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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.

# The Prerequisites for Independent Living

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Independent Living is a term that was coined in the 1960s by the American disability movement. Today it has become a buzz word frequently used and abused by consumers and professionals alike. In its most common connotation it refers to living in the community as opposed to living in an institution. But Independent Living is also an attitude, an ideology, and a social and political international movement.

If you hear the expression "independent living for disabled people" you might say that you do not know many people who could be called independent. You yourself might have a wife or a husband and four hungry children at home, your boss is breathing down your neck. Worst of all, you may not be independently wealthy. So how can disabled people expect to become independent? We are all interdependent in one way or another. What is important, though, is that within these interdependencies and limitations imposed on us we recognize the options open to us, that we work towards increasing the number of our alternatives and make conscious choices. The aim is to realize that we are responsible for our lives. Whether we take this responsibility or place the locus of control over our lives outside ourselves is an attitude that has really nothing to do with our physical characteristics.

Independent Living is also an ideology and a social and political movement. Inspired by the example of the struggle for equal rights by racial and ethnic minorities and the women's movement during the last decades, the Independent Living movement sees itself as a civil rights movement of disabled people and as a political force. An important ideological influence has come from the consumer movement. Consumerism applied to disability postulates that we disabled people are experts on our own lives that we have the right and responsibility of assuming control over our own lives. Thus Independent Living subscribes to de-professionalization and de-medicalization. With the rise of the power of professionals, society has been all too eager to label those persons as "sick" who deviate from the expected norm.

In the medical model, deviants are treated as individual cases that are to be cured by professional intervention. This view denies that deviation is a function of society's norms, definitions, and physical shape. The "sick" person is expected to be unable to take care of himself and is excused from the responsibilities of everyday life, adult responsibilities. The medical profession calls him "patient" which literally means somebody who is

suffering and waiting. This dependency and denial of common adult responsibilities is most pronounced in institutions, where the inmates are often deprived of the right to the most basic decisions such as when to eat and when to excrete.

It is the Independent Living movement's merit to have pointed out most clearly society's patronizing attitude towards and even oppression of disabled people. In the US the movement's major victory is the Rehabilitation Act of 1973, which is an anti-discrimination legislation. In the United Kingdom a move to enact a similar law failed in November, 1983. Thus, it is still legal to discriminate against people on the basis of disability in the UK - not to speak of all the other countries where most people have never had the thought that disabled people could be discriminated against, where special kindergartens, special primary schools, special secondary schools, sheltered workshops, special housing, special transportation, special public toilets, special resort hotels are still not seen as evidence of an - at best - overprotective and patronizing attitude, and of outright oppression at worst.

The growing Independent Living movement is working towards ending "handicapism" - a form of discrimination just as widespread as racism or sexism. The aim is the emancipation of disabled people in all respects. We demand the same degrees of freedom as the rest of the population in education, work and leisure, in economic, social, and political life. To this end we need to generate a multitude of options and alternatives for ourselves. We have to be able to make choices. We have to make these choices ourselves, and we reserve the right to make the wrong choices, to fail and to succeed. Only then can we advance from being the objects of planners and administrators - however well-intentioned they may be - to being the subjects of our lives exercising responsibility and control.

How do we get there? How can we get the same degrees of freedom as our non-disabled peers in all important aspects of life? What are the prerequisites for Independent Living?

The first requirement is strong consumer organizations; that is, organizations of and not FOR disabled people, organizations that are run and represented by the disabled themselves. Women's organizations, to give an example, are not run by men either. To the extent our organizations are dominated by non-disabled persons, this should be seen as a sign of weakness and not integration, as it is said sometimes here in Sweden. Strong consumer organizations include all disabled people regardless of diagnosis. Today, most of our organizations defend the interest of persons with a certain medical condition, some even call their own members "patients" In this way we perpetuate the medical model and our dependency on medical and other experts, focusing on our "defects" instead of our assets, concentrating on what divides us instead of on what unites us and gives us strength.

Another prerequisite for independent living for many disabled people is personal assistance. We who need assistance in getting up in the morning, with bathing and using the toilet and getting to work, have to have access to this service in the community, wherever we live. In most countries many of us who need this practical help must live in

institutions. In West Germany, for example, thousands of physically disabled people live in mental institutions because they need help in getting dressed or going to bed. In Stockholm, there was an article in the daily newspaper not long ago about a young person living in a nursing home because city officials decided he needed too much help to live in the community. Integration, normalization, full participation and equality - all these fine words will remain empty phrases as long as we do not have the same right to choose where we can live as our non-disabled peers. The assistance we need has to follow us, not the other way around. It is unacceptable that those of us in Sweden who need extensive personal assistance can only live in special houses or - at best - in special apartments. We need flexible attendant care solutions that are not linked to special buildings, that allow us to live in any apartment or single-family home by ourselves or with our families without having to be a burden to them.

Regarding the special apartments which some of you saw yesterday, it would be unfortunate if you went home to your respective countries and said, "Now we know what the disabled need. Everyone of them should have his special apartment with 24-hour attendant care." It must be emphasized that we need options. We are all different individuals with different backgrounds and preferences. ONE solution cannot satisfy all our different INDIVIDUAL needs. We have to be able to choose for ourselves the type of assistance we need. Only WE can define our needs.

Some of us prefer that an agency, public or private, employs, trains, and schedules the attendants who work for us. But those of us who want to decide who is to perform these often very personal, intimate tasks have to be able to do so. It can be a degrading and humiliating feeling to get assistance from somebody one does not know or does not like. We have to be able to hire, train, and fire our attendants ourselves. It all comes down to a question of power: shall we give somebody else - a social worker for example - the power to determine what is best for us or do we want to empower ourselves and take over the control of and responsibility for this important part of our lives?

If disabled people are to be fully integrated and are to participate on equal terms in the community, they have to be able to get anywhere just as their non-disabled peers can. This means that we need an environment built for accessibility, that is to say that all housing, transportation, places of work, streets, public buildings, schools, shops, businesses must be accessible. Accessible construction cannot be left to the good will of landlords and builders: there must be building codes and standards that are enforceable by law. Sweden has had accessibility building codes since the 1960s. Since 1977 these codes also apply to nearly all residential construction. The next speaker will fill you in with all the pertinent information on this legislation. I hope she will also address the difficulty of enforcing the codes in the absence of provisions for punishing builders who do not comply. But even if these laws were enforced 100 percent, we would not achieve full accessibility in Sweden - at least not within the next couple of hundred years, since there is very little new construction now and the accessibility codes referring to the renovation of existing structures are rather lenient. The reason for this leniency is, of course, the high cost of retrofitting old buildings with elevators. But these costs are coming down now, due to some exciting new developments in elevator construction.

Also, installing elevators will yield some benefits to both individuals and society, which I will take up in more detail later today. As to new construction, the additional costs of accessibility are estimated to increase total costs by two per cent, an increase that is negligible in comparison to the resulting benefits.

How accessible is Sweden, given its accessibility legislation? If I were to tell you that I see Stockholm as a highly segregated city, that I experience some of the same discrimination that I believe blacks in South Africa feel, then you would not believe me. Perhaps statistics will convince you: in a recent study I estimated that at least 95 percent of the total housing stock in the city of Stockholm is inaccessible to persons using wheelchairs. As to accessibility in public transportation, in the 1950s black people in the Southern states of the USA had to sit in the back of the bus. In the 1980s in enlightened Stockholm, people in wheelchairs cannot even get on the bus. But you might argue that you have noticed the special busses shuttling disabled people all over Stockholm. True, Stockholm has a very extensive paratransportation system, with a capacity of over 1000 trips daily. But the system does not provide equal service: trips have to be booked at least one day in advance, there is no service after midnight, the bus is often late. But even if the paratransit system delivered services equal to the regular "public" transportation network, it still would be separate. And, as the United States Supreme Court ruled in a famous racial discrimination case in the 1960s, separate is not equal. It is not equal because we are treated special. Special treatment sets us apart from the rest of the population, they think we are different, and we are made to feel different. It is not equal, because we do not have a choice. Those of you here who are not disabled can get to tonight's dinner in the City Hall by bus or subway, you can take a taxi, rent a car, steal a bicycle, hitchhike or, if worst comes to worst, you can always take a walk. My options by comparison are severely limited.

By building environments that exclude and handicap a part of the population, costs are created that have to be borne by individuals and society. These costs are both monetary and non-monetary in nature. Later today I will address some of these costs. Now I would like to focus on one consequence of inaccessible environments, their impact on attitudes towards disability.

Architectural barriers handicap disabled people not only in a physical way. In an environment where most people move about freely, hurry up and down stairs, squeeze themselves through narrow doorways, wind their way through crowded supermarkets, a severely disabled person is handicapped and, even worse, is made to feel handicapped. If you have to ask for help at every step, it is easy to see yourself as a helpless person. If everybody around you goes about their business seemingly efficient and able, it is easy to feel incapable in comparison. In all likelihood a negative self-image based on environmental incompetence can extend into a self-concept of general incompetence.

Not all disabled people and even fewer non-disabled people are aware of this mechanism. Imagine you are about to employ a new worker for your office and among the applicants for the position is a severely disabled person who needs help in getting up the steps to the office. Would it not be easy to view the disabled applicant as less competent than his

non-disabled competitors? It is my contention that many of the prejudices against disabled people could be alleviated, if the general public were used to seeing us in all kinds of places and occasions as environmentally competent persons.

At this point I'd like to make a comment on the definition of accessibility. To some planners and builders accessibility merely implies that disabled people can get into a building through an entrance without steps and can use a toilet. This definition does not say anything about which entrance we are to use, and where the toilet is located. We are tired of entering restaurants through the kitchen, museums through the basement, or hotels through the rear, passing truckloads of dirty laundry. The international symbol of access that assigns us to these entrances is the symbol that we are treated as second class citizens. Mainstreaming, the current popular American word for integration, means using the main entrance, not the back door. What do you think when you see a public toilet with three entrances, one for ladies, one for gents, and the third ornated with the wheelchair symbol? Isn't the message that there is a third sex, hermaphrodites on wheels, sexless neuters?

Accessibility has to be non-discriminatory. This implies that design elements that make us needlessly dependent upon other people have to be eliminated. At a similar event in Gothenburg a few years ago a participant suggested that it was unnecessary to plan public buildings in such a way that wheelchair users could move about independently since - as this distinguished architect said - they always have an attendant with them anyway. This is, of course, nonsense, but the example shows how prejudice or sloppy thinking leads to self-fulfilling prophecies.

I have presented what I think are the main prerequisites for independent living for the disabled as equal members of the community. What are the implications of this list for us here? How do these issues apply to researchers, government officials, and architects?

First, what are the implications of Independent Living for research? As I have tried to show, one of the main ingredients in living independently in the community is to have alternatives. In order to develop choices we, the consumers, have to identify our needs and participate in developing solutions and in determining the criteria for the evaluation of these solutions. So much research is currently carried out the world over on our behalf, where we are merely the objects of observation. Not only is this a form of colonialism reminiscent of the days when white anthropologists studied black tribes in Africa from a white viewpoint, it is also bad science, because there is no guarantee that non-disabled researchers will ask the questions relevant to us. Most research today is oriented towards the needs of government agencies, which do not necessarily coincide with our needs. Much of it is probably irrelevant and some of it may even be detrimental to our long-run interests. We need our own institutes through which we can initiate consumer-oriented research.

There are some interesting methodological problems related to research in this area. One example is the question of how to evaluate a given solution in the absence of other alternatives. I once saw a study intended to evaluate a certain form of housing and

attendant care. The residents had been asked how they liked living there, and it turned out that most people liked the place. This result was to be expected, since most of the residents had no other experience of housing except institutions or living with parents. This approach is about the same as testing the quality of several makes of car by interviewing car owners who have had bicycles all their lives and have just bought their first car.

How do we get more consumers to participate in research and the other relevant professions? One way is to invite consumer input through the formation of consumer advisory boards to which disability organizations appoint representatives.

Another way is to introduce internships at your office where on-the-job training is provided for interested disabled persons, regardless of formal qualifications.

You can ask the professional organizations to which you belong to demand that schools of architecture and planning be made accessible to students with disabilities. As a result of this meeting this group here could pass a resolution along these lines and send it to the CIB head office.

You can also work for affirmative action, i.e. the active recruitment of disabled persons to education and jobs through quota systems or by counting disability as a merit, in this way, as it were, reversing the discrimination that many of us have been exposed to for a long time.

The topic has been the prerequisites for independent living for disabled people. The list of requirements can be summarized in a few words. Disabled people are to be regarded as experts on their own lives. As experts we have to participate in the planning of all aspects of the built environment. We are individuals first, disability is only one of many personal characteristics. As individuals we have different needs. To accommodate this diversity of needs we have to have as many alternative solutions as possible. We have to be able to make choices, just like everybody else. And we have to make these choices ourselves, because we are the only experts on our own lives.