

This article is written by

Dr. Adolf Ratzka, Ph.D
Director
Independent Living Institute
www.independentliving.org

The Independent Living Institute is a policy development center specializing in consumer-driven policies for disabled peoples' self-determination, self-respect and dignity.

The Independent Living Institute is a policy development center specializing in consumer-driven policies for disabled peoples' freedom of choice, self-determination, self-respect and dignity. Our ultimate goal is to promote disabled people's personal and political power. Towards this end we provide information, training materials and develop solutions for services for persons with extensive disabilities in Sweden and internationally. We are experts in designing and implementing direct payment schemes for personal assistance, mainstream taxi and assistive technology.

We are a not-for-profit private foundation run and controlled by persons with disabilities. With roots in the Swedish and international Independent Living movement the Institute is a duly Swedish registered not-for-profit foundation. The majority of our employees has a disability.

We run a virtual library and interactive services for persons with extensive disabilities. We are experts in designing and implementing direct payment schemes for personal assistance services, mainstream taxi and assistive technology.

Independent Living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect. Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbors and friends take for granted. We want to grow up in our families, go to the neighborhood school, use the same bus as our neighbors, work in jobs that are in line with our education and interests, and start families of our own.

From patient to customer: Direct payments for assistive technology for disabled people's self-determination

Adolf D Ratzka, Ph D

Independent Living Institute, Stockholm, Sweden www.independentliving.org

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The author, AT user and activist in the Independent Living movement, claiming that direct payments for AT result in better quality and cost-efficiency than services in kind, suggests a pilot project to test the hypothesis. Plenary paper presented at the 7th European Conference for the Advancement of Assistive Technology, "Shaping the Future", Dublin, Ireland, August 31st – 3rd September 2003.

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By way of a personal introduction, I have used assistive technology since 1961, when I contracted polio in Germany. During 1966 to 1973, in the heydays of flower power and Vietnam war protest, I attended the University of California. At least as important for my personal growth and professional orientation was my scholarship which paid for tuition and maintenance plus the goods and services I needed on account of my disability, such as fellow students as personal assistants. When I needed assistive devices, I would check the market, buy what I wanted, submit the bill and get reimbursed by the scholarship agency. I bought, for example, a power chair that was my only chair for 22 years accompanying me around the world. When I finally had to take it to the city dump, I nearly cried.

Independent Living philosophy and principles

In the US, I came in contact with the Independent Living Movement that has since spread around the world. We work for the removal of obstacles to self-determination and help each other to take responsibility for our lives. Since we, the disabled people, are the best experts on our needs, we must take the initiative and show the solutions we want. [\(1\)](#)

Eliminating obstacles to self-determination

In Sweden, the movement influenced social policy in the area of personal assistance. In a pilot project, we demonstrated that direct payments are more efficient, in terms of

consumer satisfaction and costs to taxpayers, than municipal homehelp services. Our initiative shaped a national law which entitles persons with extensive disabilities to monthly payments for personal assistance. Recipients are free to buy services from the provider of their choice or to hire their assistants themselves. (2) In this way, assistance users bypass the vested interests of local government service providers who had neither the interest nor ability to improve the situation of service users. A whole new industry has emerged with many alternatives, private and public, competing for the service users' cash. Objects of care turned into customers, dependence into freedom of choice, powerlessness into purchasing power.

Present assistive devices delivery

In Sweden and elsewhere, services still exist that force disabled people to accept professional interventions which leave little room for individual needs, tastes and preferences and force users to adapt their lives to the needs of the service provider where often stereotype assumptions about our abilities, interests and life styles become self-fulfilling prophecies. (3)

One such service is the provision of assistive technology. An assistive device can decrease or increase one's limitations. I kept my power chair for 22 years, because it was simple, light yet sturdy - ideal for travel and adventure. One person could easily get me up a tall curb, two persons could help me get up a staircase. This type of chair is no longer available: the large rear wheels apparently are considered to be dangerous to my safety. Power chairs with small rear wheels confine me to accessible environments such as shopping malls and institutions. Thus, other peoples' assumptions about what is best for me limit my mobility, deny me the dignity of risk-taking and question my ability to act in my own best interest. Let us look at the mechanisms.

In Sweden, the provision of assistive devices is part of National Health Care. Devices are distributed, adapted and repaired by Assistive Technology Centers run by the health care system where patrons are commonly referred to as "patients". "Patient" describes the relationship between end user and professional staff. In Latin, it means to suffer and wait. "Patient" places us in the midst of the medical model of disability where disabled people are seen as problem bearers, where professional training is valued higher than first-hand experience, where disabled people are relegated to passive objects of professional intervention. Patients have not much to say in the process. We can describe our needs, plead for a certain solution, but do not decide. MD's, OT's and PT's - the prescribers - are assumed to know better what we need.

Before entering the Swedish market products have to pass tests which might, for example, consist of a machine pounding a wheelchair seat a million times to test its durability. User-oriented criteria are rarely included, for example, how a wheelchair handles in tight corners or how easily a person seated in the chair can be helped up curbs or steps - crucial criteria for users who need to live ordinary lives. Products meeting the test criteria are entered in the "Good Assistive Technology" list. For many, but not all, items on the list purchase contracts are negotiated by the procurement agency of Swedish County

Councils. The respective County's financial situation and resulting priorities limit an Assistive Technology Center's freedom to choose still more. (4) Even if the Center's OT agrees with me that I do need a new wheelchair, it is not at all certain that I get the one I want or that I get a new one, if a used chair is in the Center's basement, or that I get the item in this and not the next fiscal year.

In most markets, consumers by preferring a product over a competing one send direct signals to producers and distributors about their preferences and, in this way, shape product development. Not so in the market for assistive devices where the financing agency's budget or prescribers' interpretation of their patients' needs replace market signals. This might be one of the reasons why technological progress has been slow; why, for example, shock absorbers are more common in bicycles than in wheelchairs.

In summary, end users of assistive devices in Sweden and elsewhere cannot directly influence product development, have limited access to the multitude of products on the global market, frequently do not use devices that would be optimal for their needs, are frustrated and without control over an important aspect of their lives

Suggested solution

How can end users of assistive technology be empowered? How can we improve the quality of our lives through better devices and better control? After 40 years of personal experience, I am convinced that most of us would be far better off, if each of us, instead of services in kind, received direct payments in the amount of his or her present AT costs to the taxpayer.

I propose a feasibility study and a large-scale pilot project over a number of years in order to test this hypothesis. Here, some of the features of such a project.

For assessing and monetarizing a person's needs several models can be used and evaluated in the pilot project, such as an individual's historical record of AT costs or the average costs for users whose disability and life style are comparable. Whatever its construction, the payment needs to cover not only costs for purchase, installation, adaptation and service but also for the administration of the process..

Budget holders would be free to choose products and services, hire consultants - including staff at an Assistive Devices Center - pick a device in a trade fair in Sweden or on a website in the US, have it adapted and repaired locally or abroad.

In order to placate taxpayers payments would need to be accounted for. Budget holders must be able to save funds over several years to make rational long-term decisions.

What might be the results of direct payments? With cash in hand disabled people would be recognized as customers. Product functionality and design, information and advertising would be geared to our needs. Producers and distributors would receive market signals directly from users resulting in more competition and innovation.

Websites, magazines, user groups and consultants offering information and advice would enable users who take an active role in the provision of assistive technology. As educated consumers many would be able to make choices in their best interest, would take good care of what they would consider to be their investments.

Consumers and their organizations would devise a large variety of individualized solutions regarding vendors, products, adaptation and maintenance. For the first time, it would pay to use one's ingenuity, develop contacts and skills. Former frustrated embittered patients would turn into customers in control.

So far my hypotheses. By now, many of you are shifting uneasy in your seats as you listen. Here, a few comments regarding some of your doubts and questions.

Not all consumers of assistive technology would want to make use of the new opportunities. Many older persons or individuals with newly acquired disabilities would feel more secure with the old system. No problem: nobody would be forced to participate in the pilot project. Besides, budget holders could hire their services from providers of their choice including their old Assistive Technology Center, for some or all their needs. The point is, we would have a real choice.

Liability for modified devices is becoming an issue of concern in Sweden. Users of AT frequently are told that modifications are not possible, because the modifier would be held responsible in case of an accident. I do not see a problem: liability insurance for modifier is available. Its costs would be passed on to the users.

Would not the proposed solution increase costs for the taxpayer, when one of the present system's advantages are lower unit prices which the County Councils presumably can negotiate due to their immense contract volumes? My own experience and anecdotal evidence from colleagues make me wonder. When I had to buy equipment with my own money, directly from the distributor, I was asked whether the Assistive Technology Center would buy the item for me or whether I would pay for it myself. In the latter case, it was suggested, a better price could be offered. I have no way of verifying such a statement.

When the electronic controller box for my wheelchair broke down, the Assistive Technology Center sent it to the company which services all their electronic devices. Nothing happened for 6 months. Upon my initiative, we found that the company was not able to fix the box and had not bothered informing the Assistive Technology Center. At this point, I asked that the box be sent, by special courier, for repair to its manufacturer in New Zealand. Within a week I had the repaired box back. The total cost, including the two courier bills, amounted to less than what the contract repair service in the Stockholm suburb would have charged – if they'd been able to repair the box. This single incident is no conclusive proof, but does illustrate how motivated end users can come up with innovative cost-efficient solutions.

Today, in some countries, the AT market seems as infested with monopolies as the European utility market before de-regulation. In my proposal, private and public, small and large entities, companies providing the whole spectrum of services or one specialized service would compete. Competition would bring down costs.

The biggest savings might be in the area of administration as consumers take over functions, such as compiling information, comparing quality, negotiating prices, ordering products and services, paying invoices, etc. The more functions they would take on, the more mileage they would get out of their budget.

Finally, the most expensive device is the device not used. This cost would be greatly reduced, if users were free to choose.

Obstacles

In the medical model of assistive technology, power is vested with the prescribing professionals who will not easily give up their monopoly. Many might use arguments that ride on the public's prejudices against persons with disabilities as helpless people who cannot manage by themselves and need to be taken care of. How could they be entrusted with considerable amounts of public monies! That was the argument in Sweden against our pilot project with direct payments for personal assistance in the 1980's. Today, ten thousand persons receive large monthly amounts and this is no longer an issue.

There is a new generation of disabled people now. We demand to be seen foremost as citizens. We no longer accept that our lives are controlled by patronizing professionals. Like other citizens today we demand to be able to make choices and take responsibility for our decisions.

The citizenship model of assistive technology realizes that disabled people, in order to achieve equal opportunities, not only need assistive devices but also must have full control over this important aspect of their lives.

We will always need professionals with expertise, skills and emancipating attitudes – as advisors but not as prescribers!

Footnotes

(1) For a definition of Independent Living, see Ratzka, Adolf "Independent Living: A personal definition", internet publication URL www.independentliving.org/def.html

(2) Ratzka, Adolf "Independent Living in Sweden", internet publication URL www.independentliving.org/docs6/ratzka200302b.html

(3) Ratzka, Adolf "User control over services as a precondition for self-determination", internet publication URL www.independentliving.org/docs4/ar200210.html

(4) The description of the Swedish AT market is based on “Hjälpmedelsmarknaden i Sverige (The market for assistive devices in Sweden)”, Swedish Handicap Institute, internet publication www.hi.se/omhjalpmedel/marknad/Marknaden.PDF