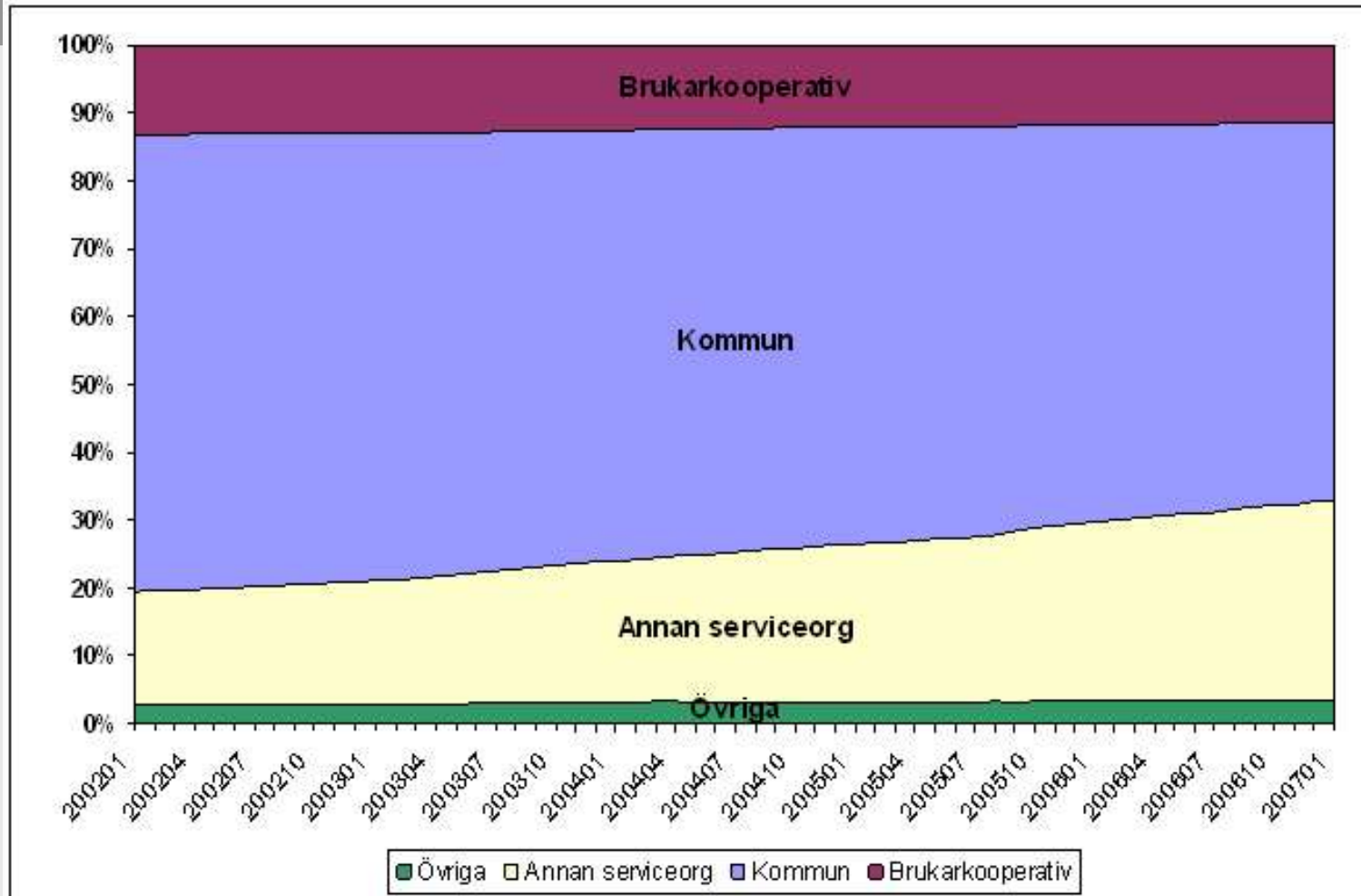
12% increase for special needs



## Forms of organizing Personal Assistance in Sweden

1. Being employer yourself and employ your assistants as a private person
2. Requesting assistance through the municipality
3. Forming an association or co-operative with other disabled persons, which will employ several assistants
4. Using another company or organisation
5. Being partly employer yourself and partly having assistance through the municipality or another body.

# Personal assistance



# Personal assistance



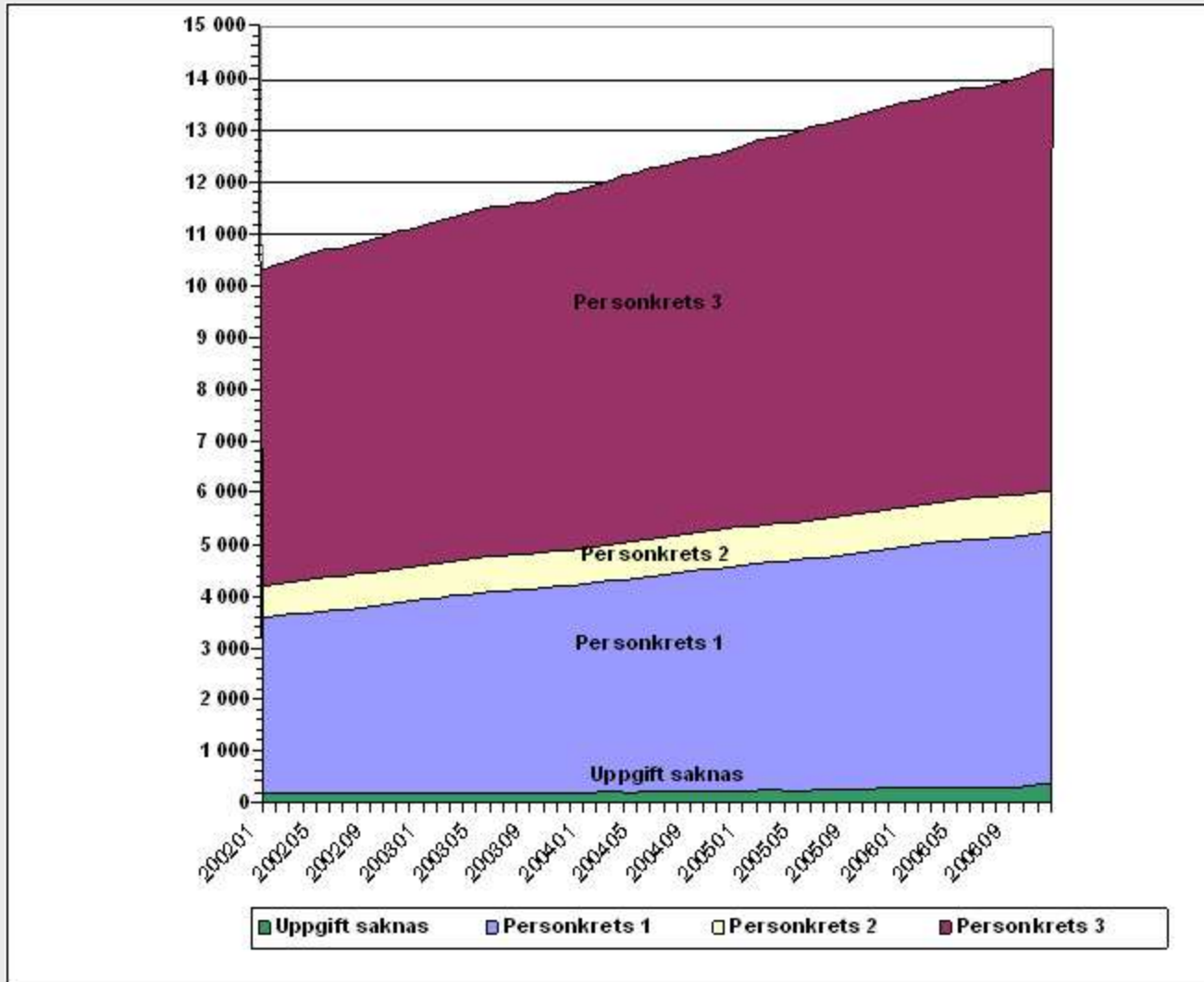
The following three groups are entitled to support under the LSS Act:

Group of persons number 1: People with congenital intellectual disabilities, autism or autism-like conditions.

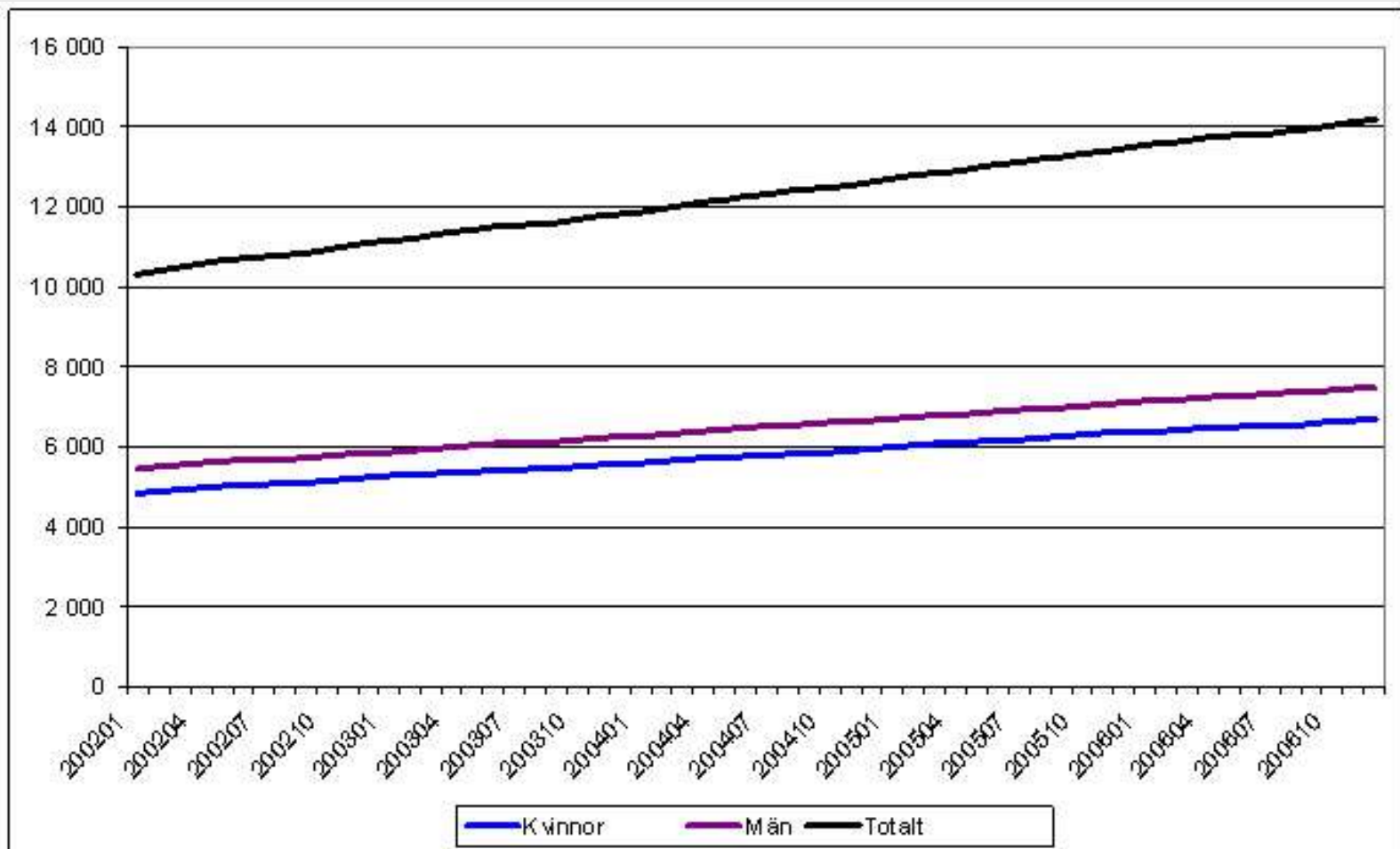
Group of persons number 2: People acquiring, in adulthood, permanent and significant intellectual disabilities in consequence of external violence or somatic disease.

Group of persons number 3: People with other permanent disabilities clearly not related to normal aging, if the disabilities are extensive and cause major difficulties in daily life and hence a comprehensive need for support or service.

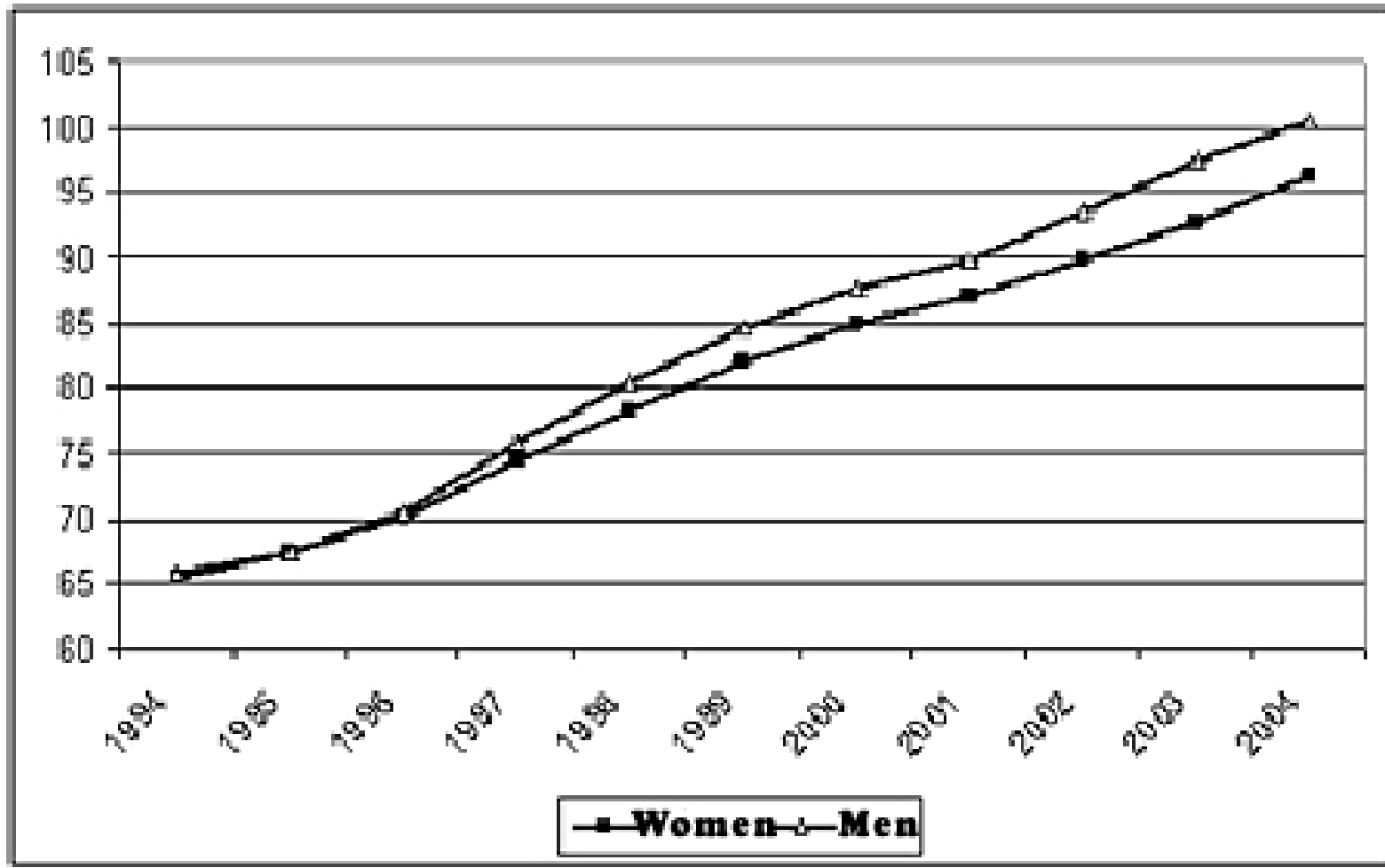
# Group of persons



# Number of PA Users



# Average user hours/week





## Personal Assistance in Sweden

Personal assistance means that the services are custom-designed to the individual user's needs, capabilities, life circumstances and aspirations, maximizing the user's control over organizational setup and input in the daily management of the services.



## Personal Assistance in Sweden

Personal assistance has led to an increased freedom and independence for people with impairments.

It is an economically positive reform when all aspects are considered.

# Personal assistance

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