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**Independent living, as the goal of
personal and institutional assistance
and care for disabled people.**

The following considerations are based on **the right of every challenged person to the greatest possible standard of living; to full participation in social life; to material and social security; and to appropriate support for individual needs.**

The goal of the **movement towards normalisation** which started at the beginning of the 1970s was: irrespective of impairments or disabilities and of place of residence, to live a life "as normal as possible".

A critical view of all special treatment, and of isolation, forms an important element of this principle.

The idea of the preference for socially integrated services arose as a consequence. From the very beginning, the movement concerned itself not with the 'norming' of disabled persons but with the promotion of a "normal life" by the use of appropriate assistance to counteract isolation.

Aimee Mullins



>> I am a normal woman <<

However, this principle of normalisation becomes limited in its practicability for systems of assistance, when one requests the inclusion of those persons to whom support should be provided. The normalisation principle requires, as part of the search for "normalcy", an analysis of the social and cultural realities which isolate disabled persons. However, it is often neglected, "that affected persons, as a reaction to the experienced handicap, could demand rights and self-determination. ... Normalisation remains an offer which the handicapped individual may only accept as such; it does not arise as a personal demand from the individual and out of his or her own experience with challenge".

"The balancing act between need-based, need-fulfilling and necessary dependence, and the greatest possible independence, as a criterium for identity, poses a central, anthropological foundation, which is common to all human beings, which unites persons with and without disabilities (of all degrees and types of disabilities) and which does not separate them from each other. The "moreness" of social dependence does not imply a basic "otherness"".

This means that the development of personal competence in "independent living" should be encouraged in a way which allows the optimal development of capabilities. Demands placed on the individual person are related to the relevant environment. Independent living is therefore only possible when living conditions are appropriately fashioned. This must be seen in the context of the basic **wish of every human being for a balance between his or her security, and autonomy.**

The drive towards satisfaction of these contradictory desires increases with age. For disabled persons this means, on the one hand, the wish for the provision of appropriate assistance and, on the other hand, also the wish towards self-determination in dealing with assisting persons and with material. In this way, unnecessary restrictions may be avoided and the emancipation of the person promoted.

The "Independent Living" (IL) movement began in Berkeley, USA at the end of the 1960s with the ambition of security and autonomy for all human beings. This initiative, undertaken primarily by young, physically- and sensorially-disabled persons, stands in the tradition of the American civil-rights and women's movements.

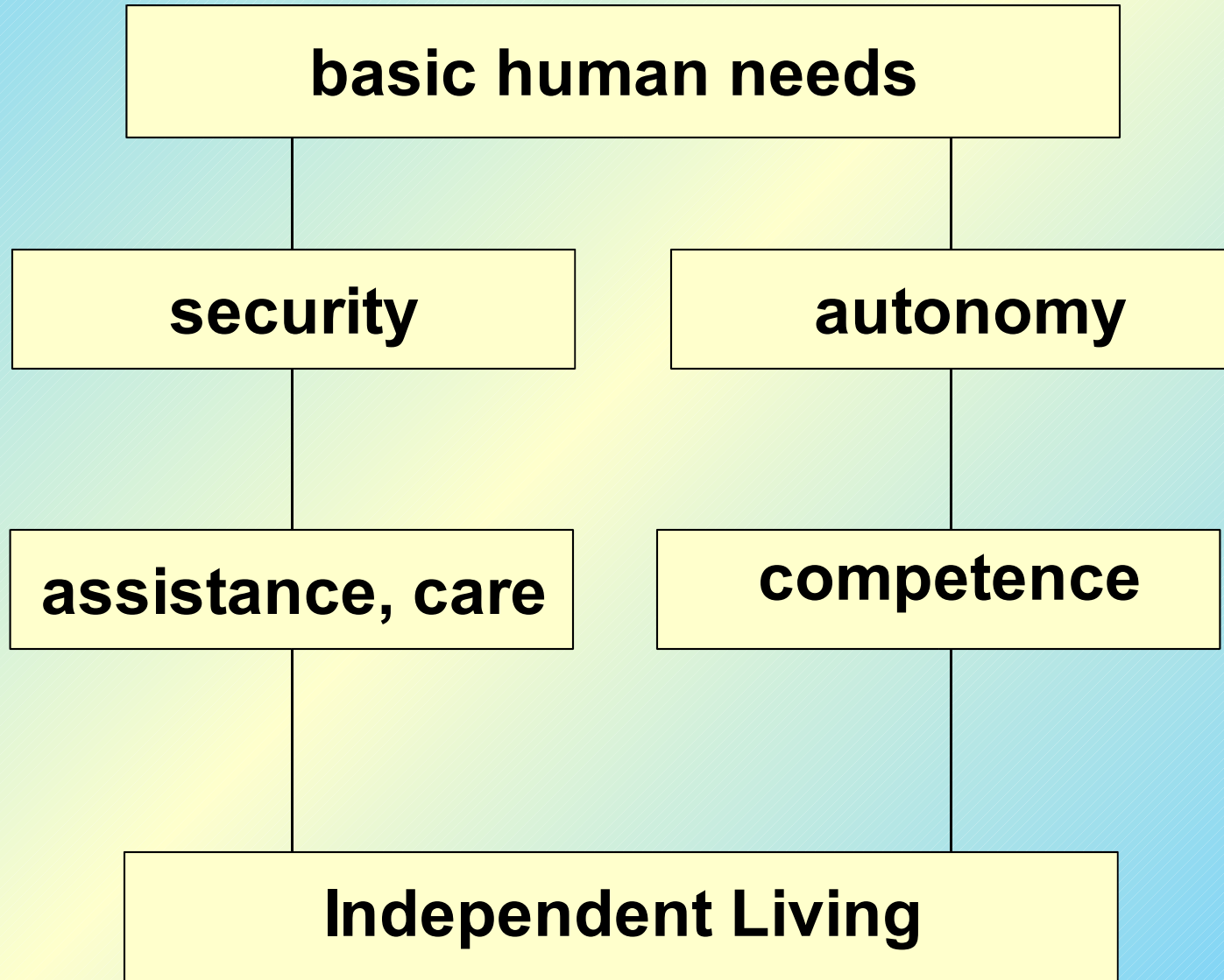
”Independent living” is the goal of a movement which assumes the perspective of the affected, and seeks to realise autonomous living. The movement assumes that disabled persons must not be necessarily ”needy and passive”, and are rather in the position to represent their own interests as ”experts in their own affairs”.

The initiative demands the equal access for disabled human beings to basic necessities such as nutrition, clothing, living space, health care, assistance, personal support services, mobility, communication, information, education, employment, political activity and so on.

It condemns segregation of disabled persons.

With critical distance to the traditional goal of rehabilitation - that is, the greatest possible creation of the ”normal condition” and the adjustment to everyday demands of life - the articulated needs of handicapped persons are here central to planning. Such basic needs are described by REINARZ as the need for hygiene, for physical wellbeing, for sympathetic care and for mobility. ”Independent living” means the ability to satisfy these needs.

Illustration 1: The "Independent living" model as bridge between competence and need for care



In reference to the **basic right to "free development of personality"** anchored in the constitution, the movement demands for all persons with disabilities the freedom to determine and shape their own lives. Disabled persons nonetheless require special assistance, material and services.

Based on their dependence, they often give up the fulfilment of their wish for autonomy.

"Independent living" is therefore seen as an emancipatory process, as becoming more independent in feeling and thought. The tracking down of personal wishes and needs is often blocked by the constant experience of dependence. The daily life of disabled persons is largely externally determined, by assistants, parents, educators and so on, which hampers them in the free development of their own thoughts and feelings. This is why disabled persons often behave in an "easy-maintenance" manner: well-adjusted and modest.

"Independent living" means therefore also, the effort to accept oneself and to perceive oneself as being of equal worth with other human beings.

Ultimately, "independent living" means to have control over one's own life.

This includes the following rights:

- to regulate one's own affairs
- to make responsible decisions independently
- to take part in public life
- to choose one's profession freely and
- to choose one's residence freely

without entering into unnecessary psychological, physical or financial dependency.

The advocates of "independent living" proclaim a change of paradigm:

disabled or handicapped persons wish to act as clients and consumers of necessary services for basic needs.

In order to change perspective and to promote equal rights of disabled persons, the year 2003 was declared the European Year of Persons with disabilities in the European Union. The goal was to promote participation, to allow self-determination and to effect equal rights.

Nonetheless, practice shows that there are still considerable efforts necessary for these goals. In Germany, for example, the Sozialgesetzbuch IX legislation established important legal bases for the realisation of these goals, but law and reality are not yet congruent. In other countries in the European Union, such as in Belgium, Greece or Austria, there still exists no appropriate legislation for disabled persons.

In a service-oriented society with division of labour, taking advantage of services

means the following:

- ➔ the provision of facilities,
- ➔ thereby to concentrate on other capacities,
- ➔ through this concentration to develop other capabilities, and
- ➔ to feel more fulfilled and satisfied.

This applies equally to persons with or without disabilities. As clients, they demand the rights and competences to determine the conditions of assistance, which include:

- **financial competence**, the access to sufficient financial resources to secure basic material needs, including the "purchase" of services,
- **personal competence**, the opportunity, as employer, to have the free choice of helpers and/or assistants,
- **directive competence**, the right to give specific information to helpers and/or assistants, so that these act in accordance with the needs and capacities of the affected person,
- **spatial competence**, the right to decide where, in which way, and with whom one wishes to live, and
- **social competence**, the opportunity to participate in public life depending on one's own capacities and wishes.

The “independent living” movement recommends that the affected person, instead of his or her assistants, should be schooled and that this should be done, whenever possible, by people who are similarly affected. **Peer counseling** is perceived as an important method in the empowerment of disabled persons.

This reduces the dominance of assistants, who too often wish to determine what is beneficial for the affected person, without considering the individual qualities of this person. Based on their socialisation under special conditions, many persons with disabilities have developed insufficient practical, organisational and social facilities.

The concept of “independent living” does not attempt to describe disabilities in a new way, but shows instead **ways of escape from the hindrances of isolation and dependency**.

Furthermore, the movement propagates “de-institutionalisation”, which means that it acts against all institutions which work against the development of individual lifestyles.

“Independent living” does not recommend the withdrawal of assistance or professional help, but seeks instead to suggest how to organise assistance which is increasingly determined by citizens with disabilities.

The creation of "independent living" may be thought of as a process. The realisation that absolute self-determination is neither possible nor desirable, remains part of the concept.

Therefore, the ultimate goal of this movement is to reinforce the **right of every human being to be the agent of his or her own life** and to promote the **extension of self-determination.**

Existent "care relationships" must be examined, whether they satisfy the above-mentioned criteria of "independent living", and whether they predetermine, or allow true opportunities for choice. The opportunity to make an informed decision increases self-determination and reduces external influences. The model of "personal assistance", in which the person with disabilities or chronic illness himself acts as an employer, is of particular importance here.

Illustration 2: Possibilities and limits of a self-determined lifestyle based on the "independent living" concept

Monika Häußler-Sczegan

I n d e p e n d e n t l i v i n g

Satisfaction of basic needs

Hygiene and physical well-being

Mobility

Independence in emotion and thought

Selfperception which recognises one's own life reality

Reduction of dependency

Detachment from parental home

Selfacceptance and selfrepresentation

Self-image, selfconfidence

Exchange of experiences in self-help groups

Realisation of discrimination based on handicap and/ or gender

Equality in interaction

Social contact with persons of own choosing

Participation in public life

Feeling of equality in interaction with persons with and without handicaps

Control over one's own life

Organisation of one's own affairs

Responsibility to oneself

Free choice and practice in employment

Choice of place and type of residence

Choice of personal assistant / caregiver

In order to make the concept of "independent living" operational, the following must be demonstrated:

how basic human needs for affected persons can be secured in a way that, through necessary support, their security can be guaranteed;

and, at the same time, that this support may be given without limiting their rights to self-determination and to the retention and extension of their personal facilities.

For persons with extensive disabilities, a primary consideration for the satisfaction of the above-mentioned basic needs is assistance in areas of daily life.

GOLDSMITH distinguishes here between

- **regular, necessary services**, which are not bound to fixed times
(for example, cleaning the floor, housework, rubbish removal, household laundry, manicures and pedicures),
- **regular, necessary services** which are bound to fixed times
(for example, getting up or going to bed, sitting in a wheelchair, affixing or removal of a prosthesis, shaving, bathing and showering, preparation of meals, feeding, dosage of medicine, injections, putting on corsets, visits to the toilet at planned times, affixing of a urine container, being turned in bed at night), and
- **emergency assistance**
(for example, visits to the toilet at unplanned times, assistance with respiratory equipment or with other special clinical needs, assistance after falling, or after other accidents).

Further elementary needs for an independent lifestyle include the wish for **independence** in feeling and thought, the wish for **self-acceptance** and **self-representation**, for **equality in interaction** with other human beings and **for control over one's own life**.

In order to fulfil these wishes, material resources are required as, at least, a basic endowment of material goods (items which belong to the individual and which include cash) over which the individual has control. The dependence upon so-called "third parties" (whether individual persons, groups or institutions) must not lead to these parties exercising decisive control over the affected person.

Choices for situational decisions in life must be available and offered, and must not be mere "projections" of the values and tastes of assistants and assisting institutions. It is insufficient merely to implement the freedom of choice; the capacity to choose must be also simultaneously promoted. It is therefore necessary to find and individually create "life models" which - without being isolated from social reality - allow a lifestyle based on these aims. The ability to satisfy the mentioned needs of "Independent Living", either alone or with assistance, creates the certainty of being able to secure one's own existence and, at the same time, also promotes the motivation and the competence to lead one's life as independently as possible.

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