Personal assistance: Key to Independent Living as illustrated by the Swedish Personal Assistance Act

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The Independent Living Movement works for the following principles:

- Disabled people are citizens
- Disabled people are experts on their needs
- Disabled people demand the same degrees of freedom of choice and self-determination that other people take for granted
According to the Independent Living Movement, Article 19 of the CRPD “living independently and being included in the community” requires

- role models, support from peers and other experts depending on one’s personal
- resources, disability and life circumstances
- accessibility in the community including housing
- Personal Assistance for persons who depend on others for the activities of daily living
Supply-driven services

- example: residential institution
- service provider is under contract from municipality or charity
- fixed budget translates into fixed number of staff
- staff decides which needs can be met
- “One size fits all” users forced to adjust their needs to needs of institution
- users are seen and made to feel as passive helpless objects of care

monopoly situations
typical for central planning economies

Outcomes: learned helplessness
stunted human growth
resignation, bitterness, depression
Demand-driven services

- example: direct payments to assistance users for personal assistance
- money follows the user not the service provider
- purchasing power creates market responses
- competition promotes freedom of choice and quality
- consumers custom-design their services according to individual preferences

Demand driven services are typical for market economies where users are customers.

Outcome:
- users’ geographical and social mobility
- incentives for users to take responsibility for the services
- learning from mistakes and successes
The Swedish Personal Assistance Act of 1994 as example

- legal entitlement, independent of Social Security Fund’s budget
- assistance need expressed in number of hours /week
- needs assessment decisions can be appealed in administrative courts
- money follows the user not the provider
- eligibility is independent of user’s or family’s income or property
- payments only depend on assistance user's needs of assistance
- payments do not depend on type of service provider
- all costs are covered incl market wages, social insurance fees, administration
- full accountability of how payments are spent
- recipients can buy services from any provider or employ one’s own assistants

Currently 16,000 persons receive cash benefits for Personal Assistance (Sweden’s total population is 9,5 million).
Nearly 1,000 private and public entities provide services
Some outcomes of the Swedish Personal Assistance Act of 1994

• tremendous improvement in quality of life for assistance users and their families

• greater visibility of persons with extensive disabilities in public

• less need for services such as home helper, respite care, special transportation, etc

• better quality of life at lower costs than municipal home helper services

• better quality of life at same costs compared to group homes

• € 3 billion savings to taxpayer compared to municipal home helper services
Definition: Personal Assistance

- permits the user to decide who is to work, with which tasks, where, when and how
- not tied to a particular form of housing or location
- not limited to particular categories of persons who can work as assistants
- pays white market wages to assistants
- covers the provider’s administrative expenses
The impact of personal assistance services on the economy

- Labor intensive

- 16% of assistance users work with the help of assistants, an additional 24% could work if they had more assistance hours

- Our assistants are vulnerable in the labor market: immigrants, youth in transition from school to work, free lancers and part-timers

- Wages are spent on basic domestic consumption

- Over 50% of costs go back to State as taxes and social insurance contributions

- Important labor market policy instrument with over 50,000 FTE assistants
Further reading:

Westberg, Kenneth et al. 2010  Personal Assistance in Sweden  
www.independentliving.org/docs1/personal-assistance-sweden.html

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www.independentliving.org/docs6/ratzka200410a.html

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