

Independent Living

Towards the New Millennium

Chapter 1. Background

Any movement that speaks for its constituency with authenticity is bound to achieve some measure of success.

Success for a campaigning agency, by its nature, produces change. And that change in turn feeds into new issues. This dialectic of success and that change in turn feeds into new issues and themes which must be addressed for future success. This dialectic of success and change informs this review of the activities and perspectives of the Center for Independent Living in Ireland.

To measure success requires an evaluation of the circumstances out of which a movement has emerged. It needs to locate the aims and objectives and judge whether these have been reached in the opinions of activists, consumers and supporters alike. Disability has not traditionally been at the forefront of civil rights agitation in Ireland. Its position has been one of marginalisation and peripherality. Any successes achieved have to be set against the enormous organisational, financial and attitudinal barriers which existed from the outset.

Without doubt the activities of Center for Independent Living have produced significant successes. These can be seen in the enhanced conditions of living achieved for its members and for the wider community of those with disabilities. They can be seen in the network of CILs which now cover the state. They can be seen in the Personal Assistance Service (PAS) and the contribution it has made to quality of life. They can be seen in establishing an accessible transport system, Vantastic.

They can also be seen in the policies, projects and training articulated by philosophy and methods of independent living which have which attained currency within the mainstream and wider disability arena.

Success also has to be measured against change. Without doubt, the pace of change since the formal establishment of Center for Independent Living in 1992 has been breathtaking. Public discourse has increasingly been informed by an ever more trenchant focus equality. This has meant a re-examination of the importance of civil rights as the basis for participatory citizenship. In terms of service provision it has meant a stated commitment to mainstreaming to anchor these rights in practice. In terms of official response it has meant the transformation and restructuring of agencies and a redefinition of their remit. In terms of policy it has meant the formal recognition that the objects of activity can and must move to become the subjects.

These significant and far-reaching changes have not necessarily been matched by parallel changes in attitude and perception. There is evidence that many social responses to the experience of disability remain locked into approaches of, on the one hand, benevolent or paternalistic charity or, on the other hand ones of stubborn discrimination and exclusion.

The experience of many working in the disability-related sector is often one of deep frustration at the bureaucracy, delay and confusion resulting from these attitudes, organisational fragmentation and sheer lack of required financial resources.

CIL prides itself on the role it has played in enabling those with disabilities to take control of their own lives, to articulate their own needs and to exert their choices through the initiatives it spearheaded. It has pioneered efforts to work at community level and has not reluctant to build on these efforts to inform and influence national policy. CIL itself now confronting the implications of change and the lessons of its experience.

This is the basis for the current Review. Any organisation that has achieved or experienced so much in such a relatively short time deserves credit for taking time to reflect on its direction and evaluate the choices and decisions it has made. Reflection is the cornerstone of the learning organisation and act as guarantor that the original motivation is even when the external environment has altered profoundly.

This Review is also motivated by the desire to ensure that the structures, aims, methods and actions of CIL are still relevant to the community it serves at local, national and even international levels.

The Review understands that organisations change as much, if not more, than their external environment. Internal change has been a notable feature of CIL. It has grown in terms of membership. It has undertaken research and planning exercises. It has argued and debated in a developing environment where for the first time the state articulated a national agenda on the status of people with disabilities. It has grappled with financial challenges and uncertainties.

In 1994 the Center for Independent Living produced a five-year plan entitled *Partnership for Change*. It has now been deemed appropriate to undertake a comprehensive review of that plan, its activities and results. This Review is not merely a reflection on the past however. It looks firmly to the future, learning from the past, determined to carry forward what is best and to shed what is least effective. No approach to the future can have any long-term relevance unless there is a clear understanding of the lessons of past actions.

In that context CIL set out two aims as the terms of reference for this Review.

These are:

- To establish a benchmark to inform further growth of CIL into the new millennium.
- To open up a debate on the Independent Living movement in Ireland.

Benchmarking practice means establishment a standard point of reference. Standards became a notable feature of service provision in the area of disability throughout the nineties. Standards are central to establishing accountability. They are also vital in ensuring quality, ethical practises and relevance. It is good that CIL accepts the challenge of standards in determining what works best for its practice and direction. This also lends a significance

to the experience of disability in being able to inform the rest of society as to what is needed in ensuring transparency and professionalism.

The second dimension of standards in this context is in the stated aim to inform growth. This sets the tone for direction, leadership and responsibility. Leadership is an issue central to CIL. Leadership does not equate with authoritarianism or regimentation or control. Leadership is about taking ownership of an agenda which has purpose. From that refreshing perspective leadership is about managing change and facilitating diversity. Again the experience of disability offers abundant examples of difference and variety. Diversity provides an atmosphere for challenge and debate and mutual enrichment through the exchange of ideas. Without this being firmly grounded in the discourse there will simply be no growth – only a stagnant recapitulation of tired and dated standpoints.

The second aim flows from this and states boldly that CIL wishes to foster a debate in the wider Independent Living movement. Again, a richness of perspective is reflected. To its credit CIL has never maintained that it has a monopoly on truth. It has demonstrated throughout its history a capacity to hand over its initiatives to those it deems better equipped to attain the objectives. The fragmentation and disjointedness in the Irish disability field, however, can often be a source of despair to activists and utter confusion to those outside. Never more than the present time is a debate more necessary.

Methodology

This Review drew on the experiences and opinions of many in CIL and in the wider disability movement in Ireland and abroad. It was conducted using a variety of methods. These included:

- Primary source materials review
- Secondary source materials review
- Literature search and analysis
- Interviews
- Group discussions
- Structured questionnaire of CIL members

Particular appreciation is due to all respondents who gave their time and opinions and to all who completed the questionnaire. A special word of thanks is due to Ann McErlain for collating materials, Sinéad McCabe, Mary Keogh and ILCS for all their assistance and to Selina Bonnie for her organisational support.

A debate whose terms of reference are fixed by the needs of those with disabilities to live full and enriching lives independently is a debate that promises to be stimulating and informative for Irish society as a whole. It is a debate that should be characterised by passion as much as by courtesy as vested interests are challenged in the new agenda.

Success and change therefore inform this Review.

Chapter 2. Introduction

Independent Living in its broadest sense is about people with disabilities moving from positions where they are passive recipients of care to a point where they acquire rights of full participation and equality. This is done by people with disabilities themselves acting for their own interest, as their own motors of change.

This agenda is developing in an Ireland where the entire framework of disability has altered greatly in recent years (a process not totally unrelated to the actions of the Independent Living movement).

The social and economic framework of disability in Ireland in recent years has shown some, at first sight, very positive developments. These developments are based around legislation, politics, economics and a growing awareness of the need to address exclusion and marginalisation throughout Irish society. In a society like Ireland's, with such recent memories of underdevelopment, poverty and colonialism, there exists an openness towards and an identification with issues of "social exclusion". In a society experiencing such profound rates of change, however, many challenges and issues remain.

In 1996 the government-appointed Commission on the Status of People with Disabilities produced a major report with over 400 recommendations concerning policy changes that were required to improve the lives and opportunities of those with disabilities in Irish society. Following from this the government established the Irish Council of People with Disabilities – intended to be the first democratically elected, state sponsored representative body of people with disabilities in Europe with a direct input into policy formulation. This Council commenced its operations in 1997. In addition the government announced the establishment of a National Disability Authority (NDA) with a remit to set and monitor standards in disability service provision.

The NDA commences operations in early 2000.

In late 1995 the ESF Evaluation Unit of the Department of Enterprise and Employment published an evaluation report on the effectiveness of vocational training services for people with disabilities. This report was sharply critical of the over-reliance on European funding (i.e. the ESF) and the inadequate prioritisation of wider social needs by an excessive emphasis on vocational rehabilitation in the service delivery system. Partly as a result of this thinking, the Government has now moved to dissolve the National Rehabilitation Board and subsume its activities into mainstream bodies like FÁS and NSSB.

Equality legislation is now in place. Disability is now one of the nine identified areas against which it is illegal to discriminate. This association with other categories is very important. It locates disability politically and morally in the context of rights and routes of redress. It does this in the context of other groups that have historically experienced discrimination disability can increasingly be regarded within a civil rights context. While this insight had been central to the foundation and development has gone a long way towards challenging traditional concepts of charity and institutionalisation.

At a national level there is a new impetus around the re-structuring of services for people with disabilities. This is meant to alter the focus towards mainstreaming and the devolution of functions within relevant departments and statutory bodies.

Mainstreaming raises many issues and concerns. Many of these have been inadequately addressed, despite worthy intentions. These relate primarily to inclusion, the threat of assimilation and awareness that, for mainstreaming to work well, the direction of the mainstream itself must be altered by the very process of inclusion. Central to all this is the concept and practice of equality.

Government agencies and departments and service providers have attempted to pursue innovative programmes and methods to enhance the role of disability awareness and service provision in Irish life. This has entailed extensive use of European Union Community Initiative, supported employment strategies, local economic development partnerships, innovative training networks and employer based training projects.

Employers have also taken the initiative in their recruitment and staff training practice and procedures. This has resulted in codes of good practice for the inclusion of people with disabilities from both the employers' body (IBEC) and the trade unions (ICTU). At a time of unparalleled economic growth in Ireland there has emerged, for the first time in our history, a labour shortage. In place of traditionally high levels of emigration Ireland is now a net importer of labour. Clearly this should, in theory, produce significant opportunities for those with disabilities are worryingly and persistently high.

There remain however many problems and difficulties in the lived experience of people with disabilities. The Independent Living movement by its nature deals with these issues on an ongoing basis. These issues determine the contours of structures as well as the quality of outcomes for individuals at all points of the compass – socially, educationally, vocationally and personally.

In Irish society there has been a history of distinction by disability category. There has been a parallel fragmentation of many years standing in service provision. Unfortunately there has emerged a sense almost of competition between groups and organisation representing different disability categories or, in some cases, representing similar groups. This has been based on many factors including, understandably, the need for organisation to survive in financial restrictive environments.

Funding availability all too often determined what little policy there was. For example, in a context where limited funding was dispersed on the basis of numbers attending vocational

training centres, there was a strong disincentive to let “clients” go into mainstream employment or training services.

There is still a very high degree of “voluntarism” in this field. Essential services and supports are often only provided through voluntary groups or parental association. These groups are heavily dependent on fundraising or charitable donations as their main source of income.

The serious and negative legacy this is that is consequently presented in terms of dependency. This does little or nothing to advance the status and role of people with disabilities as key activists in their own destiny. It does nothing to instill in young people with disabilities the sense that they can aspire to independent decision making and choice rather than an expectation of lifetime care and dependence.

Often it is left to individual families to shoulder all responsibility. This acts to further marginalise the individuals concerned. Burdens of guilt, lack of information, lack of support to meet self-defined needs and inadequate professional guidance, counselling and peer support services are well-documented characteristics of the Irish system for many people with disabilities and their families.

Despite the recommendations of the Report of the Commission on the Status of People with Disabilities and the action indicators in the recent *Programme for Prosperity and Fairness*, there is still no overall national plan or strategy in this area. This can be both an opportunity and a threat for something like the Independent Living movement as it both pinpoints existing weaknesses but also highlights needs that can be met.

Comprehensive and informed research is almost completely lacking in the field of disability. There is, as result, little informed policy. The lack of qualitative and holistic research has hampered the ability to inform, identify and lead debate in a focused and meaningful way. Fragmented statistical analysis to satisfy funding criteria is not the same as research designed to enhance understanding of issues and needs and develop policy.

Professional development has also been inadequate to meet identified needs in a changing environment. Organisations of people with disabilities complain frequently that the model being offered is still a medicalised and hierarchic one with limited scope for social analysis or associated modes of response.

Professionally there continues to be a gap in terms of the lack of independent research and analysis institutes and inadequate specialised post graduate training in disability related studies. The necessary mechanism for the development of expertise and defined skills have been seriously inadequate. Often such training as has existed has been driven by the availability of funding, usually European Union, rather than seriously researched needs identified in and by the community of people with disabilities.

The emergence of a strong and vociferous Independent Living movement since 1992 has played an important part in addressing these serious issues in the community of disability. The agenda established around access (transport, housing, training, jobs, media), equality

(legislation and practice) and rights (Education, development, professionalism) is the platform for future actions.

All these issues form the backdrop for the emergence and agenda of the Center for Independent Living in Ireland. It has attempted to bring to the forefront self-identified needs which, in promoting equality of opportunity, at same time speak to the wider constituency of those affected by prejudice and discrimination in our society. CIL has gone on to articulate strategies and actions that have the potential to influence policy and practice. At a time when Ireland is witnessing the first disturbing signs of racism and intolerance towards ethnic minorities, this perspective could be invaluable.

Chapter 3. Independent Living Issues and Themes

The concept of independence is central to the value system of Western culture. It is rooted firmly in the sense of personal dignity and autonomy. Furthermore and more fundamentally it is concerned with the ability to exercise choice. The right to exercise choice may be viewed as one of the most basic of all human rights. It affords recognition to the reality of individual freedom and dignity.

Independence is also about choosing one's own relationship with a received environment. It entails the right to enter into or leave dependent relationships. It entails the right to access whatever resources necessary to exercise it is pointless. The denial of the practical exercise of choice was the origin of the campaigning which has led to the modern Independent Living movement.

Traditional responses to disability in western societies have been dominated by concepts of institutionalisation, care and control. This has meant:

- creating and maintaining systems that viewed and treated people with disabilities as passive objects
- regarding residence as institutional or in parental homes
- designing services on the basis of professional perceptions of other's needs
- using rehabilitation as a medical tool to "cure" not as mutual process to develop
- using concepts of charity and pity rather than concepts of equal participation and contribution.

The origin of disability related service system lies in the various rehabilitation models designed primarily to aid the return to work of disabled war veterans after the First World War. The provision of vocational rehabilitation services for disabled veterans soon led to belief that these services for disabled would be beneficial for all citizens. Efforts to provide

vocational rehabilitation services for civilians resulted in the United States in the enactment of the Vocational Rehabilitation Act of 1920.

This reflects the key role of the American experience in the origins of the independent living philosophy. It is characterised by:

- legislative underpinning
- vocational and occupational emphases
- extensive research
- evolution of a rights perspective.

After the Second World War the emphasis in the United States shifted to a more professional understanding of the role of rehabilitation and the enhancement of quality service provision. The dramatic breakthrough occurred in the 1960s when people with disabilities began to identify for themselves what their needs and expectations were. The Independent Living movement is rooted in the social upheavals of the 1960s. It identified with the struggles and methods of other disenfranchised groups. It absorbed ideas of reform from many sources including civil rights, consumerism, self-help, cooperativism, de-medicalisation and de-institutionalisation.

These movements helped people with disabilities increasingly to break through destructive and inhibiting barriers. They also helped to develop personal skills and a more positive self-image for those who had been isolated and repressed by society. Independent Living was thus nurtured by new and potent forces which challenged restriction and discrimination.

It must be remembered that the old model did not disappear overnight, even in the United States. As late as 1972 President Nixon vetoed legislation passed by Congress that was designed to move rehabilitation towards broader and more social roles. The reason for the veto was that legislation "strayed too far" from the essential vocational nature of the programme. By this time, people with disabilities were quite clear that life was about more than work and production.

The first definable independent living programmes had emerged in 1940s.

These are the early prototypes for modern independent living centres. In 1948 the University of Illinois at Urbana – Champaign developed a range of support services for students with disabilities (again, many were veterans of the war).

These services included accessible housing, transport, educational support, peer counselling, assistive devices and training in ADL (activities of daily living).

Independence in the Illinois model was defined as "the physical ability to live without assistance". The Beckwith Independent Living Center became the first specially designed housing resource on a campus in the world.

The social explosion of the 1960s and the emergence of a self-help and right agenda spurred the second wave of independent living movement. These grass roots initiatives differed from the Illinois model in that they:

- catered for others than university students
- were developed and controlled by people with disabilities themselves
- viewed independence as control and not just physical self-sufficiency.

The first Independent Living Center to be initiated, staffed and operated primarily by people with disabilities themselves was that in Berkley, California in 1972. It was followed by Access Independent Living in Chicago in 1974. Today there are hundreds of independent living centres in the United States and the movement has spread to other countries to become a worldwide phenomenon, Ireland is part of that movement.

The issues and themes central to the philosophy of independent living are connected with rights as well as choice.

This gives it a broad social and civil rights thrust that draws enormous strength from the fact that it represents all people with disabilities. For members of that disability community, independent living means the ability to participate fully in society. This means the ability to work, to have a career, to have relationships, to travel, to partake and to contribute in the same way as any other citizen, no more and no less.

None of this can occur if the individual is physically isolated from the wider community or confined without choice in an institution. None of this can occur if the individual is prevented from communicating or learning through segregation or “special” facilities. None of this can occur if basic human rights are denied.

The philosophy of the contemporary independent living movement is based on four elementary assumptions. There:

- all human life is of value
- anyone, whatever the impairment, is capable of exerting choice
- people who are disabled by society’s reaction to impairment have the right to assert control over their own lives
- people with disabilities have the right to participate fully in society.

The Independent Living movement has developed greatly in recent years. This is evidenced not only by its international presence. It is also seen in its ability to articulate a legal and rights agenda in the countries where it is active. It has been able to develop policies and actions designed to produce change and improvement at all levels of social interaction. This process has been uneven and it differs from country to country. Even in countries where significant legislative advances have been made (as in the United States with the Americans

with Disabilities Act) there is an evidence of widespread social and bureaucratic resistance and an often maddeningly slow rate of real change.

People with disabilities in general and the Independent Living movement in particular have discovered that legislation, even significant legislation, does not achieve the immediate social justice which translates into acceptance and integration. The reality is that attitudinal and social and economic change takes much longer than enacting a legal document.

Internationally people with disabilities still find themselves victimised by long-standing and traditional social, psychological, physical, fiscal, architectural and political barriers. All of these are inhibitors to acceptance and participation in mainstream society. This is in spite of the significant changes in quality of life and integration that have happened in some countries.

A significant barrier is the concept of cost-effectiveness or fiscal responsibility. People with disabilities, like so many discriminated groups before them, are often advised a counselled to wait until the “time is politically and financially right”. If disadvantaged groups waited for balanced budgets and ideal socio – economic circumstances, no social change would ever take place.

Any group striving for equality must achieve power. If choice is the foundation of the independent living movement it must be borne in mind that choice without power be mere tokenism. With acquisition of power disadvantaged groups can begin the process of seeking enactment of legislation which produces change.

But legislation alone leaves much to be fought for. There are still many barriers and myths to overcome. Disadvantaged minorities with limited power often discover that social justice and difficult to achieve. Those who are powerless through physical or environmental circumstances have no control over their destinies. Independent Living is at cutting edge of addressing this question of powerlessness of the community of people with disabilities.

Its orientation is increasingly towards an analysis of what can be achieved in producing viable change for and by people with disabilities themselves. It seeks to confront the issue of empowerment through self-help, autonomy, strategic activity, advanced education and the strongest possible levels of communication and networking.

Independent Living movements have been able to think and act globally. The diversity of the experience of disability is enriched by the enriched by the international nature of the challenge facing the community of people with disabilities in achieving integration, rights and equal participation. This has meant an ability to begin to define best practice to share methodologies and to develop consumer defined standards against which legislation or policy can be meaningfully judged to see whether real needs are met.

Independent Living has evolved away from the more basic principle of living independently. It puts the consumer at the centre of the process of personal and social rights. In this context the concepts of change, choice and power acquire real meaning.

The present Independent Living movement has given a voice to those with disabilities who wish to not only play a part in their societies but who also wish to set standards for inclusion

and advancement for all disadvantaged groups. It has highlighted the commonality of purpose of those who are discriminated against.

In Ireland the Independent Living movement has been able to define itself in 1996 as a movement in which:

- People with disabilities are active and independent and perceived as a movement that is dynamic, change-focused and single-minded.
- We are lobbying for services which enable us to live as equals in the community, rather than being dependent on families and institutions.
- We decide what is best for us, i.e. as people with disabilities we have the closest possible experience of our own and therefore the only real experts at designing services to meet our needs.
- The focus is on rehabilitating society and making it accessible to us. We accept that our disabilities are part of what we are and therefore our work is concerned with creating inclusion in education, employment, social and community life, housing and transport.
- We are coming to be regarded as subjects who know what we want and actively engaged in pursuing our goals.

This perspective grows out of the worldwide independent living movement. It also reflects the conditions and circumstances unique to Ireland. It should be remembered that the international disability agenda is not a static one. Change is pervasive in all countries and this Review reflects the sense of mission and purpose which underlines that reality.

In Europe there is a wide variation in national policies in relation to disability and significantly different emphases in legislation, policy and attitudes. Institutionalisation and medicalisation, far from being rare, are in some countries the norm. The experience of the European Union in the field of disability has echoed the earlier one of the United States where primacy has been given to the vocational rehabilitation direction. The disability movement in Europe is still awaiting a common charter of rights and an agenda for action at Union level concerned with quality of choice and not merely improved skills training.

The European Network on Independent Living (ENIL) was founded in 1989. It has served as a connecting point for many European activists in the Independent Living field to debate, to promote initiatives and to strengthen structures. ENIL is an active member of the European Disability Forum.

ENIL has the following objectives:

- To pioneer, promote and develop the framework and practice of Independent Living
- To develop and strengthen a network of European Centers for Independent Living and Independent Living practitioners
- To provide training, advice and support for independent Living/Direct Payment schemes.

One of the foremost European activists in the field of Independent Living, Adolph Ratzka sums up this strategic direction in his definition of Independent Living:

The right of all persons regardless of age type or extent of disability to live in the community, as opposed to living in an institution; have the same range of choices as everyone else in housing, transport, education and employment ; participate in the social, economic and political life of their communities ; have a family ; live as responsible respected members of their communities, with all duties and privileges that this entails; and unfold their potential.

In the United States also the Independent Living movement continues to build on the success established by the Americans with Disabilities Acts. It has vigorously pursued a self-help agenda and has been able to secure significant Federal Funding to provide direct services relevant to the community it represents.

Alliances of Centers for Independent Living exist in each State and act at Federal level to pool their knowledge and experiences. Many of the services developed are practical and focused. But the wider strategic agenda has not been overlooked.

Many Independent Living activists in the United States are also aware of the need to link with the social and political realities of the communities in which they live and where disability is an integral part of deprivation and injustice. This orientation means developing a response to the problems caused for racial and ethnic minorities in inner city environments. It also means engaging with the staggering rates of incarceration. In Chicago alone 60% of prisoners have some form of mental health disability. It means advancing an Independent Living agenda in an environment where public housing, public transport and public health services are, by European standards, non-existent or woefully inadequate.

A sense of the policy direction involved can be gathered from the new Mission Statement of Access Living Chicago, the second oldest Independent living centre in the United States, which was adopted in 1998:

Access Living is a cross-disability organisation governed and staffed by a majority of people with disabilities. Access Living fosters the dignity, pride and self-esteem of people with disabilities and enhances the options open to them so they may choose and maintain individualised and satisfying lifestyles. Access Living recognises the innate rights, abilities needs and diversity of people with disabilities, works towards their integration into community life and serves as an agent of social change.

Access living's work focuses on peer-orientated independent living services; community outreach and education; policy analysis and advocacy; and community organising, covering the critical areas of housing, health care reform and personal assistance, youth, civil rights and empowerment zone. Additionally, Access Living provides information and referral to thousands of people annually.

This mission statement reflects the evolution of the Independent Living movement into community concerns where the experience of disability leads activism and does not merely follow. It speaks from the lived experience of its members but does not shrink from an engagement with the wider community of the oppressed and disadvantaged.

In one of its phrases, Access Living's statement describes the organisation as "an agent of social change". The ability to develop from the particular to the general gives a new focus for the direction of themes and issues for the Independent Living in the future. This unapologetic stance of acting for social change speaks of a mature engagement with the wider environment where results and rights are expected – not merely official platitude and legislative niceties.

To embark upon an agenda of social change also imposes responsibilities for any movement. In addition to commitment, it demands professionalism, expertise, networking and above all an agreed focus on what has to be changed and how a why. This Review occurs at a point when the Center for Independent Living in Ireland is posed with the same choice.

Chapter 4. CIL Achievements & Policy

The Center for Independent Living in Ireland was established in 1992 with the specific goal of ensuring that people with disabilities could achieve independent living and full participation in society. CIL was established by a core group of individuals, between them, had extensive experience of the issues connected with institutionalisation, segregated care and the medical model of intervention.

Much of the understanding around the Independent Living movement had been gained from exposure to programmes and projects in both Europe and the United States. Members of the core group had carried out extensive research into background of Independent Living as a model. Several had been on study and exchange visits to similar initiatives. There was a displayed openness to importing knowledge and expertise. These early international influences were to be a marked feature throughout the development of the Center for Independent Living.

This core group of individuals had identified key gaps in service provision. These impacted directly on the ability of people with disabilities to live the life of their choice as free as possible from external intervention. A particular focus was placed on gaps in the area of personal assistance, housing and transport and mobility. Service provision had largely failed, in the opinion of the founding members of CIL, to address adequately the needs of people

with disabilities to lives of their choosing, independently and as full participants in social and economic life.

Respondents have identified many reasons for this. In the opinions of some, the attitudes of charity and care which were felt to characterise much of Irish service provision, simply could not assimilate the demand for and attractiveness of independent living philosophy.

For others a medical approach to diagnosis and cure had dominated their experience of disability service provision and /or rehabilitation interventions.

For others it was a question of financial resources being heavily concentrated in areas that were not immediately relevant to the establishment and maintenance of Independent Living approaches.

Most respondents had had negative experience dealing with official services. Most strongly felt that professionals and officials overlooked their needs, opinions and experiences. A recurring issue was the unease experienced in having experienced in having able-bodied professionals deciding what was best for individuals with disabilities and how needs should be met. Respondents confirm that the strong perception was that this paradigm should be reversed to the point where people with disabilities themselves should be regarded as the experts, defining their own needs and wants, and the process controlling and managing the services being provided.

This group saw itself as a grassroots, self-help movement. It is clear that the fragmentation in Irish service provision described earlier had contributed to some degree to these perceptions. It is also clear that the Department of Health in general and many Health Boards in particular had no consistent policy on Independent Living and had no strategic plan to address the concerns the Independent Living movement was voicing.

Over the years CIL has developed many programmes and initiatives. It has also engaged in extensive lobbying, consultation and interventions regarding the entire field of disability and independent living. It has produced research, evaluations, submissions and studies to advance its broad agenda. It has also engaged in direct actions to highlight discrimination and inequality. This extensive range of activity has occurred at same time as CIL has attempted to build its own organisational base, develop its national network and operate within a dynamic international environment.

This work agenda would be pushing at the best of times. It must be remembered that for substantial periods of the last eight years funding was by no means certain nor were the resources to keep providing the results deemed necessary to maintain the momentum in independent living. It is to the credit of CIL that despite this it always prioritised the need for parallel training and development.

An independent living agenda has now emerged into mainstream disability discourse. This is partly due to the sole activities and programmes of CIL. It also due to the fact that parallel to the developmental actions of CIL, developments in the wider Irish disability context were acknowledging the importance of the issues first raised by CIL.

From the outset CIL located its activities in the context of seeing disability as a rights and investment issue to enable disabled people to have the same opportunities to participate as their non- disabled peers. This meant that in addition to identified rights issue, CIL kept to the forefront considerations around cost- effectiveness, affordability and quality in service standards. This allowed a strong partnership element to be built into actions and strategy.

CIL members played a significant part also in the deliberations of the Commission on the Status of People with Disabilities. CIL developed links and working partnerships with government departments (in particular the Departments of Justice, Equality, and Law Reform; Health and Children; Social, Community and Family Affairs), FAS, NRB, service providers, community groups and academic bodies.

The extensive range of actions of CIL can roughly be divided into two phases. The first may be termed the developmental phase. This lasted from 1992 to 1994. It was primarily centred on the INCARE action research project and a series of policy and training developments.

In November 1994, CIL produced a five year plan, Partnership for Change: a strategy for rolling back dependency. Covering the period from 1994 to 1999 its scope and actions are now being reviewed.

Developmental phase

(1992-94)

The purpose of the INCARE action research programme was to promote and develop the concept of independent living for people with significant physical disabilities and, in particular, to research, design and implement programmes aimed at:

- * Providing a range of appropriate Personal Assistance services (PAS)
- * Educating both Leaders (Participants with physical disabilities) and Personal Assistants (PA) in the acquisition of positive attitudes and skills pertinent to the realisation of efficient services in this area.

The programme, funded under the European Union Horizon Community Initiative, commenced in December 1992. It involved 29 leaders and 45 personal assistants. The programme aimed, for the first time in Ireland, to develop a range of personal assistance services managed and controlled by people with disabilities. It also sought to ensure that personal assistants were themselves educated and trained in the skills, knowledge and attitudes required to provide a professional Personal Assistance service.

The Final Evaluation conducted on this project in 1994 highlighted a number of benefits and results. These were:

- The positive effect on individuals being able, for the first time, to take control of their own lives and exercise choice
- Ending of dependence and ability to see independent living as right not a privilege.
- Enhanced social participation and involvement.
- Improvement in education (27.5% were able to use the PAS to attend college).
- Improvement in training options (18% were able to avail of further training).
- Improvement in employment access and conditions (50% noted enhanced employment options as a result of the project).
- Improved subjective sense of awareness and empowerment.
- Development of knowledge and skills.

There is no doubt that this project made an important impact in the quality of life for those participants with disabilities. It also provided training and employment opportunities for the Personal Assistants – as well as providing professional training and skills in this new field. At wider level the project indicated the potential for development and expansion of the concept and practice of independent living. The improvement in opportunity offered by this initiative would resonate in CIL and provided the foundation for much later progress.

As in any project, difficulties and problems were also identified. The Final Evaluation summarises these as :

- Lack of knowledge and experience about independent living among leaders and resultant lack of confidence and familiarity with responsibilities involved.
- Compatibility and personality clashes in finding the right Personal Assistant.
- Financial and training restrictions.
- Insecurity about the future.

Many these issues were addressed during the course of the project. The development of peer consultancy, networking and communication structures and the establishment of a Training Advisory Group in March 1994 to monitor the quality and process of relevant training were measures which, in part, addressed these difficulties.

The INCARE action research programme was a major intervention for the new Center for Independent Living. It played a vital role in developing skills. It also enabled expertise to develop and for needs to be more clearly addressed. It raised many associated issues around organisational resources, administration, project management skills and strategic planning.

In addition to the enhancement of quality of life, INCARE enabled a substantial degree of networking to occur with other agencies and organisations. Among the agencies the link with FÁS was of particular importance as it focused on the partial funding of the initiative, it also opened the possibility to avail of the Community Employment Scheme for future training and capacity building actions. The positive role of FÁS in this regard has always been important to acknowledge for CIL.

Associated activities during this phase centred on organisational development, training lobbying and the development of international links. Promoting a training agenda has been one of the prime actions designated by the Center for Independent Living. A fundamental principle of Independent Living must be the understanding of the responsibility and requirements that go with being involved in the movement. From the outset, therefore, training of leaders and Personal Assistants was a priority for CIL.

A requirement of the Horizon programme was that certain levels of training had to be attained on the INCARE project. The training was designed to cover topics such as :

- The philosophy of independent living
- Personal Care
- Disability equality.

Leaders were also trained to enable them to understand their roles as employers when working with Personal Assistants.

Parallel training was also provided for Personal Assistants.

As a general point, CIL linked the training activities to the general empowerment of people with disabilities. A key point in this was to ensure that experienced trainers with disabilities be employed to develop and deliver the requisite training programmes. CIL training programmes were designed to provide the basis for models of good practice for the involvement of people with disabilities at all levels.

This emphasised the general principle, evident from the start of CIL's organised activities in Ireland, that a positive image for people with disabilities would be achieved through people with disabilities playing pivotal roles in training.

During the developmental phase considerable effort went into identifying areas for future action and intervention. Transport, national expansion, lobbying and housing all received

considerable attention. Extensive discussion and debate supplemented this effort. It led to the development of the five-year strategic plan in November 1994.

By the end of the Developmental Phase it is clear that significant progress had been made in identifying and addressing the key issue that affected the participation and quality of life for people with disabilities in Irish society. All respondents confirm that the concrete achievements gave validity to the agenda that had been sketched out in 1992. The experience of developing training and new resource in Personal Assistance Services was seen to work by producing pronounced change in the circumstances of participants.

At another level, respondents drew attention to the emotional aspect for people who had emerged from frequently lengthy periods of segregation and institutionalisation, often in sheltered residential care settings. They had now discovered themselves being able to work together as a group while at same time experiencing what, for some, were often dramatic improvements in levels of personal confidence. This experience forged personal and social links which went into the development of a new leadership layer. That this had been achieved by people with disabilities acting on their own behalf is significant and valuable outcome.

Some respondents found this to be a very exciting development in the early days of Center for Independent Living. This is because, from their perspective, it was the clearest demonstration of what is possible. It was a clear response to needs. This is one of the last achievements of Developmental Phase and the lessons learnt were on the Strategic Plan for the next five years.

The Five Year Plan (1994-99)

The Five – Year Plan, launched in November 1994 was entitled Partnership for Change : A strategy for rolling back dependency. This was designed to be a comprehensive work programme for the following five years. It was designed to develop work activities that would do the following :

- * To influence policy makers at all levels of government
- * To raise public awareness
- * To make use of the wide range of valuable experience and knowledge that people with disabilities have to contribute in a new established partnership with government.

The programme was different in that it proposed an imaginative and exciting range of projects while at the same time taking into account funding sources as well as quality and cost benefits. It openly acknowledged that "disability is an industry "and it advocated a similar business like approach by CIL.

While the trust was very much towards meeting the needs of people with disabilities by building on and extending the activities of the Developmental Phase, it is evident that an orientation towards government was envisaged – in promoting partnership, making the widest possible impact and influencing policy. This needs to be seen against the backdrop of the activities on disability at the time when the process of discussion and debate that led to the Report of the Commission on the Status of People with Disabilities was happening.

CIL would seem to have been fully conscious of this environment and the proposed activities reflect a sense of strategic policy direction as well as practical and achievable targets. Clearly given the resources some of the proposed activities may seem very ambitious. As in so many areas of Irish disability policy and action, the plans were hampered by a lack of comprehensive research or sometimes even primary data on which to base assessment of need. The lived experience of CIL members and the lessons of earlier actions provided a valid starting point however.

The Plan identified eight areas of proposed activity. This Review will describe each of the areas, describe the targets and reflect the opinions, evidence and experience which outline the attainment or otherwise of these goals.

INCARE Beyond 94

This project was concerned with ensuring that the participating leaders would continue to avail of Personal Assistance Services after the Horizon pilot project ended. This was clearly a priority for the individuals concerned. It was planned that the initiative would be mainstreamed and that, for a budgeted amount, the following results would be achieved:

- 50 Personal Assistants
- One Leader Training Co-ordinator
- One PA Training Co-ordinator.

In fact the programme continued and was funded through a number of sources, particularly the FÁS Job Training Scheme.

Core funding was also obtained from the then Department of Health following the recommendations of the PA Advisory Group in March 1995. As CIL had decided it did not wish to adopt a service provider role, the INCARE programme was subsequently transferred to the Irish Wheelchair Association in October 1995 with funding provided by the Eastern Health Board. The Irish Wheelchair Association continues to operate this programme.

In this sense, a key objective of the plan was realised. The training component of the original INCARE project took a slightly different route. With financial assistance from European Social Fund a Diploma in Disability Studies course was developed in association with the then National College of Industrial Relations (now National College of Ireland). This course operated for one year. After 1996 various discussions took place regarding the possibility of continuing or re-commencing the programme but this has not been achieved.

The course produced definite benefit for participants who found the materials, methods and certification useful. It also provided experience to CIL on the modalities of educational and training programme development which may prove useful in the future. It also demonstrated the need to develop a professional and methodical approach to joint project work with educational institutions. The need for capacity building in this area was recognised as the potential benefits to students from appropriately designed, resourced and managed courses can be considerable.

Community Employment/Expanding INCARE

The success of INCARE prompted considerable interest in extending Personal Assistance Services to the rest of the country. This was to meet identified needs. It also served to give CIL a profile at a more national level. The development of personal assistance services was linked to use of the FÁS Community Employment Schemes. The CIL relationship with FÁS had been established during the Horizon INCARE project. Specific FÁS certified training had been given – with first group of Pas receiving their certificates in August 1994.

The plan was to establish a national presence by utilising these schemes. At the start of the plan, applications had been made in eleven centres with plans for ten more by early 1995. In addition to PAs it was planned to recruit supervisors, research officers, Leader Co-ordinators and administrators in each centre.

By the end of 1995 there were centres in operation (Dublin 7, Blanchardstown, Letterkenny, Mayo, Galway, Clare, Thurles, Tullamore, Waterford and Cavan). By the end of 1996 eight more CILs had opened. Today there are 26 Centers for Independent Living in the Republic. Establishment of these was assisted by a Mobile Support Team that was set up by CIL in January 1996. This provided back up and assistance as required.

A key development in 1996 was the setting up of Independent Living Community Services Ltd. This a joint venture with the Rehab Group. ILCS is a service provider which supplies training and expertise in management, staff training, operational skills, efficiency and administration to customers in the independent living field.

The objectives of ILCS Ltd. included:

- Provision of support, training and certification for Leaders and Personal Assistants
- Implementation of financial structures and procedures
- Maintenance of monthly management accounts for all CE schemes
- Development of business plan
- Annual budgets
- Relevant project development focusing on independent Living and community inclusion.

The expansion aspect of the plan can be said to have met its objectives. The fact that CIL has a national presence must be regarded as a positive achievement.

Individual centres have tended to develop their own particular levels of expertise and interest depending on circumstances and needs in the area. While there is now a definite network, it cannot be said that there is uniformity. Respondents confirm that there is ongoing debate about this.

Some would prefer to see a more standardised national system and structure for CILs. Others tend to feel that it should be a loose network of autonomous groups responding to conditions and issues as they arise in localities.

It is clear from respondents' comments that much remains to be done in discussing, debating and agreeing a strategic direction for future national development. While some have felt that expansion has been too ad hoc and, at times, crisis driven others point to the need to allow for diversity and flexibility. Contained within this discussion is clear evidence of substantial divergence between viewpoints in Dublin and "the rest" of the country.

Many Dublin respondents felt that attitude of regional CILs was almost exclusively towards personal assistance and needs more strategic direction. On the other hand many regional CILs expressed reservations about centralisation.

It needs to be emphasised that many CILs, while operating FÁS Community Employment Schemes for Personal Assistance Services, are also operating in at times significantly different environments vis a vis local Health Boards and authorities. National expansion of a coordinated and effective presence for CIL will require substantial debate around these concerns.

Transport

In the Five – Year Plan it was proposed that CIL would seek the creation of a subsidised accessible transport service for people with disabilities to meet their current transport requirements. This was envisaged as no more than stopgap until a comprehensive accessible transport system was introduced. The plan centred on the development of “Vantastic” – a co - operative to provide transport for people with disabilities in the Dublin area.

It was planned to purchase 20 vans which would be operated on a shift basis daily. The service would operate within a 20 mile radius of the GPO and staffing would include radio controllers, a training officer, drivers, accounts administrator and a general manager.

The advantages and benefits of this were defined as follows :

- Use of specially designed vehicles for people with disabilities
- Regular booking facility
- Advance booking facility
- Tourism opportunities
- Cross disability benefits

Transport is evidently of prime importance to people with physical disabilities. Ireland has lagged behind many European countries in the provision of planned, low - cost and efficient public transport. This is even more marked in the provision of transport for people with disabilities or impaired mobility. CIL addressed its transport initiative plans to both long and short-term objectives.

In a long-term context CIL lobbied – and continues to lobby – for the provision of a fully accessible transport system for the entire country. In June 1995 it staged an Action Day on accessible transport outside Dáil Eireann. In November 1995 CIL hosted a conference on public transport, All Aboard – Equal Access to Opportunity.

In a short-term context, Vantastic was operating two vans in Dublin by early 1995. Demand was consistent and CIL carried out additional feasibility studies in association with SIPTU and the Co-operative Development Unit of FÁS. The FÁS Community Employment Scheme also provided the funding for the drivers.

CIL continued the process of working closely with CIE on the question of accessible transport. Vantastic continues to operate in Dublin as an independent company. The transport issue is central to CIL’s strategic outlook. Most respondents confirm the sense that CIL has achieved much by providing initiatives and actions to keep accessible transport to the forefront of the agenda.

Most also confirm the sense that transport is a vast area with national implications that will continue to need to be addressed directly in the years to come.

There is an acceptance in many respondents' views that circumstances regarding accessible transport have improved in recent years with CIE taking on board many concerns. Many however are frustrated at the pace of progress.

Leader Training

- Phase 2

Building on the lesson of the Horizon INCARE project, CIL was conscious in the 1994 Plan to address the continuing training needs of leaders and others with disability. To this end INCARE Leaders designed a follow – on training course in partnership with (what is now) the National College of Ireland. This was designed to lead to a Certificate in Disability Studies. This course was to be designed, managed and controlled by people with disabilities themselves.

The rationale for such a venture was that it was felt that many existing courses were unsuitable or irrelevant for people with disabilities. Furthermore, it was recognised that a certified course was needed to open many more educational opportunities for people with disabilities.

Participant funding was made available under the auspices of the European Social Fund. Although not formally stated in the Plan, it was expected that further training course developments might flow from this initiative.

The course ran from 1995 to 1996. Withdrawal of Personal Assistants from the NCI students in February 1996 and associated financial issue have not made it possible to continue this Course. Negotiations and discussions have continued over the years. Various options regarding course delivery have been looked at including off-site learning and distance learning.

The recognised need for training, and hunger for further education are almost universal elements in responses to this Review. The need for updated training, enhanced skills and competencies, relevant and applicable research skills are all seen as central to that process of personal growth and self - confidence valued so much by people with disabilities. Qualifications and certification are also seen as a central to that process valued so much by people with disabilities.

Horizon 2

CIL in the 1994 Plan identified enormous potential for the training and employment of people with a disability in the disability industry. It was felt that the expertise available was an untapped resource which could be enhanced and used to a fuller extent.

CIL therefore decided to submit project proposal under the next round of Horizon Community initiative funding for the development of a training programme that had two aims. These were:

- To train people with disabilities as consultants in the field of disability, especially in the disability industry, leading to the establishment of a co-operative consultancy business.
- To train people with disabilities as 'service brokers'.

The project submissions to Horizon were not successful. Thus the targets established in the Plan were not met.

As a result of the thinking and planning around these issues, however, joint independent living partnerships and advisory and consultancy programmes were developed. These included programmes with the Chesire Home, Dublin City University Accommodation Office and Roscommon Support Group.

The issue of project based responses as a future direction for CIL was raised by several respondents in the course of this Review. This requires a fundamental orientation in thinking towards development of community resources, analysis of strategic needs and possibilities for service provision. In any orientation to project work it must be borne in mind that specific skills are required. In addition, the traditional route of EU funding has seen the criteria and objectives change profoundly in recent years. Many respondents acknowledge that significant thought will need to be given to this area if future initiatives are realistically to be entertained.

International Affairs

Emerging within the international debate around rights and inclusion, particularly within the United States, it is no accident that the United States, it is no accident that the Center for Independent Living has from the outset attempted to think in international terms. CIL has openly acknowledged its debt to the dynamism and proactive position of American Independent Living movement. It has also been influenced by and participated in European forums on independent living and disability rights.

This international perspective was addressed in the 1994 Plan. Here it was stated that CIL recognised the importance and need for international co-operation in the fields of independent living and disability. Valuing the knowledge obtained from international contacts, CIL established an International Working Group on Disability (IWGD). This was charged with accelerating progress in the area and also to secure legislative change and rights. It organised around four identified areas:

- Legislation
- European Affairs
- Exchange programmes

- Symposium organisation

Two other key priorities were defined as:

- The establishment of a European Centre of Excellence on Disability Studies (ECEDS)
- Contact with East and Central European counterparts.

In March 1995 CIL organised and hosted a major conference in Dublin, Disability: Investment not Burden. Over 70 delegates from Europe and United States discussed central issues around the experience of independent living and the wider international context.

The symposium stressed an investment approach to people with disability rather than a “burden” approach. The symposium is regarded by many respondents as one of the highlights of CIL’s international activities. It received extensive media coverage and attention. The main points of the Resolution adopted at the symposium were:

- Recognition and appropriate funding for the European Network on Independent Living (ENIL) as the representative of CILs.
- Establishment of a European Centre of Excellence on Disability Studies run and controlled by people with disabilities to research and evaluate policies and practices.
- Introduction of a non – discrimination clause into appropriate legislation on the grounds of disability by national governments and European Union institutions.

CIL continued to attend conferences, to visit other models of good and to host visiting delegations. In November 1996, together with ENIL, it hosted a Direct Payments Expert meeting in Portlaoise. This again paid attention to themes of non – discrimination, direct payments systems and standards and the on going plans for the establishment of a European Centre for Excellence on Disability Studies (ECEDS).

International contacts have been maintained over the years. There has been networking and co-operation with agencies like MDI, DPI and Mobility International. Key projects like ECEDS have not, however, come to fruition. Concrete results from international co-operation have further failed to develop because of the lack of success in obtaining funding under various EU innovative projects schemes.

Many respondents in this Review confirm a continuing awareness of importance of solid and focused international activities and links. It would seem that many of these links are seen to be established on a personal or ad hoc basis and in the opinion of some lack a coherent strategic orientation. Lack of formal structural relations with independent living agencies and networks in the United States is mentioned particularly. Programmes for exchange and study are mentioned by many as examples of activities upon which CIL could concentrate.

It is recognised that in a time of national structural change and with priorities oriented toward securing core funding international activities may appear as a luxury.

Disability, like other social and economic issues, is however a global issue. In terms of determining legislative best practice, accessing expertise and learning from rights driven models an international network is both dynamic and efficacious.

Many respondents mentioned the need to develop a structured plan of work in this area so as to avoid over- stretching in the years ahead.

Housing

The right to live independently is severely curtailed if a person cannot secure a home. This factor has been to the forefront of the independent living movement in Ireland as it looked at the agenda to secure rights for people with disabilities.

The option of either having to live with parents (or siblings) or to move to residential care is hardly an empowering choice. CIL therefore proposed in the 1994 Plan a housing initiative.

This was to develop inclusion for people with disabilities in the Shared Housing Scheme so that people could secure community - based housing adapted to their needs. In 1994 a company called INHOUSE had been established to actively promote the provision and availability of accessible housing for people with disabilities. Its motto was "Housing for all, housing for life ".

Although the need is great and widely recognised, housing is an area where the aims and objectives of CIL's 1994 Plan have largely failed to be achieved. As is well known the housing market in Ireland in general and Dublin in particular has become almost to enter for many people. Escalating costs and inadequate public transport have made this a central issue in Irish social and economic debate. For any group to begin to address the issue of housing would be a daunting task. For CIL it has proved difficult to make a lot headway in this area. Many respondents feel a degree of frustration with this lack of success. Again it puts the focus on setting realistic and attainable targets throughout the strategic planning process.

