

This article is written by

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**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.

# Independent Living and the family: the context of Costa Rica and Sweden

Paper presented at the First National Congress on Family and Disability,  
San José, Costa Rica, December 8-10, 1994

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Independent Living is a philosophy and a movement of people with disabilities that works for equal opportunities, self-respect and self-determination. "Independent Living" does not mean that we do not need anybody, that we want to live in isolation. "Independent Living" means that we want the same control and the same choices in every-day life 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, work in jobs that are in line with our education and abilities. Most importantly, just like everybody else, we need to be in charge of our own lives, think and speak for ourselves.

In my contribution to this congress I will address three topics that are intimately linked to the concept of Independent Living: society's present view of disability and sexuality; the tendency to place persons with disabilities in institutions; and, thirdly, ways to support disabled people to live in the community rather than in institutions.

## Society's view of disability and sexuality

In the context of the family, the concept of Independent Living implies that we need to take our rightful place in the family and the community with the same duties and rights that non-disabled persons take for granted. This also includes participation in one of the most important areas of human life, that is loving relationships, sexuality and parenthood.

Children with disabilities - as all children - need to be raised in the conviction that they will grow up to be capable and attractive human beings who will fall in love, get married, have children and support their families. Unfortunately, this is a topic that most parents of disabled children and professionals working in this field have great difficulties with. There are many persons with disabilities, in Costa Rica and other countries, who are

married, who are fathers or mothers and who successfully raise their children. Yet despite this evidence, the topic of sexuality, childbearing and raising families still seems to be taboo. Parents of disabled children and also professionals working in this field often do not picture us as sexual beings who are capable of gratifying loving relationships.

This conference about family and disability is no exception. Anybody looking at the topics of this event will get the impression that disabled people need to be taken care of like children and never grow up to be real adults with jobs and families of their own. We are seen as objects, not as subjects, as a burden to our families and not as contributors.

## Institutionalization

As one of the results of this view of persons with disabilities, there is a growing tendency in this country to commit us to institutions. In light of the recent publicity around sexual abuse of residents in institutions in Costa Rica one might well wonder whether this is really the best way of growing up for children, whether institutions are really the best places for old persons to spend their last years. Is there not enough evidence in the form of scientific studies and statements from persons who were forced to live in institutions that the best way to grow up, to live and to grow old for all people - whether they have physical or intellectual disabilities or no disabilities at all - is in one's family and the community?

Why, then, do some families send their children or old parents away and isolate them from normal community life? For some disabled persons one of the biggest obstacles to staying with their families is that they need personal assistance in their daily lives, for example, with getting up in the morning, getting dressed, going to the toilet, with eating or getting around town. Often, a paid worker who comes to the house of the family to provide these services for a number of hours each day would be all that is needed in order to keep the disabled family member out of an institution.

Personal assistance costs money, but so does running an institution. Often the institution owns its land and buildings which together represent a significant capital. The country's largest institution for disabled persons, for example, the Hogar de Rehabilitación de Santa Ana, owns land and buildings worth an estimated 450 millions Colones. If that capital was invested at, say, 10% in real terms, the annual return would amount to some 45 millions Colones. Add to that the institution's annual budget of presently 18 million Colones (for the residents) and divide the result among the institution's 20 disabled residents and you get an annual amount of over 3 million Colones per resident, on the average. This annual amount would surely be more than sufficient to enable a family to buy assistive devices such as wheelchairs, to make adaptations to the house such as adding ramps or another room, to provide transportation to the school, pay for other services such as physical therapy and, most importantly, to cover the salaries of one or two domestic workers who would provide the personal assistance.

## Supporting disabled people in the community

The task then seems to be to design services which support persons with disabilities of all ages to stay and live in the community. Yet in most countries the importance of the family as a form of social insurance is declining. As the extended family gradually disappears with industrialization and the labor market's demand on geographical mobility, as divorce rates go up and single parents become increasingly common, the ability of the family to provide mutual aid in everyday life is diminishing. One of the results is that families have fewer resources left for members with special needs such as disabled children or old parents. If there is no place for these groups in the family, where can they turn to?

In industrialized countries there has been a long history of putting persons with disabilities, old and young, into institutions. The view that disabled people belong in institutions is intimately linked to the notion that disability is some form of disease whose carriers are to be subjected to medical treatment and to isolation from the rest of humanity. Where institutions exist, disabled people are seen as patients to be cared for rather than citizens who have a right to participate in society on equal terms. Institutionalization is increasingly questioned by organizations of persons with disabilities and researchers. Their contention is that institutions are wasteful both in terms of human and financial capital. They severely limit personal growth and life opportunities and tend to be costly relative to the low level of quality of life they provide. Rather than using public funds to maintain institutions, it is argued, resources should be made available to support families with disabled children or old parents.

As developing countries, such as Costa Rica, approach the demographic situation of industrialized countries, it is not always easy to avoid the mistakes of the so-called developed countries. In the following I will attempt to outline how families can be supported in order to avoid the institutionalization of family members with disabilities. As an example, Swedish social policy in this area will be described.

Let me begin by stating that Sweden is not a paradise - neither for disabled nor for non-disabled citizens. As in other countries, people with disabilities are still second class citizens there. As a group, they are less educated, have lower incomes, are less likely to work or to get married, as recent government statistics show. But the contention is made here that some Swedish social policy measures are effective in improving the living conditions and the status of persons with extensive disabilities.

In the metropolitan areas of Sweden, almost half of all children grow up with only one parent. With a female labor market participation of nearly 80% child care is a common problem - not only for single parents - for which common solutions have been developed. By law, it is the local governments' responsibility to offer child care for children from the age of a few months up to 14 years during the times of the day when they are not in school and the parent(s) not at home. In some communities, child care centers take

children even during night hours when the parent(s) work night shift. The lion's share of the costs of these services is born by the local governments through taxes; parents contribute with a modest fee per child. Child care centers are open also to children with disabilities. For children with intellectual disabilities or deafness, for example, it is recognized that additional resources in the form of trained staff are needed. At least one child care center in each community will have such special resources. All municipal child care centers are integrated and accessible: children with and without disabilities are welcome. The situation for public schools is similar. Children with disabilities commute to child care centers or school by cabs paid for by the municipality.

All parents get a child allowance from the National Social Insurance. Social Insurance also pays salaries during an employee's sick leave. Parents can take such paid sick leave also for days when their children are sick. Social Insurance - which incidentally also covers health care including the provision of assistive devices such as wheelchairs - is funded by taxes and all payments are made regardless of the recipients' income. For children with disabilities who need more than 20 hours of care over and above what non-disabled children of the same age might need Social Insurance pays a monthly sum that covers the costs of a paid worker for the amount of hours needed for which the child has been assessed by the Social Insurance's social worker. For example, if it has been determined that a child needs, say, 45 hours a week of assistance on account of its disability, Social Insurance will pay the parents a monthly amount which corresponds to the market wage for these hours including all social insurances and other payments that law and labor union contracts oblige the employer to pay. The parents can hire anybody they find fit for that purpose including themselves. In many families one parent chooses to give up work outside the home and assist the child instead. Other parents rather continue with their career and employ outside persons for this purpose. There is also the possibility to combine these solutions and stay with the child part of the time and employ somebody else take for the remaining hours. The aim of the policy is to give parents a choice.

Social Insurance provides the payments for personal assistance also to adults with extensive disabilities up to the age of 65. These funds allow persons with extensive disabilities to hire personal assistants who will enable them to live on their own - with or without their family. The choice is theirs. Many persons with extensive disabilities have educated themselves in a profession, obtained employment and started families of their own. In most cases, these achievements would have been impossible without personal assistance.

Individuals working as personal assistants in Sweden, typically, do not have special training in this field, since their jobs entail non-medical tasks, such as helping the user to get dressed, to bathe, go to the toilet, go to bed, cook, clean and do other household work, assist with transportation and help him or her at work or accompany him around town. For sight-impaired persons assistants will function as readers. For persons with intellectual disabilities, assistants will provide cognitive guidance and structure. Often, assistants are students who need part-time work, mothers of small children who do not want to work full-time or retired persons who have some spare time. Usually the user of

such services will have several persons employed in order to be flexible enough for workers' need of free time, vacations, sick leaves and other emergencies. Having more than one personal assistant will also help to decrease dependence on the person providing these important services.

More than half of all households in the metropolitan areas of Sweden consist of single persons - mainly older people. Often, their relatives live elsewhere or are unable to visit them regularly. If these old persons acquire a disability which makes it difficult or impossible for them to manage their daily lives by themselves, their only recourse would be an old-age home - unless there exist community based services. In Sweden, the provision of assistance services to older persons is the legal responsibility of local governments. These services are designed to assist older disabled persons - mainly single individuals - in their daily lives in their homes so that they do not need to move to institutions. Assistants are employed by the local government's social services office and will typically assist with meal preparation, other household chores and personal hygiene, if needed. There are also paramedics employed by this office who will make periodic house calls to assist older persons with taking medication, shots and similar tasks.

The argument can be made that policy instruments, such as those available in Sweden, lessen the impact of a disability on the family and the community. To acquire a disability need not automatically be a catastrophe for the individual and the family, if there exists adequate support - especially in material terms. I do not claim that the family is always the best place for all persons - with or without disabilities. Obviously, that will depend on the family's resources in terms of the family members' motivation, emotional maturity and material standard. Yet personal assistance services for persons with disabilities of all ages, as described above, can support the family and prevent its breakdown. In many instances, such services not only help persons with disabilities to stay out of institutions but also enable them to become contributing members of their families and their community, to get employment, to get married and to have children - in short, to enable them to do all that which this congress should have been about!