

Myth Buster

INDEPENDENT LIVING



“ I stayed in different places, renting friends’ houses, flats and rooms for short periods of time and the worst, crashing in people’s living rooms or family members’ lofts, whilst desperately looking for accommodation. My physical disability got worse and I was in constant pain from the stairs in the places I stayed. I wound up spending a lot of time in bed hiding from the other people I stayed with or crying, generally overwhelmed and unable to manage. ”

“ I have now received support from relatives to provide me with accommodation in a shared house. Sharing limits the ability for me to receive tenancy support in my home, as tenancy support agencies will not support people with housemates who are not partners or family, due to risk assessments. So I am only able to access general mental health services, which has left me unable to manage to work, stuck in my room, with physical and mental health affected. ”

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European Network on
Independent Living
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If you have come across other misconceptions, not covered in this Myth Buster, please let us know and we will complete them. Thank you.

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Myths Buster

About the Myth Buster

The Myth Buster on Independent Living deals with some of the most common misconceptions about disabled people, independent living and personal assistance. They have been selected by our staff and members, based on their lived experience, and have been inspired by our work with policy and decision makers at the European, national and local level.

The European Network on Independent Living (ENIL) decided to publish this Myth Buster, in order to raise awareness about independent living and how it can be made a reality for all disabled people. Most of all, ENIL wanted to address the various myths and misconceptions around independent living, because of which what is sometimes referred to as 'independent living' is still a form of institution. ENIL hopes that this publication will contribute to a better understanding of the right to live independently in the community, as set out in Article 19 of the UN Convention on the Rights of Persons with Disabilities.

This publication is aimed at anyone who would like to learn more about independent living, as explained by disabled people active in the independent living movement.

About the European Network on Independent Living

The European Network on Independent Living (ENIL) is a Europe-wide network of people with disabilities. It represents a forum intended for all disabled people, Independent Living organisations and their non-disabled allies on the issues of independent living. ENIL's mission is to advocate and lobby for Independent Living values, principles and practices, namely for a barrier-free environment, deinstitutionalisation, provision of personal assistance support and adequate technical aids, together making full citizenship of disabled people possible. ENIL coordinates the work of the European Coalition for Community Living (ECCL) and is a member of the European Disability Forum and the European Expert Group on the Transition from Institutional to Community-based Care. ENIL has participatory status with the Council of Europe and is represented on the Advisory Panel to the EU Fundamental Rights Agency's Fundamental Rights Platform.

Myth

Living independently is the same as being self-sufficient.



Fact

NO ONE IS SELF-SUFFICIENT. WHETHER LABELLED AS HAVING A DISABILITY OR NOT, WE ALL REQUIRE SUPPORT FROM OTHERS AT DIFFERENT TIMES IN OUR LIVES.

INDEPENDENCE IS NOT LINKED to the physical or intellectual capacity to care for oneself without assistance; independence is created by having assistance when and how one requires it.”¹

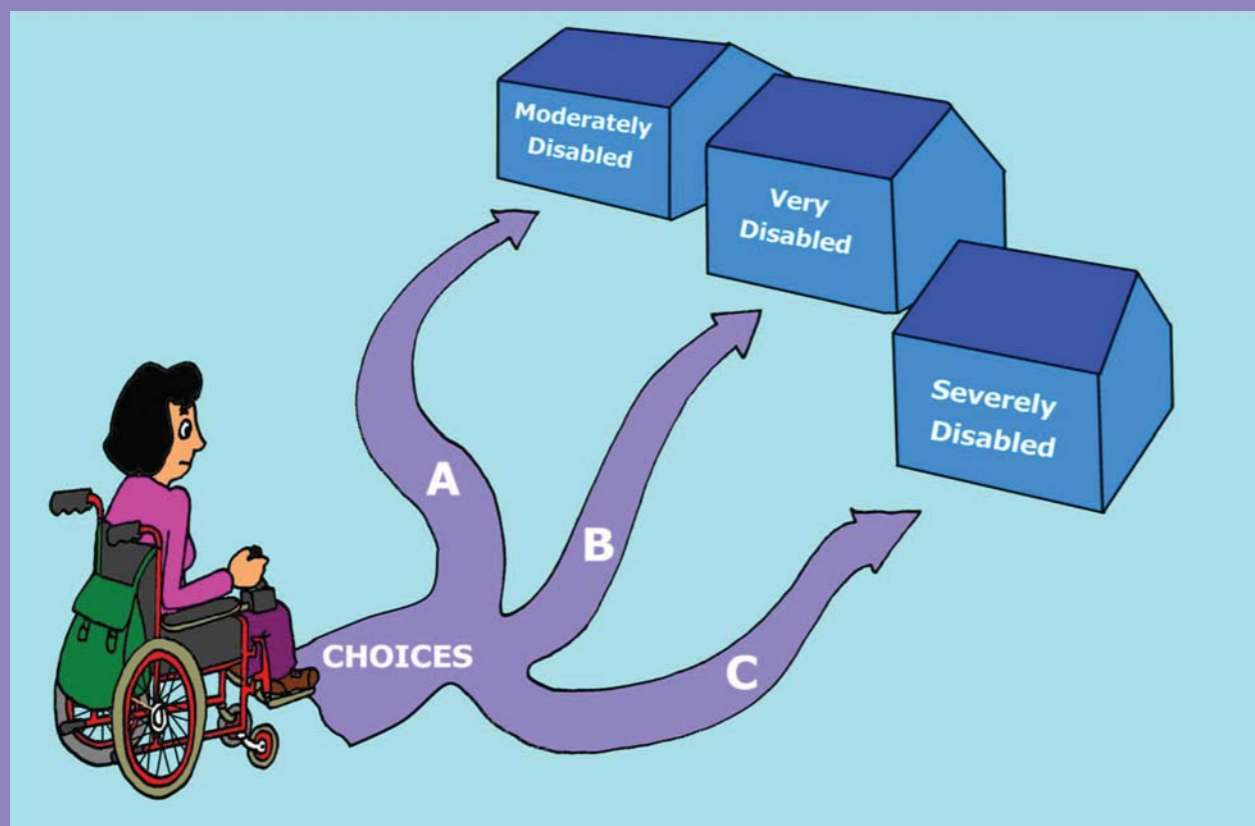
Independent living means all disabled people having the same choice, control and freedom as any other citizen – at home, at work, and as members of the community. This does not necessarily mean disabled people ‘doing everything for themselves’, but it does mean that any practical assistance people need should be based on their own choices and aspirations.

In reality, nobody is self-sufficient – we all need and use support of some sort in our lives. For example, if we need to make a decision, we may talk it over with a family member or a friend. This decision could be as big as contemplating a career change or as small as choosing what to have for dinner. At different points in our lives, we may need help in taking care of our children, emotional support because of a recent bereavement, assistance when we are ill, or financial support if we have lost our job. Disabled people are no different. Ironically, disabled people are often expected to prove their ability to be entirely self-sufficient before they are permitted the same latitude others take for granted.

1. Brisenden, S. (1989). ‘A Charter for Personal Care’ in Progress, 16, Disablement Income Group.

Myth

Living independently is not for everyone.
We will always need institutions.



Fact

IF GIVEN THE RIGHT SUPPORT,
EVERYONE CAN LIVE IN THE
COMMUNITY.

THROUGHOUT HISTORY, different groups of people have had to fight for their human rights to be respected – racial and ethnic minorities, the women’s movement and LGBT groups are just some of the examples. Disabled people are still fighting for their right not to be segregated and isolated, but to live independently in the community.

Many disabled people find their opportunities restricted by other people’s assumptions. These assumptions and the medical approach that is still common among professionals, service providers and sometimes disability organisations, are much more likely to restrict choices and opportunities than any characteristics of the individual. This is especially true for people with intellectual impairments or those with more complex mental health needs. The real explanation for the apparent need for institutions is not because some people are ‘too disabled’ to live in the community. It is because society is not ready or tolerant enough to accept, accommodate and celebrate varying and unique abilities.

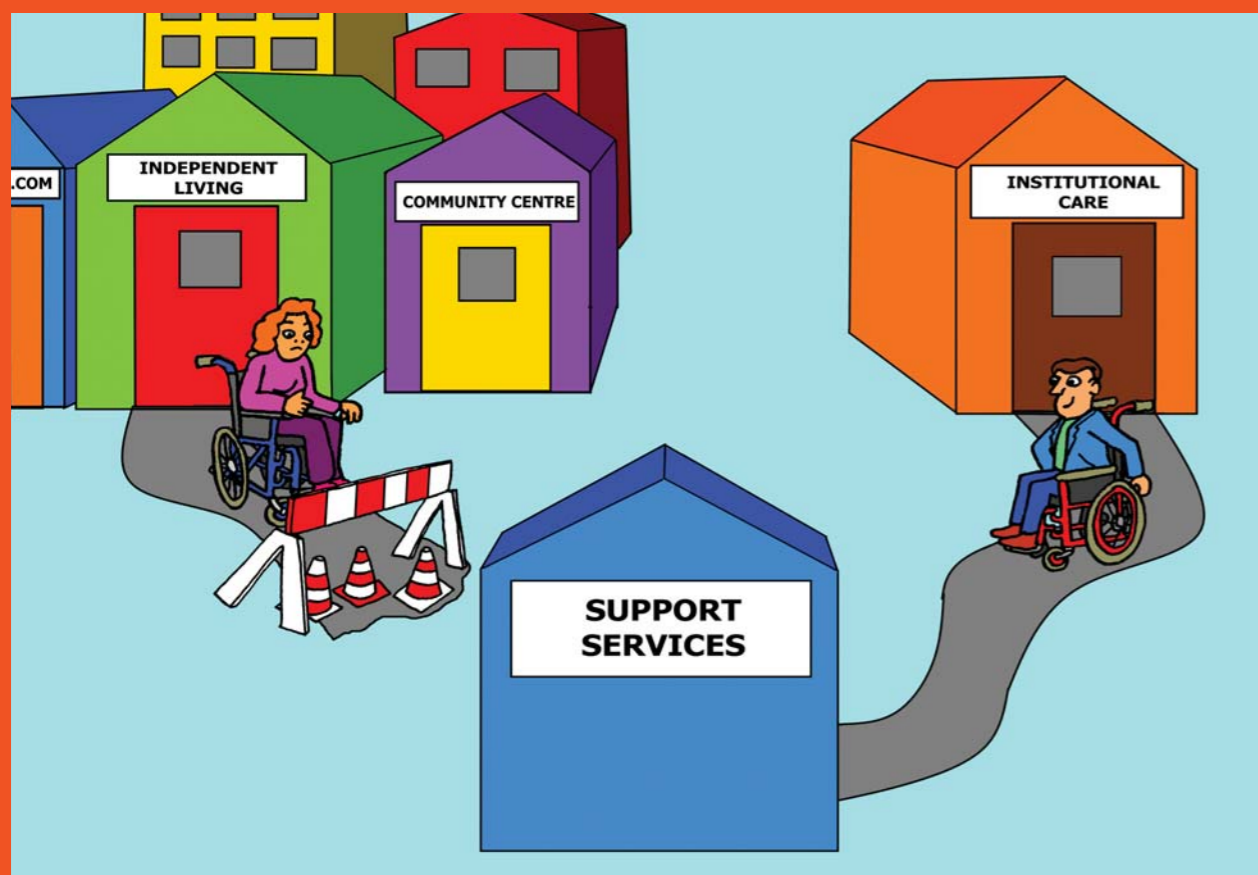
It is very often assumed that everyone with the same diagnosis has the same needs. Using this logic, placing disabled people together in one space, such as an institution, is both economically and socially prudent. However, this is simply not the case. Disabled people have varying needs, interests, talents and hopes for their future, just like non-disabled people.

In the process of deinstitutionalisation, it is often the case that some people do not want to leave the institution. This may be used as a justification to continue housing and ‘supporting’ people in institutions. However, similar to long-term inmates of prisons, residents of institutions often fear leaving the institution as a result of not knowing anything else, rather than a sign that they are not ready. The Independent Living Movement advocates for the use of peer support² when someone is leaving an institution to live in the community. Peer supporters can help individuals moving into the community gain confidence, get the right support and start building their social networks, among other.

2. Peer support is the term used to describe the help and support that people with lived experience are able to give to another individual similarly situated, such as those who used to live in an institution. This support may be social, emotional or practical (or all of these).

Myth

Independent living means having no contact with support services.



Fact

INDEPENDENT LIVING IS NOT POSSIBLE WITHOUT SUPPORT.

A COMMON MISCONCEPTION about independent living is that a disabled person must be able to live by themselves and do things on their own, without support from anyone else. For this reason, people with higher support needs are often considered as 'too disabled' to live independently. However, what independent living actually means is that the support a person receives should be based on their own wishes, their needs and lifestyle choices. Disabled people should not have to fit their lives into whatever support services are available – it is the services that should flexibly respond to each person's requirements.

In residential care settings, to receive 'support' usually means being helped with one's basic needs, such as personal care, eating and housework, with a small amount of time (if any) spent on rehabilitation and leisure activities. Placement in residential care is often motivated by the need to save money, with a limited number of staff 'supporting' a large number of residents. Independent living arrangements, on the other hand, should take account of all areas of a person's life. This includes employment, education, and being part of the local community. Independent living supports are not just about a disabled person's basic needs, but also about assisting them in accessing high-quality information, advice and advocacy services, such as those provided by disabled people's organisations. In this way, support is not something that is done to a person but rather with a person.

In independent living arrangements, it is important that the support provided is directed and controlled by the disabled person and is not dictated by service providers. In practice, this means that the disabled person should be able to decide who is their personal assistant, what support they will provide, where and when. The monitoring of this is especially important for people with high support needs, to ensure that they are in control of their support (rather than vice versa), through an advocate if needed.

Related to the above misconception is the idea that deinstitutionalisation refers to closing down institutions without developing any support services in the community. As explained, once in the community, disabled people cannot be expected to be self-sufficient. In countries where deinstitutionalisation was not planned well, many disabled people have ended up homeless and worse off than in the institution, because few or no support services were put in place. For these reasons, deinstitutionalisation should be understood as developing adequate specialised and mainstream services that facilitate independent living in parallel with the closure of institutions.

Myth

Disabled people will be isolated and lonely if they live independently. Independent living means you have to move away from your family and live on your own.



Fact

INDEPENDENT LIVING DOES NOT MEAN PEOPLE HAVE TO LIVE ON THEIR OWN, BUT REQUIRES THAT THEY HAVE A CHOICE OF WHERE AND WITH WHOM TO LIVE.

IT IS COMMONLY SUGGESTED by proponents of institutional care that disabled people are at risk of becoming isolated and lonely if they live independently in the community. They argue that disabled people are happier in residential settings, because they are with their 'friends' (i.e. other disabled people). This view is both patronising and incorrect. In actual fact, residential settings are often synonymous with isolation and segregation, for a number of reasons set out below.

Typically, people who live in residential settings have been picked to live together by a group of professionals. They have been placed in the same house or a particular building because of their identified type or severity of disability, rather than any personal preference. Also, residential settings tend to be far from where a person's family and friends are living, resulting in the loss of natural networks of support. Some individuals are placed in institutions as babies or children, which means they never had a chance to develop a bond with their family or relatives.

There are other factors to explain why residential settings typically result in its residents becoming segregated and isolated. For example, people in residential care are often not allowed to decide for themselves what to do on a daily basis. Their days are organised for them and they are overly protected. Rather than being supported to use regular services in the community, they have all the services where they live (for example, a doctor, a dentist or a hairdresser come to see them). Disabled people living in residential settings also experience barriers in the context of transport, because they are often not supported to use public transport. Instead, they are driven in 'special buses' attached to the residential unit or day care centre. Alternatively, a disabled person living independently in the community, with appropriate support, can access local services, such as community leisure options, transport and medical services, educational opportunities, etc. It is, of course, important that these services are made accessible to disabled people living in the community.

Independent living, on the other hand, takes into account the wider network already existing in a person's life. It enables every individual to choose where and with whom they would like to live. This may be at home with their family, in a shared house or flat with friends, or in their own home. Importantly, if a person chooses to live with their family, this does not mean that they should be forced to rely on informal care provided by their family members. While residential care only provides support in the same package with housing, independent living realises the importance of unbundling support from housing options.

Importantly, if children are able to grow up in families, they are more likely to develop strong and long-lasting relationships, which means that as they grow up, they will have good support networks and will find it easier to integrate in society.

Rather than forcing disabled people into isolation, independent living is about providing them with the same choices and freedoms as non-disabled individuals. This means supporting and developing the interactions between the disabled person and their family and friends. When disabled people are provided with individualised support, they are not only afforded greater choice and control over their lives, but able to actively participate in and contribute to their local community.

Myth

There are too many risks associated with living independently, so disabled people are 'better cared for' in institutional care. Independent living arrangements such as personal budgets are too risky for disabled people and may lead to fraud, neglect or abuse.



Fact

INSTITUTION IS A FAR MORE DANGEROUS PLACE TO LIVE IN THAN THE COMMUNITY.

HISTORICALLY, DISABLED PEOPLE have been viewed as being dependent and in need of 'care', rather than as individuals with varying needs and desires similar to any other citizen. This has meant that traditional models of service provision, such as group homes and service apartments often focus on incapacity, inability and/or risk, and in doing so create and perpetuate dependency. These traditional models of service are often over-regulated and over-professionalised, whereby disabled people are expected to fit into services, rather than the services being able to respond to individual needs and wishes.

Ironically, research has shown that an institution is a far more dangerous place to live in than the community. There are many risks associated with institutional care, such as neglect, physical and sexual abuse, forced medication and treatment, forced labour etc. Reasons for this include low staffing levels, overcrowding, decisions being made by staff without knowledge or meaningful input by the residents, a lack of transparency about how funding is allocated or spent, and the sheer isolation of institutions. In contrast, independent living arrangements, such as personal budgets, empower people to take control over the type and level of support they receive. The processes involved in these arrangements are more transparent and the funding follows a particular individual. It is linked to their individual needs, including their lifestyle choices, and is not tied inflexibly to a group of people, or worse, a particular building.

However, despite this being widely recognised at the international and European level, some disabled people are still being forced to move into residential care settings against their wishes. This may be because where they live, independent living arrangements are inadequate/non-existent and because resources are tied up in existing residential provision.

The Independent Living Movement is strongly against disabled people having to move away from their natural support systems, such as friends and family, to live in residential care due to a lack of appropriate individualised supports. On the contrary, the Independent Living Movement promotes creative models of services and support that enable disabled people to participate in their local communities, to have their own families and to be economically active and independent, if they wish.

Myth

Independent Living can be achieved by building group homes and day care centres for disabled people.



Fact

DISABLED PEOPLE ARE OFTEN PLACED IN GROUP HOMES AND DAY CARE CENTRES DUE TO A LACK OF OTHER SUPPORTS AND SERVICES AVAILABLE.

WHILE GROUP HOMES and day care centres can be of great help to their families in the absence of other options, it means that disabled people often spend their days mostly with other disabled people, lacking basic freedoms and doing activities they may or may not like (such as drawing, pottery or gardening). Group homes and day care centres can easily replicate institutional care for the following reasons: strict routines and red tape followed by the staff; the patronising attitudes of the staff; the large group of people being catered for, the lack of individualised support; no opportunity for residents to be in control over their own lives; the lack of freedom and autonomous decision making; the lack of meaningful activity; the overuse of medication etc.

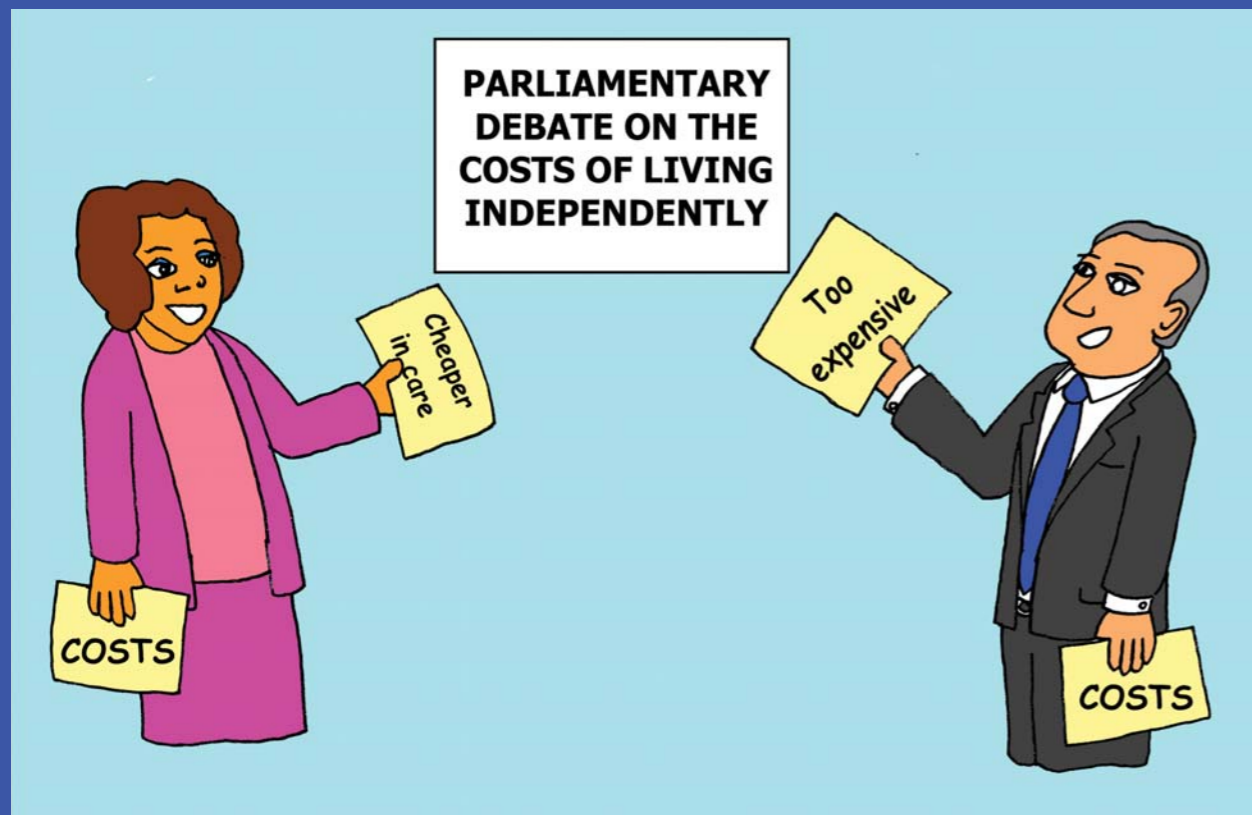
Moreover, group homes and day care centres perpetuate the 'us and them' mentality, and the view that disabled people should be separated from the rest of society. By living in a group and doing everything as part of that group, an image of disabled people as 'different' and unable to function in the mainstream environment is kept very much alive.

For this reason, independent living cannot be achieved within residential care settings, such as group homes. An important principle in developing services for disabled people is that housing should always be separated from support. If an individual would like to move to another place, they should be able to do so without losing the support they receive.

Simply speaking, disabled people should have access to the same housing options as other citizens, including privately rented housing, social housing, privately owned housing, housing co-operatives etc. Disabled people should also be able to access personalised and individualised support services, such as personal assistance, if and when required. These support services should not be solely focused on the basic needs (such as personal hygiene and eating), but also offer disabled people genuine opportunities to develop and participate in family and community life, such as accessing a local college, exploring employment opportunities, getting involved in community activities, etc.

Myth

Independent living for everybody is too expensive.



Fact

INDEPENDENT LIVING IS A HUMAN RIGHT, THEREFORE IT SHOULD NOT BE DENIED IN ORDER TO MAKE SAVINGS.

IT IS OFTEN ARGUED that, while living in the community is undoubtedly better than residential care, it is too expensive to provide independent living support to everyone who needs it. There are a number of problems with this presumption.

First and foremost, independent living is a human right and cannot be denied because it is deemed to be too expensive. Secondly, the claim that independent living is always more expensive than residential care is usually made without any proof or analysis.

Unfortunately, the funding structure of health and social care services generally creates a financial incentive for local authorities to use residential care options. Those that do provide independent living options generally put a limit on how much support one person can get. Residential costs are determined on a group basis and it is generally difficult to establish how money is allocated and what it pays for. Meanwhile, independent living requires resources to be allocated according to individual needs, in the form of individualised budgets, which the disabled person can use to pay for their support. For the above reasons, and many more, comparisons of expenditure on institutional care versus independent living have proven very difficult. Independent living requires radical changes to the way in which services are delivered and funded, and does not work as just an add-on to existing services.

There is also a failure to see expenditure on independent living as a form of social and economic investment. In residential care, instead of supporting disabled people to actively contribute to their communities and society, resources are used in ways that maintain and create dependency. This results in higher than necessary expenditure on social security benefits, as well as lost revenue from taxes that could have been paid by disabled people, were they supported to work and employ their personal assistants.

Because independent living is wrongly considered as very expensive, it can also be thought of as something that only works in rich, developed countries. However, the fact is that in developing countries significant state funds are spent on running institutions for disabled people. Therefore, this same funding could be re-directed to independent living services, as an alternative to institutional care.

Myth

Independent living options, such as personal assistance, are not appropriate for children with disabilities.



Fact

EXPERIENCE SHOWS THAT CHILDREN AND YOUNG PEOPLE, AS WELL AS THEIR FAMILIES, CAN GREATLY BENEFIT FROM PERSONAL ASSISTANCE.

INDEPENDENT LIVING SUPPORT OPTIONS, such as personal assistance, are often available to adults only. This means that the only support offered to disabled children and their families occurs in segregated settings, such as special schools, children's institutions, day care centres, institutional respite centres etc. This is especially true for children who have been diagnosed with having intellectual impairments or who have complex support needs. A lack of support in the family home or in mainstream educational settings can cause very stressful environments and can lead to a child being needlessly taken away from their families and peers. It also perpetuates the idea that 'special' services and institutions are necessary.

Independent living is not just for adults. It spans the full range of life experiences faced by disabled people, from early years and transition to adulthood, through to adult life and employment, extending into old age. The earlier an individual receives independent living support and has a chance to grow up in their family and alongside their peers, the more likely it is they will be confident and active as adults. On the other hand, early institutionalisation often leads to additional impairments and a lifetime spent in institutional care.

It is self-evident that personal assistance is not meant to replace the care provided by the child's parents or carers. Rather, its aim is to supplement it where needed, so that the child's parents or carers are able to work, spend time with their other children and get respite when needed. Personal assistance is also key to ensuring disabled children can attend mainstream education. If disabled people are able to experience independent living from a young age then they are afforded similar opportunities to develop their own life course and personal networks as their non-disabled peers.

Finally, one argument used to justify why personal assistance is not suitable for children is because they are not able to employ and manage their assistants. However, as evidenced by countries where children can have personal assistants, their parents or carers (with the support of Centres for Independent Living and similar organisations) are well placed to help ensure that personal assistants provide the type of support required by their child.

Myth

It is impossible to control the 'quality' of the independent living support options.



MEASURING THE 'QUALITY' of service provision is an incredibly subjective exercise and it should be primarily based on the experiences of the person receiving the support. This is easier to ensure with independent living service options, because disabled people have much more choice and control over what their support looks like. Independent living support options allow disabled people to employ and train their assistants, and give them an option to fire them if needed. With 'direct payments' or 'personal budgets', disabled people can decide on their own support and that support is individualised. For this reason, it is much easier to control 'quality' than in larger settings. Disabled people's organisations, such as Centres for Independent Living, are available to support disabled people in this process, by providing information about employing personal assistants, helping with the administration of personal budgets, choosing the right type of support etc.

In institutional and residential settings, there is a preoccupation with measuring tangible, practical things in order to evidence quality (such as how clean the building is or if a person's medical needs are being looked after). This is usually required by organisational measurement tools to justify or validate service contracts with the authorities or funders, and does not take into account the residents' views. The fundamental evidence of quality in independent living, on the other hand, is based on whether the support provided enables the individual to live as they wish and to realise their full potential.

Fact

BECAUSE INDEPENDENT LIVING ALLOWS INDIVIDUALS TO CHOOSE THEIR SUPPORT, IT IS MUCH MORE LIKELY THAT THE SUPPORT WILL BE BETTER SUITED TO THEIR NEEDS.

Glossary

Independent Living is the daily demonstration of human rights-based disability policies. Independent Living is possible through the combination of various environmental and individual factors that allow disabled people to have control over their own lives. This includes the opportunity to make choices and decisions regarding where to live, with whom to live and how to live. Services must be accessible to all and provided on the basis of equal opportunity, allowing disabled people flexibility in our daily life. Independent Living requires that the built environment and transport are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services. It is necessary to point out that Independent Living is for all disabled persons, regardless of the level of their support needs.

Personal assistance is a tool which allows for Independent living. Personal assistance is purchased through earmarked cash allocations for disabled people, the purpose of which is to pay for any assistance needed. Personal assistance should be provided on the basis of an individual needs assessment and depending on the life situation of each individual. The rates allocated for personal assistance to disabled people need to be in line with the current salary rates in each country. As disabled people, we must have the right to recruit, train and manage our assistants with adequate support if we choose, and we should be the ones that choose the employment model which is most suitable for our needs. Personal assistance allocations must cover the salaries of personal assistants and other performance costs, such as all contributions due by the employer, administration costs and peer support for the person who needs assistance.

Deinstitutionalisation is a political and a social process, which provides for the shift from institutional care and other isolating and segregating settings to Independent Living. Effective deinstitutionalisation occurs when a person placed in an institution is given the opportunity to become a full citizen and to take control of his/her life (if necessary, with support). Essential to the process of deinstitutionalisation is the provision of affordable and accessible housing in the community, access to public services, personal assistance, and peer support. Deinstitutionalisation is also about preventing institutionalization in the future; ensuring that children are able to grow up with their families and alongside neighbours and friends in the community, instead of being segregated in institutional care.

An institution is any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size.

Institutional care refers to the 'support' residents receive by staff working in the institution.

A residential care setting is terminology used by service providers to denote settings specifically designed for disabled people (such as group homes, service apartments³, protected/sheltered homes and living centres), where people are grouped together depending on their labelled type/severity of disability. Such settings can cater for children and adults, and can be smaller (for example, for 6 people) or bigger (for example, for 30 people). It is a model of service which links the supports a person requires with a particular type of housing, thereby restricting people's choices about where and with whom they will live. Residential care settings, despite being physically placed in a city neighbourhood or a suburb, are often based on a 'one size fits all' model and can be as isolating as an old-style institution. Residential care and institutional care are often used interchangeably by independent living activists.

3. A cluster of apartments in one building primarily offered to disabled people where 'support' is provided on a group basis.

“ I believe housing has a massive impact on how disabled I feel. In suitable accommodation, with a couple of hours of weekly support, I am able to thrive, work, take an active part in society as a volunteer, activist and community member and just to live. With unsuitable accommodation and no support, I feel so trapped. I miss being able to shower everyday, no longer feel I can cope with life or have hope for the future. This is compounded by not having much possibility to have people to stay over when I am not coping well. ”

“ I was lucky to be accepted for a flat this year. This means that my personal assistant can assist me in everyday living skills that I need and that I can have a life where I decide when and where I go, along with what to eat, and unlike paying a service contribution charge, that I can see where my money goes. I am known for socialising in the community where I live, as well as attending a disability focus group monthly. Therefore, I can truly say that independent living works for me. ”

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