

Shaping Our Futures

A conference on Independent Living
sponsored by the European Network on Independent Living (ENIL)
London, June 1998

Contents

Introduction

Conference background

Conference participants

Conference content

Assessment

Information on development, progress and achievements

Action plan

Detailed reports of proceedings:

Day One

The Amsterdam Treaty - what does it mean for disabled people in Europe?
Trends in government thinking on welfare and long-term support

UK
Norway
Sweden
Ireland
Germany
Austria

General issues from these discussions

Day Two

Welcome - Jon Snow, Channel 4 News, UK
Human Rights and Independent Living, Rachel Hurst, Disabled People's International
What Price Independence, Gerry Zarb, intro by John Evans, UK

Workshops

Work in Germany and Austria
The UK situation
The situation in Eastern Europe

Plenary

Facing Our Future summary, Anne Marie Flanagan, Dublin Centre for Independent Living, Ireland

Closing keynote speech: Crip Utopia or the end of the welfare state? Adolf Ratzka, Institute on Independent Living, Sweden

Day Three

Making the dream a reality - action to follow up this event

Introduction

Facing our futures was planned as a five day event, bringing together disabled experts on independent living, to share experience and map out future strategies, with one day also including a wider group, to share ideas.

This report covers the part of the event which took place in London. Two associated publications are the report from the Southampton part of the event, and a summary document covering the whole event. (See reference section for details.) Independent living is the emancipatory philosophy and practice which empowers disabled people and enables them to exert influence choice and control in every aspect of their life.

A crucial facet of independent living is personal assistance. "Personal" means that users exercise maximum control over how services are organised, and custom design their services according to their

individual needs, capabilities, life circumstances and aspirations. A personal assistant will perform all the required tasks that a disabled person is physically or intellectually unable to do in order for the person to achieve his or her goals.

In Europe, personal assistance users came together in 1989 at the European Parliament in Strasbourg, where they agreed a set of principles on independent living (the Strasbourg resolution) and founded the European Network on Independent Living (ENIL). A copy of the resolutions and information about ENIL are included as an appendix to this report.

Summary

The conference set out to consider the social and economic arguments for independent living and to address questions such as:

- How can we plan so that all disabled people get the choice of independent living, with assistance under their control?
- Who should pay for this?
- What are the costs and benefits of doing it (or the costs of not doing it?)
- What can different European countries learn from each other on this?

Conference background

The organisers were all disabled people who are connected to the European Network on Independent

Living (ENIL). One of ENIL's aims is to ensure that the option of direct payments to employ personal assistants is available to all disabled people who want it.

Across Europe the question of who should pay for long term support for disabled and elderly people is being debated. In many places in Europe disabled people do not have an opportunity for independent living, the choices are family care or some sort of institution. In a modern Europe this should not be tolerated. The right to control basic aspects of existence should extend to all citizens.

The conference took place towards the end of the UK presidency of the EU. We see this event as having made a real contribution to European Social Policy. It also gave the UK the opportunity to showcase some of its pioneering independent living services.

Conference participants

The participants were disabled experts in independent living. For the middle day they were joined by an invited group of politicians, policy makers, researchers and practitioners who have an interest in human rights, disabled people, independent living, or long term care.

ENIL member group representatives

Frances Hasler - UK (London)
John Evans - UK (Hampshire)
Adolf Ratzka - Sweden
John Doyle - Dublin

Declan O Keefe - Dublin
Jaimie Bolling - Sweden
Bente Skansgard - Norway
Manfred Zrb - Austria
Carl Ford - UK (Shropshire)
Arthur O Daly - Dublin
AnneMarie Flanagan - Dublin
Swantje Koebfels - Germany
Gordana Rakov - Yugoslavia
Gianni Pellis - Italy
John Roche - Dublin
Hazel Peasely - UK (Southampton)
Selina Bonnie - Dublin
Nick Danagher - UK (Sussex)
Jane Campbell - UK (London)

Other participants:

Michael Turner (notes)
John Wall (Thursday only) - UK

Additional participants, Friday only:

Jon Snow, Channel 4 News
Kevin Mulhearn, Link Programme
Diane Leigh (admin)
Ann Macfarlane, independent consultant
Andrew Bruce, independent consultant
Rachel Hurst, Disabled People's International
Denise Platt, Association of London Government/Social
Services Inspectorate
Jenny Morris, writer/researcher
Daphne Statham, National Institute for Social Work
Gail Elkington, Help the Aged

Mike Oliver, Professor of Disability Studies
Vic Finkelstein, researcher
Patsy Holland, Dept of Health
Howard Leigh, Royal Commission on Long Term
Care
Michael Jeewa, Asian People with Disabilities
Alliance
Kenneth Kilduff, Ireland
Steve Harris, Cardiff & Vale Coalition
Etienne D'Aboville, Glasgow CIL
Frances Slack, Manchester Council

Conference content

This conference was grounded in a human rights approach. It ran over three days in London on the 4, 5, 6 June 1998.

The first and third days involved a group of representatives of the Independent Living movement in Sweden, Germany, Ireland, Italy, Norway and the UK carrying out an assessment of the current situation for Independent Living in Europe, and looking to the future and mapping out the best way forward for the movement to develop.

The morning session of this day was chaired by Jon Snow of Britain's Channel 4 News and began with a keynote speech from Rachel Hurst, chair of Disabled People's International. A newly commissioned paper on the social and economic costs and benefits of independent living was presented on by John Evans on behalf by Gerry Zarb of Policy Studies Institute in the UK.

Workshops debated the issues of planning for and paying for long term support for disabled people in different parts of Europe, themes which were explored in a plenary session chaired by disabled broadcaster Kevin Mulhern. It concluded with a provocative speech, Crip Utopia or the End of the Welfare State? by Adolf Ratzka, outlining the long-term benefits of the Independent living approach.

Assessment

This event was different. Perhaps for the first time, disabled people were able to interact with the some of the powerful people who shape our lives, on a basis of equality and mutual respect.

We believe the outcomes include a deeper understanding of the aims of the Independent living movement; a shared commitment to extending the opportunity of Independent living to more disabled people; some strategies for directing money out of dependency creating services and into independence supporting ones; new partnerships; a sense of energy and enthusiasm for shaping the future.

Information on development, progress and achievements

Disabled people at the event noted some urgent need issues:

- organisations outside the movement trying to take over the name Independent living without fully taking on board the concept;
- ensuring that the concept of Independent living is not diluted - "to hold on to the original dream."
- develop approaches to Independent living other than direct payments;
- to make economic arguments for Independent living while ensuring that the human rights angle remains paramount;
- the importance of the process of Independent living and making sure that people get the right support with their arrangements for Independent living;
- the importance of self-assessment;
- the need to spread the concept world-wide, and the need to do this through a cellular approach, so that the idea is spread throughout society;
- a recognition of the danger of becoming too bureaucratic and professional and ensuring that the movements maintains its grassroots approach;
- the need to be responsible and take on the issues of Independent living by being part of the overall movement;
- considering the direction of the CIL movement, and particularly issues around finances;

- the importance of remaining political and making sure that the movement keeps its "bite";
- the need to raise the profile of the movement

They set up an action plan to take work forward:

to work in alliance with older people with all sorts of disability and impairments, in an alliance with groups which help advance our goals noting that older people are facing institutionalisation against their will, so have strong shared concern with IL movement, however no political voice on this issue as yet

to develop training for disabled people on principles of Independent living, including needs/interests of disabled people from all impairment groups, all ages noting the need to share training resources, to develop a European standard

revisit basic principles of ENIL (Strasbourg resolution) jointly with Disabled People's International

spread information about economic case for IL to member organisations

developing CILs, bringing together all the CILs in each country try to develop the definition of a CIL (particularly to guard against all sorts of places with no Independent Living ethos being called CILs)

to raise awareness of independent living noted need for a public relations strategy

to continue pressing for anti discrimination legislation at national level

ensure Facing our futures report is widely disseminated.

Detailed reports of proceedings

Day One

The Amsterdam Treaty - what does it mean for disabled people in Europe?

This session aimed to look at the legal situation on disability rights in Europe and how it could affect the independent living movement.

John Wall Chair of the UK Disability Forum Member of the Legal Rights Group of the European Disability Forum Chair of the Royal National Institute for the Blind, UK.

There has been much talk, for many years about the European Union, and some politicians get very hot under the collar about issues like surrendering our sovereignty.

The European Union has been in existence for quite a long time now and the Amsterdam Treaty is just the latest attempt to get the rules of the Union together. The fifteen countries have now agreed that certain areas of activity be done together, and the result of this is that around sixty per cent of new laws

will come from the European Union in Brussels. It doesn't really matter whether you see it as surrendering sovereignty or cooperation with our friends abroad, it is matter of pure factuality that what comes out of Brussels is very important, and therefore what they call their competencies and we would call their powers are very significant.

I make this point to begin with to make it clear that we are not dealing with some distant organisation, perhaps such as the United Nations which has very little impact on our lives at all, although it does do many good things. We are talking about institutions which actually affect our lives in very significant, day-to-day ways.

It is interesting to realise that although all of us who have disabilities know that we are discriminated against because of our disabilities, it took a long time before this was ever recognised. I am sure that all of you have heard of the European Convention for the Protection of Fundamental Rights and Human Freedoms on Human Rights, and how when these rights are infringed people can go to the European Courts of Human Rights in Strasbourg - though this situation will change now that they convention is gradually going to be incorporated in English, so instead of the farce of spending three years taking cases to Strasbourg, people will be able to fight cases in the English courts.

Be that as it may, Article 14 of the Convention which deals with discrimination says:

"The enjoyment of the rights and freedoms set forth in this convention shall be secured without discrimination on any grounds such as sex, race, colour, language, religion, political or other opinions, national or social origin, association with a national minority, property, birth or other status."

Disability ain't there! It's remarkable to me as a disabled person that we are not considered as possible

victims of discrimination, as we all know we have been for a very long time. I mention this because when we started looking at this seriously when the new treaty was being considered, the European Disability Forum commissioned a report called Invisible Citizens which formed the basis of a certain amount of campaigning during 1995. It showed that the tendency among governments was just to say that discrimination did not exist or it was not a great problem.

This report was really a starting point for us. One of the things we realised was that we would not only have a battle with the entrenched conservatism of many of the governments which were around at the time, but that we were also fighting against what have been described as an enlightened document, the Convention on Human Rights.

The run up to the Amsterdam Treaty started in 1996 and there was an inter-governmental conference which looked at a whole list of issues, and for about a year the European Disability Forum and other disability organisations were trying to obtain a non-discrimination clause in the treaty. This was initially based on the idea of doing something similar to a non-discrimination clause which relates to nationality -since they were incorporated in 1957 treaties have had a provision in them to say that people cannot be discriminated against on the grounds of nationality and that means, for example, if you are a French national who has come to England you can claim all the rights of an English national.

We initially wanted to get something along these lines so that there would be provision that citizens in European Union countries would be protected against discrimination on the grounds of disability. I have to say that although many of us felt that there was ample justification for this, we had to recognise what was possible, and it became clear that this were a number of countries who wouldn't agree to it at all.

Following the change of government in Britain it became possible to work on a compromise, and this is the clause that was eventually agreed:

Without prejudice to the other provisions of this treaty, and within the limits inferred by it upon the council, the Council acting unanimously upon a proposal of the Commission, and consulting the European Parliament, may take appropriate action.

The treaty also allows the Union to take appropriate action to combat discrimination. One of the failings of previous measures had been that it did not allow for any action to improve the situation through positive discrimination and other measures.

That is the good news. We have put disability on the map and established that there is discrimination. What is unsatisfactory about this is that if it is going to be effective any universal anti-discrimination proposal has got to be approved unanimously, we all know how difficult it can be to get unanimous agreement on anything in the European Union. That is the battle for the future. I am told that there is already a move in the Commission towards unanimous agreement provision against race discrimination, and sex discrimination was one of the first issues to be tackled, and although there is still widespread sex discrimination there is at least agreement that it should be addressed.

While unanimity is difficult to get, it is possible to shame countries into action where there is a strong moral case for action, and my own feeling is that on the need for anti-discrimination it would take a very hard country to actually stand up against a reasonable non-discrimination directive. The second point for the future is that there is a move away from the need for unanimity, and it is likely that qualified majority voting will come.

The clause in the Amsterdam Treaty was not the end of the story. The European Disability Forum was concerned about addressing two other issues. Firstly, there was the provision for the internal market which allows Brussels to lay down standards for goods across the Union.

This has led to a number of issues, such as the draft buses and coaches directive which was going to create standards for vehicles but took no real account of the access needs of disabled people and a directive on lifts which also ignored disability issues. As a result the European Disability Forum successfully pressed for a declaration within the treaty which says that the Union must take into account the needs of disabled people when preparing directives. Although this is not legally binding it will give weight to campaigning by disabled people in the future.

The final important point in the Treaty for disabled people is the Social Chapter which incorporates many regulations on employment. When it came to power in May 1997, the Labour Government agreed that Britain would sign up to the Social Chapter, which states that:

"The Community is to pursue the following objectives: the promotion of employment, improved living and working conditions so as to make possible their harmonisation while the improvement is being maintained; proper social protection; dialogue between management and labour; development of human resources; with a view to vast and high employment and the combating of exclusion."

We all know how difficult it is for disabled people looking for work, and the combating of exclusion is an important consideration for us. So, the inclusion of the Social Chapter in the Treaty and the UK's acceptance of it is really very important.

The British government plans to ratify the country's acceptance of the Treaty. Other countries have already ratified the treaty although others, such as Greece and Portugal, are moving somewhat slower. The legal effect of the Treaty will be limited until it has been fully ratified.

Questions and comments to John Wall

Q. What will Treaty mean in reality?

A. It is obviously hard to say until it is implemented. On the issue of procedures, the European Commission will pursue directives that will then be discussed in the European Parliament, they will then go before the Council of Ministers, who will vote on whether to accept it. Individual members states then have a timescale within they must pass legislation to incorporate the directive into their laws, though on some occasions directives are given immediate effect. So it may be some time before we feel the full effect of the Treaty.

Q. Looking at directives on services, a directive on lifting and handling of disabled people may have severe implications for Independent living as it limits the weight people are allowed to lift.

A. John Wall was not aware of this directive but offered to investigate it. He pointed out that one of the problems with Europe is that the distance involved can make it difficult to keep in touch with developments. One of the ways to keep in touch and find out about issues is through the All Party Disability group in the European Parliament.

Q. Following on from this, it was asked how the Independent living movement can lobby effectively at a European level?

A. The European Disability Forum is actively encouraging the Commission to ensure that it has to appropriate structures to ensure that it can consult with disabled people Europe to make certain that it fulfils the commitments made in the Amsterdam Treaty. The Forum has quarterly meetings with the Commission already, but there needs to be better lines of communication, as happens in Britain with the government publishing papers for consultations about laws under consideration.

Q. One questioner gave examples of the very active implementation of the directive on lifting, and asked why there is a wide variation in the level of implementation of different directives?

A. This depends on interest groups taking up and using a directive. In the case of the lifting directive, trade unions may have been very active. But commercial interest, labour interests and other factors have a strong influence on what gets through and how it is implemented, so the problem of being aware of what is happening is very important. "You can't influence something if you don't know it's happening."

One person observed that with the lifting directive the important thing should have been ensuring that disabled people are in control of how they are lifted, and that should have been the way to tackle this issue.

John Wall noted that it would still be possible to have the directive changed.

Q. The issue was raised of how difficult it is for people with care packages to move around the country because of problems around getting the same care package in different authorities.

A. This is really an internal issue for member states, as European interest would only start when crossing-boarders becomes the issue.

Issues were unfairness in the way European funding for disability groups works, as there is only one area that disability groups can apply to and other funding programmes will not consider applications relating to disabled people.

John Wall that this problem exists, and that there are other forms of discrimination in the way the Commission works in terms of employment practices and also on issues like holding conferences in

inaccessible venues. The ratification of the treaty will have many implications for the Commission itself as well as its members.

Q. How does the Treaty define disability and discrimination?

A. Unlike most British legislation the Treaty does not actually define any of its terms. While may be problematic in some ways, recent practice by the European Court of Human Justice, which will be responsible for any cases brought in relation to the Treaty, has generally been very broad in terms of interpretation of laws on other issues. The disability movement should be able to make case for a very wide definition of discrimination, taking in forms of indirect discrimination. The court has also been establishing a set of general principles which it applies to all its work, and these principles are grounded very much in human rights and this is likely to include non-discrimination in the future.

Q. A query was made about how European directive restricting workers' hours to 48 hours a week should be applied to people employing personal assistants. Many people have their PAs on lengthy shifts. PAs may be covered by an exemption for domestic staff, but advise from the British government is not clear.

A. It is unclear how and the directive has been fully implemented. It is was suggested that the issue be taken up with the All Party Group on Disability in Parliament.

Q. In the light of the provision for anti-discrimination in the Amsterdam Treaty, how important is it for people to push for anti-discrimination in their own countries?

A. It is important to continue to press for anti-discrimination legislation in individual states because it clarifies the country's position, and because of the issue of subsidiarity, which means that it is often

better to use the laws that apply within a state. The European Disability Forum is encouraging people within member states to continue to press for anti-discrimination legislation.

Q. One person pointed to European funds being used to support segregated services, such as transport services particularly for disabled people, and asked this type of service could be stopped.

A. There is a growing emphasis on inclusion and mainstreaming, and this can be particularly important as it other voices to the issues we are working, such as parents with push-chairs also wanting better access to buildings and public transport.

This led onto some wider consideration of funding and the fact that funding is being reduced for many groups, including the European Disability Forum itself. Concern was expressed about the decreasing number of programmes on disability, which that means there is likely to less scope for disability groups to apply for funding.

It was agreed that the situation is unsatisfactory, although some work will now be under the heading of social exclusion.

Trends in government thinking on welfare and long-term support

This session aimed to get details of the situation of the Independent living movement in each of the countries represented at the conference, and to look at the way forward for the Independent living movement in Europe.

UK

The main development in Britain has been the introduction of legislation to enable local authorities to make direct payments to enable disabled people to employ PAs. This is a unique situation as it was the direct result of campaigning by disabled people.

There have been positive and negative issues as a result.

The positive things have been that many more people have access to direct payment, and virtually all local authorities have responded positively and said they will use the legislation. Negative points have been around changing the scheme which existed before the new law to fit in with the new system, which has brought people within the community care system and led to people being reassessed which has led to concern about people losing out on support.

Other problems have arisen around the relationship between direct payments and the charges for services which are levied by local authorities. It was suggested that this would be resolved by the government's emphasis on getting disabled people to go to work where possible, and that the point will be made that disabled people are unlikely to want to do this if all their earnings are taken by paying for support services.

The overall issue of welfare, and Independence living in the context of the welfare system, is becoming ever more important with the growing argument that Britain cannot afford its welfare system, and that disabled and older people are too expensive. There is increasing emphasis on only providing services and support to people who are seen as "vulnerable", and this makes things very difficult for Independent living because its about people not being vulnerable.

Areas of spending are divided into different local areas and by different types of impairments, and this creating wide differences in the support that people receive. Eligibility criteria are being made increasingly tight, and people are finding it increasingly difficult to get services, and getting less and less in the way of services. Some who have been relatively independent are beginning to lose their independence because of this.

Jane Campbell made the distinction between people receiving Independent living packages in some areas, but in others people with the same level of need are only getting what she called "survival packages".

Another important issue is recent moves towards returning to institutional care for people with mental health problems.

It was thought that while we have good legislation, restrictions through charging, eligibility criteria and rationing of services is restricting people. Services have become resource led, and the legal framework is supporting this as the courts have ruled that it is appropriate for local authorities to decide the assistance a person receives by the resources available, even where this contradicts the rights people have for services.

There are questions about the availability of resources. It is felt that rather than lack of resources, the problem is that they are spent on the wrong services, such as residential homes and day centres.

One person highlighted the fact that larger amounts of money are often spent keeping people in the criminal justice system, which is indicative of the value society puts on disabled people.

Norway

Using personal assistants is still quite a new idea in Norway. We started as a co-operative in 1990. There is no law for disabled people to have the option of personal assistants, so we have to fight each individual case. This is the biggest problem, and there are calls to get a law to cover personal assistants and the campaign for this is growing. On one day there was an e-mail protest day, and people bombarded their MPs and government departments with e-mail, and there have been other traditional methods of direct action.

However, there is some concern that legislation might undermine the current co-operative approach.

Assessments are also an issue. They do not take account of the fact that the more active you are, the more assistance you are likely need; There is meant to be self assessment for people who can do so, but this does not always happen;

Sweden

The direct payments system began in 1994 but the movement for Independent living had begun in 1987. It had started as a pilot project which then spread quite quickly with groups persuading local authorities to use resources that were used for home help and community care services for direct payments.

The success of this attracted the attention of politicians who supported moves for a national framework, although there was considerable opposition from those who believed that a strong public sector was essential to maintaining social welfare.

There are considerable limits to the project law. It only covers people under 65 and personal assistance for not more than 20 hours a week to cover essential activities. This was only around 7,000 people.

Other people remain covered by previous laws which require local authorities to provide support, and this can include cash payments in some circumstances.

One drawback of the national scheme is that pay rates are now decided through a centrally negotiation system, which removes some of the flexibility and has led to less generous terms for many PAs.

As in other countries, there is a strong establishment of charities which are not controlled by disabled people, and these tend to push politicians their way and squeeze out the organisations of disabled people.

Economic pressures are also beginning to cause problems. When people are re-assessed some are given fewer hours of assistance. People can appeal against this, but even when they win this the authorities disregard it and say that they just cannot afford to provide what the person is entitled to. There is talk of means testing direct payments, and as this has already happened in some places in relation to transport for disabled people, it seems likely that this will also happen.

Ireland

When the Dublin CIL was established it set up structures to ensure that member groups and other agencies it worked with adhered fully to the concept of Independent living in policy and practice.

There are now 17 CILs in Ireland and, partly due to funding and partly because it was in their original plan, these became decentralised and independent in 1997. They all have to be controlled by disabled people.

There is now a problem with charities encroaching on the CILs' territory. The network is particularly

vulnerable because direct payments are not covered by legislation, and many of the schemes are resourced with finance from government employment initiatives, so they are set up in terms of enabling people to become employed.

In some areas it has been local disabled people deciding that they want to do different things. Dublin CIL has set up a company to work nationally to try and influence and support local CILS, and to work politically and strategically to get the principles of Independent living taken on board by statutory services.

However, this is proving difficult because of funding limitations, and working against established funding systems for traditional services like respite is a struggle. There is also a lack of faith in disabled people's ability to manage money. This has led to some of the money which should have been used for PA services being spent on traditional services, which are often provided by the traditional charities.

The fact that families of disabled people receive a care allowance can also make it difficult for people to become independent, as it means taking money from their family.

Despite these problems, there was a feeling that the CILs in Ireland have dramatically and permanently improved the situation of disabled people in the country, and that it is important to note and celebrate this achievement.

Germany

A law on long-term care insurance which was passed in 1995 is causing considerable problems for the movement in Germany. It has led to a much more medical approach to support for disabled people.

Many people have been reassessed, and many fear that they may have to go or go back into institutions.

It had been promised that most people's long-term care needs would be met through the insurance scheme, but in practice many people need additional money from the social security system, and this is means tested. Payments from the insurance scheme and social security are limited to cover what is seen as essential support and direct employment of PAs is ruled out by the legislation.

The level of support a person is given depends on an assessment and points system determines what a person gets. People have little say in their assessments. They can then choose whether to receive a service or a cash payment - but anyone who chooses to receive cash has to be visited by a nurse several times a year for an assessment of their health. The person has to pay for this visit!

Services which are run by disabled people have had to cut themselves back to ensure that they can survive in the new system.

The new system was the result of a long running debate on how long-term care should be paid for. Costs had risen steeply in Germany because of increasing demand and because a previous system of using conscientious objectors from conscription to provide support had kept costs artificially low.

Austria

A direct payments system was introduced in 1993 but the level of payments is very low. People are free to spend the payments as they wish, including employing PAs, but there is currently some debate about whether there should be more control over people.

Most disabled people still receive assistance from their families. People without families often have difficulty getting by.

Economic issues connected with meeting the criteria for the single European currency have led to substantial cut backs in public spending in Austria. Spending on direct payments have been cut by about 10 per cent, and future plans include the introduction of a voucher school.

Concerns about the costs of social welfare are very high.

General issues to come out of these discussions

- there is a problem with charities which try to take over the name of Independent living without using the ideas and concepts which should be attached to it;
- there have been attempts to patent the term Independent living, but it has not any possible;
- we need to try and set standards for independent living, but avoid over-professionalising the movement;
- the movement needs to tap into the human rights agenda, especially as this has a strong profile at the European level.
- most countries have severe controls on public expenditure and there is widespread debate about the cost of welfare;

- we need to promote the idea of inclusion backed up with anti-discrimination legislation.

Day Two

Welcome
Jon Snow, Channel 4 News, UK

Too few of us are aware just how delicate much of this equipment is. It's not just baggage handlers, it's us as well who need to recognise just how sensitive this equipment is. Here am I, somebody who can only complain about a rare puncture on my bicycle.

Human Rights and Independent Living
Rachel Hurst, Disabled People's International

Many of us have met at independent living meetings here, in other parts of Europe, in the United States, and we have to go on because the concept is still not fully understood.

The 48 member states of the United Nations which signed the Universal Declaration of Human Rights in 1948 recognised the, "inherent dignity and the equal and inalienable rights of all members of the human family," as "the foundation of freedom, justice and peace in the world". They declared that, "all human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood."

Article 2 says that "Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind..." But disabled people are not mentioned specifically. At that time we were not conceived of as a specific group whose rights might be violated, but as unfortunate individuals who should be the passive recipients of charity and social provision - where the national economy allowed.

Even returning heroes from two World Wars, who were unable to maintain their pre-war lifestyles, were excluded from their communities in special villages or institutions, albeit that these were often in pleasant surroundings and the disabled veterans were given ample funds to reward them. There was no idea - anywhere in the world - that these men and women had the "right to self-determination and to freely pursue their economic, social and cultural development" as stated in Article 1 of the International Covenant of Civil and Political Rights - nor that they had the right to full and equal inclusion in the society for which they had fought so hard. Nor was it a consideration that democratic societies perhaps had a duty to alter to ensure the inclusion of their disabled veterans.

Most countries, with the exception of the Nordic bloc treated their civilian disabled population even more carelessly, either consigning them to institutions or living lives without social benefit or service protection.

And so things remained for disabled people until the end of the 1960s when disabled veterans started returning to America from the Vietnam War. Because they were a living example of the futility of the war, they were fodder for the anti-Vietnam press, so the government did not reward them and many were treated extremely badly - as were the very severely wounded soldiers from Britain's Falklands War in the early 1980s. At the same time as the veterans' return, a group of severely disabled people had managed to get an integrated university education at Berkeley, California, which was a hotbed of the many civil rights movements that were active in the USA.

These disabled people learnt many things both from their own experience and from the other civil rights movements. They realised, along with the disabled war veterans, that disability was not a matter of impairment but one of discrimination. They knew, just as black people and women had articulated, that it was not their personal characteristics that were the problem, but the discriminations they faced within society itself. And they knew that rights had to be fought for not just for some groups of people with impairments but for all disabled people, regardless of impairment.

This realisation of disability as a human rights issue also clarified for disabled people what the solutions were to getting those rights. Undoubtedly there had to be legal support for civil rights but there also needed to be legal protection against discrimination. Services for disabled people had to be based on the concept of equal opportunities and non-discrimination and not on the traditional solutions of segregation and specialisation. We needed inclusive education and transport, not special buses and special schools. We needed programmes that allowed us choice and control over our own lives. And it was in this human rights context that Independent living was born.

Independent living is, in fact, the practical solution to ensuring self-determination and the free pursuit of an individual's economic and social development - those empowering philosophies of the Convention on the Civil and Political Rights.

It should be impossible to break the link between Independent living and human rights. The basic principles under-pinning Independent living should be reflected in civil rights legislation for disabled people and in all policies and programmes that support our inclusion into society.

But, as most of us know only too well, neither the legislation nor the policies to support our Independent living have been implemented or enforced in many countries. In fact the term "Independent living" has been hijacked by many professionals to give credibility to their programmes and policies which are, in

reality, based on the needs of administration and cost and not on the rights of the individual.

At the international level, disabled people have always been invisible in the human rights Conventions. It was only in 1983 that the World Programme of Action Concerning Disabled People talked about disabled people and equal opportunities and integration and full participation. In 1991 the United Nations produced a special report on Disability and Human Rights, where, for the first time, the systematic and daily violations suffered by disabled people were catalogued. There was no direct mention of Independent living but a great deal was said of the horrors of putting people into institutions as a solution to their exclusion.

Up until 1992, the only policies regarding disabled people in the European Community were based on rehabilitation. Although both the European Union and the Council of Europe talked about integration in their rehabilitation policies, there was no promotion of the concept of self-determination and freedom for the individual, nor any duties put on the member states to legislate directly for provision based on self-determination. After 1992 and the inclusion of disabled people's own organisations in advising the EU on disability policy, the words "Independent living" were used but there was little clear understanding by policy-makers as to what that really meant. The many strong, well-funded professional rehabilitation organisations operating at the European level did not understand the concept either.

However, in 1993, the UN Standard Rules on Equalisation of Opportunities for disabled people says: "The purpose of these Rules is to ensure that girls, boys, women and men with disabilities, as citizens of their societies, may exercise the same rights and obligations as others". The Rules cover all the areas necessary to ensure Independent living and even go so far as, in Rule 4, including personal assistance and interpreter services as important measures to achieve equalisation of opportunities.

As I said at the beginning, Independent living is disabled people's solution to achieving our rights. Despite the slowness of international commitment to disabled people's rights, disabled people themselves have been working on Independent living initiatives all over the world. As you will have read in the accompanying literature to this conference, disabled people in Europe have been running Independent Living Centres since the late 1970s. Disabled people have come together to network regionally on Independent living since 1989.

Many of the programmes in the developing world which are described as community based rehabilitation or income generation are, when they are run by disabled people's organisations, Independent living. Different words are used to describe the same process. People often only identify a programme as Independent living if it concentrates on personal assistants or advocacy. Others see Independent living as advice and information and access, but it is all these things or any combination of rights based factors.

What has to be remembered is that there is no blue-print for Independent living except the blue-print of rights. Implementation of Independent living cannot happen unless the programmes are based on rights, promote rights and ensure rights. What Independent living is not - is service provision. It is disabled people sharing their knowledge and expertise to empower others and to ensure their freedom and self-determination.

Nation states in Europe have different approaches to giving disabled people their rights. Several countries have non-discrimination measures enshrined in legislation - but only Sweden has an enforcement mechanism in the appointment of an ombudsperson. Many of the Nordic countries have policies underpinning services for disabled people that support their rights and legislation too, but in reality are far from ensuring rights for all disabled people. The UK has the direct payments legislation supporting the employment of personal assistants, which is a major breakthrough for disabled people in

this country, but this does not extend to all ages or impairments and is voluntary not obligatory.

This highlights another important point about Independent living - it is only rightful when it is available to all disabled people, regardless of impairment, severity of impairment, age, gender, race, culture, sexual orientation, class or caste. If I have left anyone off of this list, please add them! When

Nor should there be any discrimination in recounting its history. I keep on reading accounts of the history of the Independent living movement and words like "founding fathers" are bandied about. I think it is most important that when we are talking about a rights based approach that we bring rights into everything we say, as well as what we do. There is no doubt at all that the first Independent living initiative in Berkely, California, happened because of one disabled man - Ed Roberts - but since he joined forces with both men and women to form the rolling quads and then set up the first Centre, disabled women have been significant leaders too. We need her-story as well as his-tory!

I would like to end by again referring to the Universal Declaration, Article 7. It says that "All are equal before the law and are entitled to equal protection of the law." As I have shown, disabled people in Europe and the rest of the world, do not have protection of the law. We have to ensure that we cause a revolution that gives us that protection. Not only protection through non-discrimination legislation but also protection in all legislation which is relevant to disabled people - legislation regarding social welfare and benefits, health, safety - but above all legislation that supports personal freedoms and justice.

I hope that this conference is yet another instrument of that revolution, and perhaps we're going to have to be just a bit louder and a bit more revolting.

What Price Independence??

Gerry Zarb and John Evans, UK

This paper was due to be introduced by Gerry Zarb, Senior Research Fellow at the Policy Studies Institute in the UK. He was unable to attend due to illness and the paper was presented by John Evans of the Hampshire Centre for Independent Living, UK and Chair of the European Network on Independent Living.

John Evans gave the following introduction to the paper:

We were hoping that Gerry could be here to present his paper, but his spirit is here in his work. Some of us have been engaged in a lot of the work that Gerry has been doing on our behalf and I would like to point out that the British Council of Disabled People commissioned the Policy Studies Institute at the time when we were campaigning for legislation for direct payments, and the work that Gerry did then, published as *Cashing in on Independence*, was probably one of the key factors which influenced the then Secretary of State for Health, Virginia Bottomley, and other influential groups like the Association of Directors of Social Services that helped us to secure the change in the law to allow direct payments.

I think the fact that it influences national policy making is indicative of the strength of Gerry's work. He has worked along with us ever since then, and I'm sure he will continue to do so.

Research is an area which is very debatable in the disability movement. We've always felt there are lots and lots of people wanting to do research on our behalf around Independent living issues, but they are not always coming from the right place. The important thing we must remember is that we must be in control of that research, we must instigate it, and we must direct it. As long as we do that, it is usually research which bears the results of showing the importance of what Independent living is all about.

We are the experts. We started the movement. We have to maintain control of the movement and not allow researchers to take it over.

Main paper:

Introduction

This paper is intended to contribute to two linked contemporary debates concerning the further development of independent living options for older and disabled people, and the funding of long-term care. The paper attempts to set out some of the key issues which need to be incorporated into the agendas for these debates. It also outlines the main factors which would need to be taken into account in any fully developed analysis of the social and economic costs and benefits of independent living.

What we know about the costs and benefits of Independent living

First, I have looked at the evidence from existing research on the costs and benefits of independent living - particularly the various forms of direct or indirect payments schemes which are (in the UK at least) increasingly available to certain groups of disabled people.

What the research evidence tells us is that direct payments have consistently been shown to be a cost effective mechanism for enabling disabled people to access high quality support which maximises choice and control at equivalent or, often, lower cost than other forms of community based support. The most detailed study carried out in the UK, for example, showed that support packages based on direct payments were on average 30 to 40 per cent cheaper than equivalent directly provided services. This

study also indicated very clearly that people receiving direct or indirect payments had higher overall levels of satisfaction with their support arrangements than service users. This was particularly noticeable in relation to reliability and flexibility and the degree of confidence people had in their support arrangements being able to meet their needs.

Other smaller scale studies have shown similar results. The evidence from this research demonstrates that user controlled money goes further, so investing in Independent living is a more cost-effective use of public finance.

Current debates about the future development of Independent living options

Given that the arguments about both cost and quality have largely been settled it is perhaps surprising that direct payments and similar independent living options are still far from universally available. We need to consider why this is the case and to identify some of the key points of contention which are yet to be fully resolved. I suggest that there are four key issues which need to be placed at the centre of debates about the future development of Independent living for older and disabled people.

First, that the fundamental contradictions between 'Care' as conceived in health and social care systems and 'Independent living' have not yet even been fully acknowledged, let alone resolved. The implementation of direct payments in the UK is an illustration of this, where a concept with choice and flexibility at its core is being squeezed into a system of rationing resources and pre-determining what constitutes "need".

Second, that contemporary debates around the future funding of long-term care are fundamentally flawed. While it is of course both legitimate and prudent to be considering how future support options

should be financed, the basic problem with the existing approach to this question is that the whole debate is premised on the assumption that residential care will continue to be presented as the option of first choice for the majority of older and disabled people requiring higher levels of support. A contrasting approach would be to explore ways in which alternative community based, non-institutionalised, support systems could be developed.

The disability movement has developed alternative models on a small scale; until these are developed more widely, most older people will never have the opportunity to access alternatives to institutional care and, hence, will continue to choose this option until their perceptions are altered by the range of alternatives on offer.

Third, the development and expansion of Independent living options for a larger number of older and disabled people is also being held back by the absence of any conception (outside of the Independent living movement itself) that independence could, or should be, established as a basic and universal human or civil right. Despite the considerable expansion in availability of direct payments which is currently taking place, access to Independent living is still essentially granted on a discretionary, rather than mandatory basis. This is true even in systems (eg. Germany) where - on the face of things - everyone is entitled to access Independent living options. This is because, typically, there are still considerable restrictions on both the level of resources people can receive, and on the ways in which they are allowed to use these resources to organise their support.

Most importantly, practically all of the existing support systems place some kind of ceiling - either in terms of cost or eligibility criteria, or often both of these - on the level of resources at which Independent living is deemed to be viable. This means of course that people for whom Independent living is considered to be unviable are faced with a stark choice between struggling to maintain their independence in the community, or entering institutional care. Effectively, this amounts to putting a

price on peoples' lives. No amount of rhetoric, however well intentioned, about 'Enabling', 'Empowerment' and so on will disguise this while some older and disabled people continue to be institutionalised against their will.

Reconceptualising investment in Independent living

Discussion of universal access to Independent living options points in turn to the need for debates about funding these to be re-conceptualised. The fact that access to Independent living is often denied once a certain level of resources have been reached reflects the widespread concern about funding for public services. A key objective for future debate would be to shift the existing focus on costs towards seeing expenditure on Independent living options as a form of social and economic investment. Another related issue which needs to be factored in to the debate concerns the balance between expenditure and investment at the individual and macro levels. In particular, that the costs and benefits of investment in Independent living need to be analysed at an aggregate (ie. macro) level in order to demonstrate the overall impact of such investment in terms of both social justice and economic efficiency.

Existing approaches to this question are seriously limited by the narrow focus on individual investment decisions (eg. as typified by the process of assessment for community care). This not only precludes any meaningful discussion of overall costs and benefits but it also tends to systematically exclude individuals and groups at the extremes of the cost scale for whom such investment is deemed not to be cost-effective.

A shift in focus away from individual investment decisions towards consideration of macro-level social and economic costs and benefits also implies a need to analyse the impact of investment in Independent living as a process which occurs over time. This is because the cost and benefits of individual

investments made at any particular point in time will obviously have longer term effects and the 'pay off' - if there is one - may only be demonstrated over time. Similarly, at a macro level, the long-term impact of investment in Independent living needs to be analysed in terms of the potential for bringing about changes in patterns of demand for particular forms of support and, hence, on the overall effect on public finances. I will return to this point later.

This long-term approach to investment is equally important at an individual level as it opens up the possibilities for considering how particular investments may be cost-effective over time, even if they appear expensive at the outset. Similarly, this approach would allow us to take account of the social and/or economic contribution which such investment enables people to make and, where necessary, to 'offset' costs at one stage (eg. in older age) against the benefits at an earlier stage (eg. when people are working). However, there is of course a danger lurking within this approach as it could be distorted to 'justify' the exclusion of certain groups and individuals (eg. those who are never economically active). This could - to a certain extent - be countered by analysis of investment in Independent living at an aggregate level. Any pattern of social investment will always include 'outliers', individual cases with relatively high costs. However, these cases are only relevant when investment decisions are made on an exclusively individual basis. When the nature of investment in Independent living is reconceptualised at a macro level, the key outcome is the overall impact in terms of social and economic costs and benefits: in other words, the fact that particular people have higher costs at some stage does not matter as long as it can be demonstrated that the overall impact of investment in Independent living is in a positive direction.

Social insurance and funding of long-term care

The issue of investment in Independent living is also linked - albeit indirectly - to the question of funding for long-term care. It has a particular bearing on the current debates about social insurance being used as a vehicle for funding of long-term social support by requiring people to make financial provisions during earlier stages of the life course which would then be used to pay for entitlements to

support in later life. A number of concerns have been raised about the principle of using social insurance in this way and the relationship between investment in Independent living and the principles of social insurance remains an uneasy one. In one sense there does appear to be a common underlying objective in terms of promoting greater self-reliance, autonomy and choice. But whereas investing in Independent living is about the exercise of collective rights and responsibilities, a state support system is driven primarily by economic imperatives, in particular the perceived need to limit public spending.

What do we need to know about the costs and benefits of Independent living?

Restructuring the debates on future development of Independent living options and funding for long-term care would need to be supported by appropriate evidence to demonstrate the social and economic benefits of investment in Independent living. There are some the key pieces of evidence which would need to be collected and I will suggest some possible approaches to developing appropriate forms of analysis.

As discussed earlier, shifting the focus of debates about funding for Independent living away from individual costs towards the concept of social investment would require that analysis of the costs and benefits of alternative models needs to be carried out at the macro level. Equally important is the need to try to develop forms of analysis which examine the net effect of costs and benefits over time. Given that it would obviously be impractical - and, quite possibly, unethical - to carry out large-scale social experiments in real time, we need to utilise models for simulating the cost-effectiveness of investing in Independent living over the longer term. As mentioned earlier, there is also a need to consider the net costs and benefits at different stages of the life course (for example, by looking at how cost savings at earlier stages might be offset against increased expenditure in older age).

Conventional approaches to analysing cost-effectiveness in health and social services are typically based on two main factors:

- utilisation and demand (actual and/or projected);
- and,
- unit costs (staff, capital costs plus overheads).

Although there is considerable variation in how these factors are applied to different services, the basic approach is usually the same. The cost-effectiveness of one type of service compared to another is assumed to be a function of the relative demand plus the actual costs: although some economists might also want to analyse predicted variations in relative costs which might follow from changes in demand (changes in demographic trends, for example).

Basically, this would involve estimating future cashflows and translating these back to current prices in order to inform potential investment decisions. So, for example, cashflow models for people purchasing their own personal assistance using direct payments could be built up for a given time span and compared to the costs of providing the same level of assistance provided through service based options. This kind of model would need to take account of both direct unit costs, indirect costs (such as administrative overheads), cost savings, and revenue transfers (such as savings on social security benefits, earnings from employment, and the generation of tax revenues for people who are enabled to become more economically active). The model could also be used for further sensitivity analysis to look at the effects of building-in certain assumptions: for example, assumptions about the future level of demand for direct payments.

It is also essential that any discussion of cost-effectiveness takes account of the benefits associated with alternative funding mechanisms. This requires setting appropriate measures for the quality of outputs associated with the various options. Such measures can then be related to the costs (direct and indirect) involved. In the context of investment in Independent living, the principal "benefits" which we would need to measure are those relating to:

- how well particular personal assistance options satisfy people's needs (which could be measured by factors such as reliability, degree of choice and control and so on);

and,

- the wider benefits which follow from the degree of efficiency with which these needs are met (for example, by enabling people to take up employment or participate in social or cultural activities; the impact on family members, and so on).

However, it is important to recognise that "need" is a normative concept and will involve an element of subjectivity in measurement. Some analysts have suggested that, in order to carry out a meaningful cost benefit analysis, needs should be conceptualised in terms of final objectives, rather than the means by which those objectives are achieved.

So, when we talk about a need for a home help or a personal assistant, for example, we are really only talking about the means. The final objective would be the benefit to the individual in terms of improving quality of life; giving them security and control; addressing their requirements for physical assistance and so on. It is always possible, therefore, that these needs could be met by a number of alternative means. The focus for analysis should be the effectiveness of alternative forms of investment in meeting these needs.

In welfare economics needs are often expressed in terms of "shortfalls", or unmet needs. But, these are - by definition - subjective and individual. There is also the problem that, people may either be unaware that a need is not being satisfied (for example, because they do not know that particular support options are available); or, they may not have the motivation to make them known - particularly if they have very low expectations.

In view of this, there are three alternative approaches which have generally been adopted:

- i) taking expressed unmet needs which are backed up by objective demand (as indicated by ability and willingness to pay for example);
- ii) adopting measures of minimum standards or "absolute need";
- iii) using set criteria defined, for example, by assessment procedures (in other words, professionally defined needs).

The second and third of these alternatives are increasingly seen as arbitrary and inflexible and are not, in any case, consistent with the principles of Independent living. The concept of expressed demand is more promising however as this opens up the possibility of developing measures which are meaningful to older and disabled people themselves. Factors like choice, reliability, and flexibility can all - potentially at least - be assessed in an objective way. The challenge for analysing the effectiveness of investment in Independent living therefore will be to develop appropriate measures for such factors which can be universally applied to people with a range of different needs and support arrangements.

The cost efficiency of any particular support options is usually related to the most efficient means of meeting needs in a given set of circumstances. A cost-efficient support option can be defined as one

which maximises the output (or benefit) achieved from given resources, or one which minimises the resources required to achieve a specified level of output. In the context of Independent living options, the main focus would be on the first of these - assessing the extent to which different options maximise the benefits to users.

Basic elements of cost benefit analysis

There are three basic elements which need to be included in any cost-benefit analysis of investment in Independent living. These are:

- i) resource inputs - including things like staff costs, consumables, capital costs, and a measure of time used by both support agencies and users;
- ii) the actual costs - both direct and indirect costs and intangible costs such as the effort involved in organising a personal assistance package);
- iii) non-resource inputs - including social environments (which refers to the extent to which independence is promoted in other ways such as through removing transport and access barriers), interpersonal relationship between users and workers, disabled peoples' own personal resources, and collective expertise (the knowledge and experience provided by Centres for Independent Living for example).

In addition to the basic resource inputs and costs - such as direct unit costs, overheads, wages, and time spent on organising individual support arrangements - there are also a range of indirect costs which need to be factored in. These include things like:

- occasional costs for purchasing supplementary or back-up support;
- holiday and sick pay for support workers;
- other miscellaneous or occasional costs (for example, meals, travel time, telephone calls, recruitment);
- (Dead time) - such as time spent waiting for support workers to arrive;
- reduced earnings (either for disabled people themselves or other family members);
- the subsidy provided from sources of informal support.

Other factors for analysis

Other factors which need to be built in to our model for analysis relate to the potential social and economic benefits of investment in Independent living. These would include things like savings on social security benefits; earnings from employment; generation of tax and consumption revenues associated with increased participation in social and economic activities; the potential reduction in demand for health and social services; and the scope for reduction in dependency on informal support.

These are, of course, all outputs at the macro level. In addition we also need to factor in the outputs relating to the benefits to the end user which might be produced by a range of different support options. Not all of these can be measured directly so, in some cases, proxy indicators need to be developed.

These would not necessarily be assigned a monetary value however. Some of the principal benefits to consider include: the reliability, flexibility and security provided by different support arrangements; the amount of productive time freed by people being able to access suitable support; the degree of choice people have over how and when support is provided, and by whom; the level and scope of support provided; the time and energy involved in organising individual support arrangements; and, longer-term viability of support arrangements.

Wider social and economic costs and benefits

Finally, the discussion of macro level outputs benefits leads us back to the issue of the wider social and economic costs and benefits of investment in Independent living. There are three issues in particular which are likely to be the most important in terms of economic arguments about the value of such investment, although they are also likely to be the most contentious in the context of the welfare reforms which are currently being considered around the world. These are the relationship between earnings and benefits; the implications for demand for health and social services; and, the potential scope for reducing dependency on informal support. First, as discussed earlier, one of the most fundamental distortions in current debates about funding for Independent living and long-term care is that there is a very narrow focus on the costs to public finances. There is almost no consideration at all of the potential cost benefits or savings which may be produced by a more positive approach to investment in Independent living. In particular, that little consideration is given to the net effect of increased tax revenues and lower expenditure on social security which might be associated with increased social and economic participation. These are likely to be very important - particularly for younger age groups.

However, it is also important to emphasise that the level of disabled peoples' participation in economic activity is determined by a much wider range of factors than the straightforward ratio of earnings to

benefits. Perhaps even more important are the range of barriers to employment associated with both wider labour market conditions and the organisation of work itself.

Unfortunately, the considerable range of barriers to economic activity faced by older people will mitigate against these benefits. For example, recent research on what happens to people after a spell on incapacity benefits in the UK shows that there is only a very slow rate of return to economic activity for most people in older age groups and, once past the age of around 50, the prospects of ever finding employment are virtually zero. It is important therefore that we do not replace one narrow focus with another as this would create a very real danger that this could be used to justify the exclusion of older people from the benefits of Independent living.

Over the longer-term there may also be financial benefits in the form of potential savings associated with a reduction in demand for health and social services. For example, research on ageing and disability suggests that people who have been living independently for longer periods in their youth and middle age may be less inclined to seek assistance from directly provided social services when they are older.

Other savings may come from a reduction in demand for acute and/or long-term health care on the basis that full independence may well be associated with higher levels of quality of life and the associated benefits in terms general well-being. Where living independently also contributes to increased economic activity then obviously people will also be in a better position to build up their own financial resources for older age. This is in fact becoming increasingly important given that the proportion of pensioners' incomes coming from savings and occupational pensions has been rising markedly over the last two decades.

The other side of the coin however is that there is a growing divide between cash and asset rich pensioners and those who have not been able to build up their financial resources because of their

limited participation in economic activity. Again, this suggests that there are potential benefits in investment in Independent living earlier in the life course as, if people are not able to build up sufficient resources they will inevitably remain dependent on a higher level of state support when they are older. Given the well documented association between economic activity, financial resources and health, such investment may in turn contribute to a reduced demand for acute and/or long-term health care. However, at this stage, these are little more than hypotheses which need to be tested.

Another of the potential benefits of investment in Independent living could be a reduction in overall levels of dependency, including dependency on informal support from families or Carers¹ - who would themselves be enabled to increase their levels of participation in other areas of social and economic life. However it is important to keep in mind that this would, in turn, mean a reduction in the existing informal cost subsidy from carers. So, this would also need to be factored in to any analysis of the costs and benefits of investment in Independent living.

The importance of this factor can be demonstrated by reference to the scale of subsidy provided through informal support systems. A recent study in Ireland, for example, indicated that family members spend an average of 47 hours a week in providing informal support, rising to 86 hours a week for people in the oldest age groups. These findings are very similar to those from UK research on comparisons between the costs and benefits of payments schemes and services. This indicated an average of 40 hours informal support per week for people with packages based on direct or indirect payments, and 55 hours per week for people using directly provided services. While this source of support - by definition - has no monetary value attached, this does not mean that is free because there are of course indirect costs attached.

Concluding comments

Most of this discussion has focused on the economic arguments about the value of investment in Independent living. Obviously, this is partly because it is what the conference organisers requested as the topic for this paper. However, it does also raise some broader questions about what should be seen as the fundamental justification for investing in Independent living. To a large extent, the arguments presented in this paper reflect the agenda set by utilitarian economics which defines a properly functioning economic and social system as one which gives priority to efficiency over equity.

There are of course alternative standards which could be used to assess the value we place on different forms of investment - particularly values based on social justice and basic civil rights. While many of us may well feel that these are more appropriate values in the context of enabling independence, we have to realise that the parameters for the debate are constrained by the principles of utilitarian economics which are central to the organisation of contemporary public support systems.

This in turn suggests that moral arguments based on the principles of rights and equity alone will not be likely to cut much ice unless additional economic arguments can be mobilised. This paper has hopefully provided some ideas on how such arguments could be effectively constructed.

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Questions and observations

One person noted the differences between the situation of younger disabled people who are able to achieve Independent living, albeit with a struggle, and older people who invariably have no option but to go into residential care.

Dr Michael Oliver picked up this point, saying that even amongst those who are sympathetic on this issue, "the basic assumption remains that the appropriate place for older people is in a home". He noted his growing concern about his own situation as he gets older, and that many organisations for disabled people are failing to address the issue.

Rachel Hurst followed on from this by observing that issues around Independent living are not being addressed in general social policy debates. She noted particularly that there is discussion of disability in the current moves to address social exclusion in the UK, even after having made direct representations to the Prime Minister. She recounted being put on a waiting list to go to a European social policy conference, saying, "disabled people should be up there talking about the solutions that we have come up with, because our solutions and the way we are approaching everything are examples of good, hard social policy of the type that they want and need. But they will not recognise them because they come

out of the socially excluded mouths of disabled people."

She concluded that breaking down these barriers is, "one of the most important hurdles that we have to overcome."

Jon Snow followed this by saying that this is becoming a wider political issue as there is a growing care industry. "Old people farming is growth industrial from which people are making very large sums of money," so there are people with a financial interest in seeing older people put into residential homes. He went on to consider the difficulties of educating society at large about the benefits of Independent living, noting that direct action can be very "enlightening" but not without drawbacks, and that the way forward on this is uncertain.

Nick Danagher made some comments about the importance of employment. Jon Snow agreed, saying that some of the most important progress is made from disabled people taking their place in at work. He pointed his experience in the British media where disabled people are almost wholly excluded.

Jane Campbell moved on to consider how some organisations "for" disabled people, which are not controlled by disabled people, are trying to take over ideas around Independent living. She pointed to the example of the Leonard Cheshire Foundation in the UK, which had published achieved a high public profile by publishing research about discrimination against disabled people and a major advertising campaign, while at the same time she sees the Found as keeping disabled people dependent and not consulting the Independent living movement.

She questioned whether these types of organisation are really committed to Independent living, "or are they just learning our language." In terms of reaching a wider audience, she argued that we need to be cautious of organisations like this taking over our ground.

Rachel Hurst also noted that such organisations also often employ a token few disabled people who are used to justify it as involving disabled people.

Jon Snow noted that this is a "double edged sword," as we do want to see disabled people doing the jobs that they want to do, particularly if that job relates to educating the wider world on issues around disability.

This led onto a short debate about whether charities which are not controlled by disabled people can provide true Independent living. It was suggested that the key difference between what the Independent living movement defines as "Independent living", and what organisations "for" disabled people would describe as "independent living," is that it is rights based.

The way forward was said to be picking up the case made in Gerry Zarb's paper and to push the arguments about the economic and social benefits of true Independent living as defined by the movement.

A representative of the UK's Royal Commission on the Future of Long-Term Care noted his appreciation of the debate and gave delegates information on how to make submissions to the Commission, and that it is considering issues relating to younger people as well as older people . He went to say that the Commission is considering fundamental issues about long-term care, such as that about whether it has to be institutionally based, and that it is considering all possible options for the future.

Jon Snow concluded the morning session by thanking the speakers and participants in the subsequent debate.

Workshops

Workshop A: Work in Germany and Austria

Chair: John Evans, Hampshire Centre for Independent Living, UK.

Speakers: Swantje Kobsell (Germany) Manfred Zrb (Austria)

Germany:

On 1 April 1995 the Federal Government introduced a new law on long-term care insurance which was said to be an improvement on the former system where means tested benefits were paid to cover the costs of personal assistance.

Article 2 of this Law was titled 'Self-determination' and it stated that the benefits from the insurance should enable people in need of assistance to lead an independent life and achieve human dignity. It also emphasised that the care provided should focus on maintaining or regaining physical, mental or psychological strength. In a further paragraph it stated that people had the right to choose the service provider.

Disabled people and their organisations had little influence on the passage of this law, and four years after its implementation there is increasing concern amongst disabled people that this new system is threatening personal autonomy. The reason for this concern is the way the Article 2 regulations, of which there are more than a hundred, are being interpreted. The encouraging spirit of the law is being

lost and in practice it is starting to control people's lives. .

This practice consists of the disabled person being assessed for one of three financial levels by the insurance company and then being awarded a sum of money which can be in cash or in kind. Prior to the introduction of the new law, politicians claimed that people would not require additional funding but this has not proved the situation as nearly 70 per cent of all claimants require additional benefits.

All health insurance companies are independent and people select the company according to what they offer. If the money awarded is insufficient when a claim is made, the disabled person then has to apply to Social Services. We have lost the progress made on getting the social model of disability accepted during the 1970s and 1980s. The new system is based on the medical model, and focuses only on personal hygiene and sustenance, plus a small amount of housework. Care tasks are timed, allotted points, and limited to an average of 30 minutes. Social activities are excluded.

Disabled people are also subjected to a visit by a nurse between one and four times a year to check their health and wellbeing.

Service provision by disabled people for disabled people is struggling to survive in this new scheme as they are expected to work on the same basis as the non disabled service providers. The Bremen Co-operative, of which Swantje is a part, is very demoralised as its contract is based on the units system.

It was recently placed in a position where it either went bankrupt or gave in to this system. The Co-operative has opted for submission in the hope that it can still somehow work out and maintain a quality service.

It works to four competencies and disabled people can:

- select their own personal assistants
- decide when and how this personal assistance will be delivered
- control the personal assistants
- control the money spent on personal assistance.

These competencies are not part of the insurance wording or practice. Schedules and the provision of personal assistants are determined by the service providers. Disabled people can seek another service provider but the practices are similar and disabled people are finding it hard to maintain the self determination they had gained previously.

Self-determination was not on the agenda of the law makers who ruled out the employer model of personal assistants by stating that personal assistants cannot be employed by the disabled person. If a disabled person lives within a family, the money is paid to the relative/s to continue providing the support required. This is obviously the incentive to keep the disabled and or older person at home, with all the ramifications that can have for the disabled person.

Austria

In Austria disabled people only have a cash service which is given under the Assistance Money Law that came into force in July 1993. Social services have little or no influence on what is going on. Since

the law has been in force, increasing numbers of care providers have come into being. Unlike Germany, there is no regular medical monitoring.

There is a growing discussion about how money is given to disabled people but there appears to be little movement towards changing this situation to the relief of disabled people and their organisations. Disabled people are free to make all decisions about employing personal assistants.

The disability movement made five demands under this particular law but only four were permitted. These were:

- The money should be paid directly to the disabled person;
- Payments to be irrespective of age Include all impairments;
- Financial services should be equal throughout the whole of Austria;
- Financial services should be the same amount as the actual cost of the care

This last one was not accepted, making it difficult in some instances to get all the support required. A disabled person also has to require upwards of fifty hours of personal assistance a month. Eighty five per cent of funding comes via Federal Government and fifteen per cent through social services who are responsible for improving the structure of providing care.

A decision has been taken by Federal Government not to build any more institutions before 2010 at the earliest.

Participants questions:

Q. How is the money raised in Austria?

A. Through taxation. Before the new law financing care money was only available for older and disabled people if there were no other state benefits for them. The volume of payments is 10 billion Asch. per year. This money was financed in part through the tax volume and pensions contribution. Since July 1993 an additional 0.4% is a sickness fund insurance which is paid half-and-half by employees and their employer, and an additional 0.5 per cent contribution by those already pensioners. (volume around 8 billion Asch.).

The effect of this mixed system was never seen as part of the health insurance system. We who are affected by this system are obviously very pleased about that.

Q. Is there any difference in cash for the under and over 65s in Germany?

A. There is no differentiation in law concerning age. In the development of the law, disabled people and older people were served by different agencies. We had been worse off when we were in the same organisations as the service was even further reduced for disabled people.

Manfred added: In Austria there is a difference where someone works but if neither partner works there us less of a difference.

Swantje continued: Lots of nursing agencies have been set up and there have been many changes for disabled people since the introduction of the new law. 400 DM is lowest amount in the three levels of payment. 10 DM per hour = 40 hours, and 10 DM is a very basic payment. 700 DM = 20 hours from

agency.

Q. Is the disabled person the legal employer in the German cash system?

A. If you take the cash you can do what you like! Promotion of the black economy.

Q. Do you think older people in Austria want to be looked after by relatives?

A. They have gained because they can stay in their homes.

Q. In Austria are the costs covering being a legal employer adequate?

A. We have a regulation which covers part time or low earnings workers which mostly applies to students and housewives. On 3800 AS per month, there are no insurance requirements, other than accident insurance which is the lowest amount of insurance. Disabled people employ several PAs so earnings do not go above 3800 which saves considerable taxes. It also saves a lot of personal administration.

Workshop B : The UK situation

Facilitated by Jane Campbell and Frances Hasler, co-directors of the National Centre for Independent Living, UK.

The workshop began with a brief appraisal of the situation for direct payments in Britain following the passing of the Direct Payments (Community Care Act) in Britain in 1996.

Research by the Policy Studies Institute has shown that most local authorities say that they will introduce direct payments schemes, although the situation in each local authority area varies. The National Centre for Indicative Living (NCIL) is in touch with around 30 per cent of local authorities.

Local authorities remain concerned about proper use of and accounting for payment, although there have not been any examples of misuse. They are also concerned about equity between people receiving direct payments and people using direct services, and there is also concern about how to show value for money.

There are a number of issues which need to be addressed:

- the assessment system looks at the need for care, need Independent Living - we need to change the way that assessments are made and improve training for staff involved in assessments;
- there can be inequity between direct payment users who need 24 hour support and can use PAs for social activities, and those who need less support and can only use them for essential tasks;
- local authorities have tended to use pilot schemes which provide direct payments for those who ask loudest and leave out the rest. This is dangerous and we to work to ensure that direct payments are available to people who are less articulate and have less experience;
- there is need for better information on direct payments - video may be especially useful;
- pilot schemes may delay implementation of a full, proper scheme;
- there is a need for direct payment support schemes, and there are some good examples of these.

- the exclusion of people over 65 needs to be addressed.

Questions

Q. Are administration costs as high for people on direct payments as they are for local authorities?

A. No, but good employment practices can increase the cost. Some authorities allow people to pay below the threshold where they would have to begin to pay National Insurance contributions, but government guidance says that the authority should include enough to cover these contributions which are legally required.

European Union directives may have an effect on this situation.

Q. How do direct payments relate to charging systems?

A. Most local authorities in Britain now charge for social care services, and direct payments do conflict with this and also act as a disincentive to disabled people going out to work. It is important to lobby on this issue

Q. Will political changes in Northern Ireland affect direct payments?

A. There is not an Independent living movement in the Province. Resources are very low and the funding base needs to be increased. NCIL has had a consultant working in Northern Ireland with the Health Boards, but not social services. People in Northern Ireland may have more success working with

the CIL in Dublin.

The future

Several points were made for the future progress of direct payments and Independent living:

- efforts should go beyond just lobbying and be put into people becoming policy makers;
- social work must be re-constructed (or de-constructed) and social work practice must reflect the social model of disability;
- training for social work staff needs to change;
- we need to get past having "pilot" schemes and set up an "airforce";
- we must keep to the principles of direct payments and Independent living;
- we must concrete on and highlight the cost benefits of Independent living.

Workshop C: The situation in Eastern Europe

Facilitated by Gordana Rakov and Adolf Ratzka

Eastern Europe is a very broad area, with many different states which are diverse in terms of their political systems, economics, social policy and cultures. This makes it difficult to sum up the overall situation of Independent living in these countries.

However, there things that the countries in this area have in common. All countries are post-communist and are in a state of transition. The social infrastructures are very limited, with little public transport, poor housing and virtually no accessible accommodation, poor availability of enabling aids and waiting lists for entry into institutions. There is generally a very low level of disability awareness and disabled people remain largely "invisible" in these society.

There some good points, such as the culture of collective responsibility and some state disability benefits. The services that have been available, such as some "home help" type services, have been based on a very medical approach.

It is therefore unsurprising that disabled people living in these countries tend to have low levels of ability and lack self assertiveness. This means there little in the way of organised activity by disabled people for Independent living, although some initiatives do exist in Prague, Slavia, Bratislava, Moscow, and Belgrade. ***** Some others which I can't read *****

The use of the term Independent living is not consistent. Some schemes concentrate on providing wheelchairs and transport and working on access issues, others are running Personal Assistance schemes. This work is mainly funded from abroad, from aid from the United States and European Union and PHARE (????????????????)

Some support also comes through commercial sponsorship and donations, although it is not always

clear whether the prime aim of this is to assist disabled people or raise the profile of the companies' involved.

There are some very clear parallels that can be drawn with disabled people in Western countries in general, and some specific similarities. There are general parallels in terms of disabled people striving to be de-institutionalised, families taking control of disabled people's lives, and the shift in responsibility for disabled people from the medical profession to the social care professions.

Specific similarities which were identified included the strong influence of religion, as in Ireland, and the dangers of professionalisation of Independent living amongst a select few disabled people, which some people saw happening in the UK and elsewhere.

A number of steps were identified for future progress:

- build up networks to provide mutual support and learn from each other;
- develop exchange programmes;
- establish training programmes to ensure that a wide range of people develop skills for Independent living;
- improve the use of existing resources by diverting them into Independent living schemes.

Plenary

Chaired by Kevin Mulhern, disabled broadcaster and producer of the long-running television series Link, which covers disability issues.

Kevin Mulhern began the session by noting that the day's discussions, both formal and informal, were looking at Independent living, as opposed to independent existence, and going beyond just talking about people being enabled to live in their own homes.

He recalled making a television programme about a person trying to leave a residential institution and talking to one of the people who ran the institution and claimed that it was, "virtually a hotel," and the disabled person being interviewed said residential homes would be a viable alternative to Independent living on the day that the head of a major charity looked at their watch four thirty and saying that they had to get home because dinner is at 5 o'clock and a bath is at 7 o'clock.

Facing Our Future summary

Anne Marie Flanagan, Dublin Centre for Independent Living, Ireland

There followed a brief summary of the discussions which has taken place at the Facing Our Future conference in Hampshire the previous weekend. This had covered what was referred to as the "dream of Independent living", and touched on issues around:

- organisations outside the movement trying to take over the name Independent living without fully taking on board the concept;
- to ensure that the concept of Independent living is not diluted - "to hold on to the original

dream."

- approaches to Independent living other than direct payments;
- to make economic arguments for Independent living while ensuring that the human rights angle remains paramount;
- the importance of the process of Independent living and making sure that people get the right support with their arrangements for Indicative living;
- the importance of self-assessment;
- the need to spread the concept world-wide, and the need to do this through a cellular approach, so that the idea is spread throughout society;
- a recognition of the danger of becoming too bureaucratic and professional and ensuring that the movements maintains its grassroots approach;
- the need to be responsible and take on the issues of Independent living by being part of the overall movement;
- the direction of the CIL movement, and particularly issues around finances;
- the importance of remaining political and making sure that the movement keeps its "bite";
- the need to raise the profile of the movement

A number of ideas about the way forward came out of these discussions:

1. Ensure that there are adequate resources for the Independent living movement and the whole disability movement to work collectively.
2. Ensure the inclusion of all people with disabilities - looking particularly at older people, people with learning difficulties, and people with mental health problems/survivors of the mental health system.
3. Develop local, national and international strategies.
4. Oppose all rationing and means testing of said.
5. Look at more international exchanges to enable people in different countries to learn from each other and share experiences.
6. To emphasise the ordinariness of our lives - "show that we are just ordinary people living ordinary lives. We are not special."

This was summed up saying that people just want, "the right to boldly go where everyone has gone before."

Main debate

After feedback from the workshops (detailed outlined above) the floor was opened up for comments, information and debate.

Kevin Mulhern set the ball rolling asking how disabled people in Eastern Europe perceived people in the West? Gordana Rakov answered that disabled people in the West are seen as very fortunate, and that when people from the East visit they often marvel at the equipment and support available. However, he did go on to point out that disabled people in East tend to forget that things in the West are only like this because people have pushed and fought for them for a long time.

Further discussion followed, covering:

- the disparity between support for Independent living available to disabled in different areas where local government administration within countries;
- the importance of Independent living continues to come up from the grassroots - the recent legislation for direct payments in the UK creates the possibility that it might be imposed on people;
- Independent living must be properly resourced and we need to address the arguments that there are not enough resources to fund support for disabled and older people.
- Independent living and direct payments schemes should not just be a way of reducing the costs of care;

There was particular discussion about how Independent living can be paid for. People argued that taxes need to be at an appropriate level to pay for support for disabled and older people, but the difficulty was

pointed out that in most cases people will vote for lower taxation at elections and that this constrains public finances and services.

It was suggested that part of the problem here is the lack of a framework of rights and that if such a framework were in place that funding would have to follow. It was that a framework such as this would need to be underpinned by a principle of universalism. In order to achieve this, we need to get beyond politicians and take our message to the wider public. (Jenny Morris)

One person identified the problem that the cost of issues such as support for disabled people are being highlighted more than those in other areas, such as road maintenance, and that this is part of the wider issue of disabled people not being valued in society. (Carl Ford)

Kevin Mulhern pointed to an opinion poll conducted for the Link television programme which showed how the public very clear ideas about there being disabled people who should be helped, but there is also a view that there are some people who are not in need of support - disabled people who are well off and people who are not "genuinely" disabled and are defrauding the system. He highlighted the problem of tackling these perceptions and the need to convince the public.

This problem was seen as happening in many parts of Europe, and that politicians and the media were presenting a very negative view of disabled people, and as a result the public is not getting a true picture of our lives.

Some people remained concerned that the public is not prepared to put adequate resources into benefits and support for disabled people. Others suggested we need to re-face the argument onto the cost of segregating disabled people, just as we have moved discussion of the medical model of disability to the social model.

This was picked up by another participant who pointed to the large amounts of money being spent on "care" that denies people their freedom, and we need to argue for support that frees and enables people.

Another person (Vic Finkelstein) highlighted the contradiction in public thinking which endorsed high levels of public spending on primary health care, but then was unhappy to pay the cost of supporting a person who had become disabled as a result of a health problem that is treated successfully.

The difficulty of changing this when disabled people are almost wholly excluded positions of power. There was some discussion about using the media, and the need to adopt shock tactics which we may not be entirely comfortable with.

Kevin Mulhern concluded the discussion by reinforcing the points made about increasing public awareness, and saying that there is still much to be done to achieve this.

Closing keynote speech: Crip Utopia or the end of the welfare state?

Adolf Ratzka, Institute on Independent Living, Sweden

Day Three

Making the dream a reality - action to follow up this event

Each participant was asked to come up with a short and a long term action.

These were listed:

- develop support and training programme for individual users - empower people at local level
- seek specific funds to develop European Network on Independent Living (ENIL) approved training
- review and renew the Strasbourg principles to mark their tenth anniversary
- ***** what's this*****

- develop a long term communication strategy
- start PA programme in Yugoslavia
- ENIL to network more with central and eastern European countries
- join/infiltrate employers' organisations, increase our strength
- create a training course for disabled people
- establish a CIL, with staff
- education - for disabled people, for families, for older disabled people
- alliance with older people
- influence the Royal Commission on Long-Term Care in the UK
- expand our numbers
- awareness raising
- anti discrimination law
- bring philosophy and practice about older disabled people together
- make Gerry's paper accessible and spread it about
- networking for CILs
- inclusion, equal opportunities
- damage limitation on law (Germany)
- more funds for PAs

- publicise IL - let more people know what it is make the case for funding and reallocating resources

Next we summarised this long list into topic headings: