

# The right to a personal assistance budget

Sweden (Socialstyrelsen – The National Board of Health and Welfare) - THE ACT CONCERNING SUPPORT AND SERVICE TO PERSONS WITH CERTAIN FUNCTIONAL IMPAIRMENTS & THE ASSISTANCE BENEFIT ACT

Many countries are still far from the goal of enabling persons with extensive disabilities to choose the support that best suits their needs. Sweden stands out in offering citizens a wide range of alternatives and control over the services they need, including the right to a personal assistance budget.

## IN BRIEF

Sweden is one of the few countries that legally entitles persons with severe disabilities to a personal assistance budget (PAB). This monthly sum from the National Social Insurance covers 100 percent of service costs, and enables individuals themselves to purchase self-directed personal assistance services from public and private entities. The amount of the PAB is independent of the individual's or the family's finances. Notably, the policy has created a demand-driven market for personal assistance where providers compete for customers on the basis of service quality.

## FACTS & FIGURES

- Initial Year: 1993
- In 2013 some 19,500 people received a personal assistance budget.
- 98 percent of recipients pointed to personal assistance as the most important factor for their quality of life.
- By 2014, 230 local governments and over 800 private entities offered personal assistance services on a competitive basis.

## INNOVATION

### Legal right

The legislation established special support measures, including personal assistance, as legal rights that are independent from state or local government budgets.

### Competition-neutral direct payments

The personal assistance budget goes to the user and is granted in the form of assistance hours, which are based on the individual's needs, instead of the type of service provider.

### Promoting equality in living conditions

Sweden's citizens with extensive disabilities no longer need to live in institutions to receive services. They are free to choose where and how to live. By choosing their individual solutions, they can make their own plans and have greater equality of living conditions and enjoy fuller participation in community life.

## CONTEXT

The disability movement was the main force in bringing about the Act Concerning Support and Service to Persons with Certain Functional Impairments and the Assistance Benefit Act, which were enacted by the Swedish Parliament in 1993 as part of a broader disability policy reform. Previously, persons with extensive needs for daily living were deeply dissatisfied with the municipal community-based home-helper or semi-institutional cluster home services, in which they had no influence. Many different, often unfamiliar, workers would come and assist with even the most intimate tasks. The reform, inspired by the Independent Living philosophy, enables individuals to customize services according to their particular needs, with maximum control over everyday life. The need for personal assistance, however, grew faster than expected, and therefore the law and its interpretation have been amended many times.

*"Independent Living means having the same range of options and the same degree of self-determination that non-disabled people take for granted."*

—Dr. Adolf Ratzka, Independent Living Institute

## KEY FEATURES

With the provision of ten measures for special support, including the right to a personal assistance budget, Sweden enshrined the right to "good" living conditions for persons with major and permanent physical, mental, and intellectual impairments. The personal assistance budget is granted in the form of assistance hours, which are based on the individual's needs. The budget can cover up to 24 hours a day/7 days a week, and can even be used for more than one personal assistant, if needed. A monthly sum from the National Social Insurance covers 100 percent of service costs and goes directly to the users who, with maximum self-determination, can contract providers of their

choice (municipality, company, or cooperative) or employ assistants by themselves (by starting their own private company). The amount funded for 2013 was SEK275 (about €28) per hour.

## OUTCOME, IMPACT AND EFFECTIVENESS

- Sweden's citizens with extensive disabilities are free to choose where and how to live. About 90 percent live in ordinary homes, either alone or together with a partner, a housemate, or parents.
- Approximately 80,000 people work as personal assistants – 2 percent of the labour force.
- Taxpayers have saved an estimated €3 billion since 1994, compared to the costs of home-helper services.

## TRANSFERABILITY, SCALABILITY AND COST-EFFICIENCY

In several countries similar legislation has either been enacted or is under discussion, including Belgium, Finland, Germany, Norway, and the United Kingdom. In 2004 the Swedish law served as the basis for developing a model policy for personal assistance.

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