

“Nothing About Us, Without Us”

Evaluation of the INCARE Personal  
Assistance Service Programme

Final Report

Gráinne McGettrick Centre for  
Independent Living

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“If you have come to help me, then you can go back home. But if you see my struggle as part of your own survival, then perhaps we can work together.” (Coalition, September, 1992: 2)

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## **FOREWORD**

I wish to convey my congratulations and best wishes to all involved in the Establishment and work of the Centre for Independent Living. Run by people with disabilities for people with disabilities, INCARE has given an outstanding example. You have created opportunities for people with disabilities to manage their own affairs and look after themselves through your personal assistant scheme. This is an innovative scheme which provides independence for people with disabilities and very worthwhile jobs for people who were unemployed. I am delighted to have been able to provide practical assistance as Minister for Social Welfare to make this programme possible and help secure its future. The creation of opportunities such as this for people with disabilities will vastly improve their quality of life. With the help of a personal assistant they can look forward to becoming more active and independent participators in society. You have also made a great difference to many unemployed people, by providing them with training which will improve their long term career prospects. I am delighted to be associated with this excellent and timely report which INCARE has produced.

DR. MICHAEL WOODS, T.D., Minister for Social Welfare

## **1. INTRODUCTION AND BACKGROUND**

### **1.1 Aims of the Report**

The report aims to describe and analyse, using the independent living paradigm as the framework of analysis, the Center for Independent Living's INCARE programme, its impact at various levels and the extent to which the programme has achieved its aim -the development of a consumer controlled Personal Assistance Service (PAS) to enable people with physical disabilities to achieve independent living. It aims also to compare what life was like without and with the personal assistance service - "the before and after" scenarios.

Furthermore, it explores the role of the Personal Assistant (P A) and his/her contribution to the achievement of the programme's ultimate aim. At the outset, the report places the INCARE Action-Research Programme in the overall context of the independent living movement and the independent living philosophy. It describes the action and training aspects of the programme and outlines the research methodologies used in the evaluation. Finally, the report examines the limiting factors and disadvantages, the future prospects and contains a set of recommendations for future action.

### **1.2 Overall Context of the Research**

In order to understand the research it is necessary to provide a backdrop to the research by placing it in the overall context of the independent living movement, the philosophy of independent living and the theoretical framework adopted for the analysis. By tracing the origins and the development of the independent living movement, it clearly illustrates how it has evolved from a social movement, with a distinct constituency and history to become a concrete analytic paradigm, redirecting the course of disability policy, practice and research. The importance and relevance of the independent living paradigm to the present research is noted.

### **1.3 The Independent living Movement - Origins and Development**

"No one can stop an idea whose time has come " (Disabled People's International, 1991)

Independent living is an idea whose time has come. All over the world, people with disabilities are themselves acting as catalysts of change. The desire to no longer remain as passive recipients of care has resulted in their struggle to acquire new rights to achieve full participation and to demand equality with their fellow citizens. The struggle referred to as "the last civil rights movement" (Dreidgner, 1989 :3) comes after a long series of movements for rights -labour, black people, women, and now people with disabilities. This grassroots movement marks another significant and crucial chapter in the lives of people with disabilities. It represents a new beginning, a shift in the balance of power and a source of hope for disabled people, who have historically been forced to remain on the periphery of an able-bodied world. Like any other social movement, independent living is a product of

its culture and its time. Such movements become possible when, according to Turner (1969 : 321 ), "there is a revision in the manner in which a substantial group of people looking at some misfortune, see it no longer as a misfortune warranting charitable consideration but as an injustice which is intolerable in society".

The independent living movement, initiated in the United States in the 1970's, was inspired by a strong, and indigenous leadership from the disabled population. The first practical manifestation of the movement resulted in the setting up of a Center for Independent Living (CIL) in Berkeley University, California. It incorporated itself as a self-help group in 1972 to be managed by persons who were themselves disabled. (DeJong, 1979) Critical to its organisation at that time was the fact that the University contained critical masses of young people who, free from familial or economic responsibilities, were better able to organise around the issue of independent living.

Since Berkeley, numerous CILs have been set up in the United States and Europe offering a wide range of related services such as peer consultancy, advocacy services, training in independent living skills and personal assistance services. According to Oliver (1990) in *The Politics of Disablement*, CIL's represent both an attempt to achieve self-actualization and a form of direct action aimed at creating new solutions to problems defined by disabled people themselves. CIL's are, he says, 'poised at the fulcrum of the contemporary struggle to tilt the balance of the history in the favour of a fairer and more equitable future for disabled people.' (Ibid: 42) Regardless of the type of services offered or role played, the CIL's have one thing in common; it is people with a disability who are at the centre.

#### **1.4 The Philosophy of Independent Living**

The philosophy of the independent living movement is based on four assumptions; that all human life is of value; that anyone whatever their impairment is capable of exerting choices; that people who are disabled by society's reaction to physical, intellectual, or sensory impairment have the right to assert control over their lives and that disabled people have the right to fully participate in society. (Morris, 1993 :7) Essentially, the independent living philosophy espouses living like everyone else -being able to have control of one's own life, having opportunities to make decisions that affect one's life and being able to pursue activities of one's own choosing, regardless of disability. Disabled People's International, as a consumer-led organisation, sees independent living as a process over which disabled people must control individually and collectively. The philosophy they say, (DPI , 1991) "... emphasises our right to self determination. Self determination implies that we take responsibility for our own lives and see ourselves not as objects of care or humanitarian concerns but as citizens with all the rights and duties that full citizenship entails. The philosophy also includes the possibility of failure and risk. Dejong (1979 :442) points out that the dignity of risk is what the independent movement is all about: He states, "Without the possibility of failure the disabled person is said to lack true independence and the mark of one's humanity -the right to choose between good or evil. " Independent living is a relative

term and what is important is the freedom to choose the degree of independence or dependence most suitable to an individual's lifestyle and social pattern. Furthermore independent living must be distinguished from living independently. The latter implies that a person with a disability is trained by so called 'experts' and 'professionals' to do everything for themselves and live without help, whereas the former is concerned about quality of life, with help. The disabled person is seen, not as a patient in need of care, but as someone who requires assistance with certain activities, a process over which the disabled person him/herself must control and manage. Independent living is not simply concerned with the mundane physical tasks of living. The philosophy expands the notion of independence from physical achievements to political and socio-economic decision making. It is concerned with the personal and economic choices which disabled people make. As Crewe and Zola ( 1987 :347) write, "It is not the quality of tasks we can perform without assistance that matters but the quality of life we can lead with help. To retain the old physical criteria of independence only contributes to the very isolation we seek to avoid."

### **1.5 Independent living as Analytic Paradigm**

The independent living movement has now developed into something much more than a grassroots effort on the part of disabled people to acquire new. It is beginning to reshape the focus of disability policy, promote new forms of service delivery and revise the thinking of professionals and researchers. In other words, the movement has led to the emergence of a new analytic paradigm (Dejong, 1979) which is at variance with the current rehabilitation paradigm. In recent years an important anomaly appeared that cannot be explained by the rehabilitation paradigm: people with significant physical disabilities were achieving independence without the benefit of, or in of professional rehabilitation. Co-operation with professional rehabilitation was not a necessary prerequisite for independent living. Therefore, an increasing number of people with a significant physical disability sought a new paradigm and thus the independent living paradigm emerged. The locus of the problem of disability within the independent living paradigm lies in both the environment and the social control mechanisms in society at To cope with these environmental barriers, the disabled person must shed the 'client' role for the consumer role. Advocacy. peer consultancy, self-help, consumer control and barrier removal are the trademarks of the independent living paradigm. A comparison between the rehabilitation model and the independent living model illustrates their central differences. In the rehabilitation paradigm, problems are generally defined in terms of inadequate performance in the physical activities of daily living or in terms of inadequate preparation for gainful employment. In both instances and central to the rehabilitation model, the problem is assumed to reside in the individual. It is the individual who needs to be changed. To overcome his/her problem the disabled individual is expected to yield to the advice and instruction of a physician, physiotherapist, occupational therapist or vocational officer. The disabled individual is expected to assume the role of the 'patient' where success is based on whether or not the patient complied with the prescribed therapeutic regime. Unlike the rehabilitation model,

the independent living paradigm sees the problem of disability located in the physical, architectural and attitudinal environments. Therefore the solution to the problem is not in changing the individual but the environments in which the person with the disability lives. DeJong (1979 444) summaries the main differences between the two models which in turn illustrates the essential relevance of the independent living paradigm to this research;

“As a paradigm of research, independent living offers us an opportunity to steer away from the myopic pre-occupation with unalterable individual characteristics that direct our attention from the larger institutional and environmental context in which disabled people live. The institutional and environmental context have for too long been accepted and given.”

## **2. THE ACTION PROGRAMME**

### **2.1. Introduction**

This section provides an insight into the present situation for people with significant physical disabilities (those who require assistance with everyday activities) in Ireland, which in turn, provides the background and rationale behind the development of the Center for Independent Living and the INCARE personal assistance service programme. In doing so, it attempts to paint some of the picture of the reality of disabled people's lives and why it changed for a small group of people with disabilities (referred to as leaders within the INCARE programme). It discusses the training for both leaders and P A 's. and examines the role of nondisabled people in the Disability Movement.

### **2.2 The Existing 'System'**

The notion of independent living is certainly not a new one. The desire to take control and responsibility for one's own life is central and relevant to all our lives, and is no different for people with disabilities. Independence is something we all strive for and for most, it is an automatic and unconscious progression. However, people with significant physical disabilities who require assistance have been excluded from this process. They have never been afforded the opportunity to be independent, to be self-determining, to take control of their own lives or exert choices. Due to a combination of social and economic factors, many people with disabilities in Ireland have been forced to remain on the margins of a society which has not been prepared to accept them. Instead, they have been 'tucked away' in

residential care, special education, special training and provided with segregated housing and specialised transport. As a result of the numerous attitudinal, architectural and institutional barriers, that the task of supporting people with a disability falls mainly on the family and the charitably minded. The reality of many disabled people's lives is merely one of existence. It is a life of survival at 'minimal levels of subsistence and tolerance' (Faughnan, 1979) and thus contributes to their historically reinforced dependency status. The emphasis on institutionalisation remains despite the ideological and philosophical shift in the policy from institutional to community care first introduced in the 1970 Health Act. In theory, the implications of the new Community Care Programme were far reaching and should have allowed even those with significant physical disabilities to live in the community (Faughnan, 1984). In practice, it has done little to enhance the disabled person's realisation of his/her potential, achievement of independent living or participation in society. The situation is that the majority of 'care' in the community is given by informal carers, usually members of the immediate family. But as Morris (1992) illustrates in her study, reliance on-a family member for help with the activities of daily living significantly restrains the autonomy of both the disabled person and the person providing the help and ultimately leaves the person with a disability with little or no choice and control over his/her own life. Furthermore, both the policy of institutionalisation of people with a disability who require assistance and a lack of any other alternative, has led to their segregation, isolation and exclusion. Residential care services, view people with disabilities as passive recipients, where the relationship between the carer and the person being cared is one of dependency. The disabled person has no choice or control over what work is done, how and where it is done and by whom. As a result, the majority of people with a significant physical disability in Ireland are unable to achieve independent living. Their only experience has been one of the systematic disempowerment, reinforced dependency and lack of power and control over their own resources.

### **2.3 The Centre for Independent living**

Since the setting up of the Center for Independent Living (CIL), this situation has changed for a small number of people with disabilities. As a practical manifestation of the worldwide independent living movement, a group of people with significant physical disabilities officially established the first Irish Center for Independent Living in August 1992. The CIL addresses many of the elements necessary to the achievement of independent living including housing, personal assistance, accessible transport, access, peer consultancy, employment and education. However, training is the most important and essential part of the organisation's activities. Both leaders and personal assistants are involved in comprehensive training programmes which are discussed later. The CIL gained much of its knowledge and experience of independent living from similar groups in Europe and the United States. Extensive research was carried out prior to the setting up of the CIL, including study and exchange visits, importing expertise and the exchange of knowledge and know how from other countries who had been through the same process. (see Appendix I for a

more detailed description of the CIL's international activities). The group of people with disabilities, involved in the setting up of the CIL in Ireland, saw a need to bridge the substantial gap in service provision especially in relation to housing, transport/mobility and personal assistance. To service provision had failed to identify the importance and necessity of enabling people with disabilities to control their own lives, participate in social and economic life and achieve independent living. Furthermore, there was a growing demand among disabled people as service users to have a voice in the how, where and when of service provision.

Through the development of the there has been a shift in the balance of power, where previously able-bodied professionals decided what was best for them and how their needs should be met to where people with disabilities are now the experts, defining their own needs and wants and for the first time, controlling and managing the services provided. The CIL is effecting change from others working for disabled people to people with a disability working for themselves as part of a self-help, grassroots movement.

#### **2.4 The INCARE Programme**

Personal assistance, as one of the services most closely associated with the independent living movement and one which has acquired unique importance as a symbol of empowerment (Bristow, 1994) became the starting point for the Center for Independent Living. Following three years of research, the INCARE programme began in December 1992 on a two year long pilot basis. The programme involved 23 people with significant physical disabilities (the leaders) and their 45 personal assistants. The programme emerged as a result of an ever growing demand from people with disabilities to have what the majority of people take for granted -an opportunity to control their own lives, to exercise choices, to take responsibility and to make their own decisions and to take risks with the freedom to fail.

Many people with disabilities in Ireland are what Brisenden (1989 :9) refers to as 'victims of an ideology of independence', which he says, "...teaches us that unless we can do everything for ourselves we cannot take our place in society. We must be able to cook, wash, dress ourselves, make the bed, write, speak and so forth, before we become proper people, before we are independent ". However, the INCARE programme challenges this notion and argues instead that independence is created by having assistance when and how the person with a disability requires it. The 'when' and 'how' of assistance becomes a reality when the leader as a person with a disability assumes the role of 'employer' and 'trainer' to manage and train his/her own personal assistants. 'Personal' in the sense that the assistance is individualised and not shared and with emphasis on assistance as opposed to 'care'. In the words of Ratzka (1992 :41) "...the assistance has to be customized to my individual needs... " As outlined in the original INCARE proposal, the programme aimed to develop the concept of independent living for people with significant disabilities and in particular to research design and implement a programme aimed at: 1) providing for the first time in Ireland a

range of appropriate personal assistance services, managed and controlled by people with disabilities; 2) educating and training both Personal Assistants and people with disabilities in the acquisition of the skills and attitudes pertinent to the realisation of an effective Personal Assistance Service (PAS) (INCARE, 1992). Because of the attachment of the values and the philosophy of the independent living movement, the INCARE personal assistance service differs from the traditional provision of 'care' in terms of the service setting, the delivery method and the helping style. The paternalistic notion of care developed under the institutional model, where passive dependency is created and sustained, is rejected. Instead the focus is on consumer control, peer consultancy and independence.

## **2.5 Main Features of A Personal Assistance Service**

A personal assistance policy is ultimately what makes independent living a reality for people with significant physical disabilities (Morris, 1992 :7). This is not surprising, for an inability to do things for oneself physically has historically created and still creates the risk of segregation and institutionalization.

The personal assistant (P A) assists people with disabilities in tasks of everyday living ranging from personal care, household maintenance to assistance in the study/work place and social/leisure activities.

Personal assistance tasks are described as ones that individuals would normally do for themselves if they did not have a disability (Dregener, 1992). The person with a disability delegates the tasks which they cannot do themselves, because of their disability. A personal assistant is recruited, trained, supervised and if necessary fired by the disabled consumer. The distinguishing feature of a personal assistant service is that it is the consumer, not the provider who directs the provision of assistance.

As Dejong and Wenker (1987) point out, disabled individuals, as consumers of personal assistance are best able to evaluate the adequacy and quality of assistance they receive. Having the closest possible knowledge of his/her own disability, the disabled person is highly qualified to establish the level of assistance he/she requires. In this area the self-help movement goes beyond the consumer movement in assuming that disabled people are not only capable of evaluating service quality, but they are also able to manage, direct and control the providers of the service they need.

## **2.6 The Training Programmes**

The training of both leaders and personal assistants is an essential element of the INCARE programme and is the main method used to achieve the aim of independent living. Indeed, the CIL is essentially a training organisation but differs from the traditional vocational training organisations for people with disabilities in the method of delivery of the training. It is more a 'training for life' approach which is consumer controlled and more often than not, consumer delivered. The training offers direct support to the individual on both a one to

one and group training basis. The training programmes which have been developed represent the culmination of the work and research carried out by people with disabilities between 1989 and 1992. prior to the establishment of the programme. The nature and style of the training allows for constant evaluation and restructuring if necessary; the training programmes can be added to, changed or enhanced as required.

Both leader and PA training are organised by a Training Team. A Training Advisory Group, made up, in the main, of people with disabilities was subsequently set up in March 1994 to monitor and steer action and policy in relation to all the CIL training. It also plays an instrumental role in the design and development of future training programmes.

## **2.7 Leader Training**

For people with a disability who have only experienced a passive dependency culture, where they have had no control of their own life, with no choice, responsibility, decision making power, or experience of independent living, training is vital and essential.

Training to enable people with disabilities to achieve independent living has focused on three main areas:

- to understand, preach and practice the philosophy of independent living
- to understand their role and obligations as an employer
- to understand their role and duties as a trainer

The main method of training is facilitated peer consultancy, where leaders exchange experience, knowledge and expertise on every aspect of living, an opportunity which was rarely afforded to people with significant physical disability before, due to isolation, segregation and exclusion. Outside guest speakers were also used in relation to training leaders about the tax system, social insurance system (PRSI, PAYE) and their obligations as both employer and trainer. Leaders have also engaged in empowerment and assertiveness training to enable them to take control and responsibility for their own lives and to communicate effectively with their personal assistants.

Peer consultancy also takes place on a day-to-day informal basis. Peer consultancy was specifically chosen over peer support or counselling. The latter imply professional requirements and a challenge to the peer, shifting responsibility onto him or her. Peer consultancy, however, is different in that the relationship is an equal one and responsibility still remains with the individual. Peer consultancy has proven to be one of the key elements of the programme. It is the 'magic' ingredient and the secret of its success.

As one leader discussing peer consultancy puts it; "It has welded us together and was developed purely by chance, through a number of informal get-togethers, house warmers, birthday parties, celebrating our being there, our participation, our hoping for each other

and discussing the difficulties of being disabled, understanding each other and most importantly, knowing that I wasn't alone. "

Leader training is now moving into its second phase and has developed into a one-year long training programme leading to a Certificate in Social Studies (Disability Studies), developed in partnership with the National College of Industrial Relations. The programme will facilitate leaders, reviewing the history of people with disabilities to critically analyse the concept of disability and the disabling society. Gaining an understanding of the process of marginalisation whereby people with disabilities and other excluded groups are forced to remain on the margins of society is a central theme. A key feature of the programme is to train leaders to be effective 'employers' and 'trainers' and to manage their own affairs. It also aims to empower leaders to clarify the vision and to actively influence the planning of all social and economic policies in relation to people with disabilities. It aims to provide specific skills, knowledge and attitudes to enable participants to gain employment and/or progress further education/training. The programme will consciously structure group and individual peer consultancy as a major training method. (CIL (1994) Training Programme Specification).

## **2.8 Personal Assistant Training**

75% of the training for Personal Assistants is given by the leader in the workplace to meet his/her own individual requirements. The remaining 25% is classroom based, organized mainly over a series of 'training weekends'. A one year long PA training programme, underpinned by the philosophy of independent living was devised.

The PA training programme encompassed four modules: -

- Philosophy of Independent Living –
- Health, Hygiene and Safety
- Communications
- Career Guidance

Training in the philosophy of independent living is essential for PA's to enable them to gain an insight into and understand the historical context of the lives of people with disabilities, to understand and appreciate the role of the personal assistant by placing it in the overall context of the Independent Living Movement, and to appreciate the essential differences between 'care' and 'assistance'.

The Health, Hygiene and Safety module covered a number of areas including lifting techniques, first aid, fire precautions, dietary and nutritional matters, food preparation, techniques in basic massage and physiotherapy. Training in these areas is required as the health and safety of the PA's equally important to the leader as it is to the individual PA. Communications training enabled both leaders and PA's to develop effective and open communication skills, to maximise their personal abilities, increase their awareness towards

each other and to develop the attitudes and interpersonal skills necessary for a good working relationship between a leader and the P.A.

The Career Guidance module focused on the development of Personal Assistant, a new category of personnel in Ireland, as a career in its own right, with recognition of their status, training and certification. This is despite the commonly held belief in the Movement that increasing the status of the P A reduces consumer control of the service. Indeed, we strongly argue to the contrary. With quality, consumer controlled training and increased status of the job of personal assistant it is the consumers (people with disabilities) who will ultimately benefit.

Many of the leaders were involved in providing training themselves, alongside other professionals. Since its establishment, members of the Training Advisory Group brief all outside guest speakers and ensure that a leader is present at all training sessions.

When PA's complete the year long training they receive a Certificate in Community Care (City and Guilds/FAS). The first group of trained Personal Assistants graduated in August 1994, twelve of whom received the City and Guilds certification. The PA training programme is at present under review by the Training Advisory Group and the Training Team.

A listening survey of leaders and PA's has been completed to redesign P A training and to obtain certification more compatible with the philosophy of independent living. Depending on the leader's PA requirements, alternative forms of training will be devised for the different groups of PA's, using either the FAS External Training Grant, Job Training Scheme or Community Employment. As a greater number of people with disabilities begin to see personal assistance as an option for a more empowering, qualitative life, the demand for trained personal assistants will undoubtedly increase. The CIL have anticipated this and have planned for national expansion.

The CIL is breaking new ground at international level in terms of the training of Personal Assistants - a notion which has been rejected by many within the independent living movement. However, the INCARE programme has proved the necessity of good quality consumer-controlled training for P A 's which has in turn led to certification, recognition of their status and the development of 'Personal Assistant' as a real career. Training PAS has enabled them to assist in the best possible way enabled leaders to maximise the potential of the P A and to gain from the knowledge acquired. The leaders truly value the notion of personal assistance in the fullest sense and believe that if there is no recognition or value attached to the PA's work this directly affects the person with a disability - i.e. there is little worth or significance attached to their lives, to their right to go to college, to work or to pursue training and to live the lives of their own choosing.

## **2.9 The Role of FAS**

FAS, the Training and Employment Authority, has played a key role in the development and training of PA's. The FAS Job Training Scheme (JTS) was adopted by the CIL as the most appropriate training programme for PA's. The JTS is a quality work-based training programme provided by employers in cooperation with FAS. It is a new training approach linking the world of work and training in a practical way. It is ideal to the leaders because it uses the training capacity and expertise within the workplace to train potential employees. The JTS also allows the CIL to layout its own training requirements and to hire personal assistants for training on an ongoing basis, depending on leader requirements, which has proved successful for the organization, leaders and trainee personal assistants' needs. The day-to-day support from the FAS 'Services to Industry' department ensured the CIL's confidence in executing the P A training programme.

## **2.10 Role of Non-Disabled People in the Irish Disability Movement**

Through recognition of the crucial role PA's play in the achievement of independent living and as the means to real empowerment, there is an ever increasing acknowledgement of the role non-disabled people play in the Disability Movement in Ireland. This is contrary to a commonly held belief that it must be exclusive to people with disability and illustrates the strength and security of the Irish Disability Movement. The CIL and INCARE programme are now challenging this notion and are gradually instigating a change at international level.

Like Woodill (1994 :47) those involved in the Irish Disability Movement argue that; "Disability consciousness', that is, an understanding of the sociopolitical disadvantages of disabled people in the world is not confined to persons with disabilities. Those able-bodied persons who have a disability consciousness can be useful allies in the disability rights movement."

Through appropriate training the non-disabled person can participate in the Disability Movement under the following conditions:

- they do not assume a leadership position in the movement –
- they enjoy the support of an organisation of disabled people which has asked them for their participation –
- they are prepared to learn to see the world from the perspective of a person with a disability (Ibid).

## **3. THE RESEARCH PROGRAMME**

### **3.1 Action Research and Evaluation**

The action-research approach adopted by the INCARE programme serves a number of important functions. As the action is the research, the goals and methods of practice and research are interdependent and closely woven. Whenever necessary changes and modifications in the action are introduced reflecting the research task of evaluation. Thus

the research is built in as an integral part of the INCARE programme, and not viewed as a separate 'academic' activity. It comes from the participants/consumers, who traditionally have been the 'weakest elements' in most research concerning them. It involved leaders from the very outset in designing the action-research to be undertaken as well as being the central informants.

This in turn led to an alternative social view (as opposed to the individualistic/medicalised assumptions underlying much research on disability) being presented and applied to the research. Instead of it being oppressive, this action research programme is both participatory and emancipatory which as French (1992 :183) argues is necessary through translation into practice, to assist disabled people in their struggle for empowerment: "Action research focuses on the way change can be achieved. It assumes that there is a dialectic between participation in a social process and understanding a social process; it tries to work on both these aspects, because it further assumes that in developing the dialectic, the process will be more effective."

Therefore because of the emphasis on the 'action research' approach, the evaluation is not restricted only to an assessment of how far the objectives of the INCARE programme have been achieved. It also seeks to describe and define the processes by which the programme has led to certain outcomes and has been carried out. This according to Kilmurray (1985), entails a clear awareness of the changes and shifts as the work develops. The evaluation also focuses on what Blackwell (1993) refers to as the single most important aspect of social policy analysis -the 'with-without' criterion. It is essential to ask the question 'what does the world look like for the consumers without the project and with it ?' -the 'before and after' scenarios.

### **3.2 Research Methodology**

Using the independent living paradigm as the framework for analysis, a variety of research methodologies have been used in the research to obtain both quantitative and qualitative data, but with emphasis on the latter. Leaders were involved in evaluating and assessing the project on an ongoing basis through periodic groups and individual discussions and by maintaining a set of evaluation sheets in relation to the training programmes and the overall programme. A questionnaire was administered to the 23 leaders in April 1994. questionnaire contained mainly pre-coded questions and was designed only to obtain basic and preliminary data on all the INCARE leaders. questionnaire aimed to collect data in order to develop demographic, age, gender profiles on all leaders and to obtain information on the current occupational/employment status, examining whether or not the personal assistance service enabled the leaders to develop vocationally in terms of employment, education or training. Information was also sought on the level of personal assistant support each leader had, the role of the PA and the types of settings in which they used personal assistance.

While the questionnaire led to the collection of quantitative data a follow up semi-structured interview was conducted with leaders allowing for the examination of the all important qualitative aspects of the programme. The decision was made to prefer in the main, an inquiry that was qualitative rather than quantitative in character, and the semi-structured type of interview allowed for the maximum opportunity for interactive dialogue, enabling leaders to identify the relevant issues from their own perspectives and to press individual views further. The focus of the programme is on quality of life, which cannot and should not be quantified into hard statistical data. The qualitative approach encouraged the collection and recording of individual experiences and opinions with all their idiosyncrasies and inconsistencies to capture the 'living' part of the programme and to convey the variety and texture of the experience of the leaders. Qualitative methods enable the researcher to understand and capture the points of view without predetermining them through prior selection of questionnaire categories (Silverman, 1993). It allows for the expression of indepth personal experience such as the way individuals have organised their world, their thoughts about what is happening to them, their experience, and their basic perceptions, which is evident from the findings.

Consequently, the part of the report findings takes the form of verbatim extracts from the interviews. The interviews were conducted over a number of weeks in a private setting, usually in the leader's own home. At the outset confidentiality was stressed, the overall context of the research explained and the research aims and objectives outlined. All interviews were recorded with prior consent of the leader and transcribed in full. The text of these interviews are used in the report for both descriptive and analytical purposes. Some leaders had their personal assistant present to assist with interpretation.

## **4. RESEARCH FINDINGS**

### **4.1 Introduction**

Using the independent living paradigm, the research findings describe and analyse the impact of the INCARE programme at three levels: 1) the impact on die individual 2) the impact on potential for education, training and employment 3) the macro impact, relating mainly to influence on present policy and service provision, public attitudes and awareness and on other people with a disability. The above, in reality cannot be compartmentalised into the three neat categories -they are inextricably linked and interwoven, and one would not exist without the other. But for practical analytical purposes, they are considered separately. Firstly, as a starting point and in order to provide background information on the leaders, a brief age, gender and demographic profile is presented, along with information on living arrangements, type of housing and the role and type of work leaders employed their Personal Assistant to carry out. Secondly, for comparative purposes, the research findings outline what life was like for leaders pre-INCARE, the type of assistance they availed of and leader's opinion of the 'care' services (statutory and non-statutory) which they utilized prior to the establishment of the programme.

## 4.2 The Leaders

Leaders come from various backgrounds, all of whom have a significant physical disability and require assistance in a variety of settings and in a variety of ways. In some cases, the information presented here does not add up to the total number of leaders (23) for two reasons: (1) insufficient information supplied by the leader on the questionnaire or (2) the question was not applicable to the particular leader at that time.

### 4.2.1 Age, Gender and Demographic Profiles

The leaders ages range from between 18 to 50 years with 16 males and 7 females.

Table 1 gives a more detailed breakdown of the age profile of leaders

Table 1 – Age of Leaders Age in Years

U-20 3

20-25 8

26-30 3

31-35 2

36-40 2

40+ 3 5

N=23

21 of the 23 Leaders live in Dublin and two of these 21 leaders moved from other parts of the country to Dublin to avail of educational and employment opportunities.

### 4.2.2 Living Arrangements and Type of Housing

Tables 3 and 4 contain a breakdown of the current living arrangements and the type of housing of leaders

Table 2: Leader Living Arrangements With Parents/Other Family Member(s) 7

Husband/Wife/Partner 2 Alone 6 Sharing (with non family member) 3 Residential Care 4

Other 0 Information not available 1 Table 3 – Type of Housing Privately Owned 7 Private Rented 8 Local Authority Housing 0 Social Housing 1 Residential Care 4 Other 0 Information not available 3

## 4.3 Role of The Personal Assistant

While doing the research between 1989-1992 the 'Personal Care Attendant' (PCA) notion was still in existence, where the person with a disability had someone to put him/her to bed, get him/her up and give him/her breakfast. However, leaders were not interested in developing this type of service in Ireland and set about developing and expanding the

potential role of the PCA and choose instead the idea of a 'Personal Assistant'. The INCARE programme has expanded and continues to expand the role of the Personal Assistant to far beyond both the traditional personal care attendant 'bed and breakfast' model.

Furthermore, it challenges the world-wide interpretation of the role and status of the PA. Within the INCARE programme, the PA plays a dynamic and often complementary role to that of his/her leader and the variation in leader's personal assistance arrangements illustrates the flexibility and numerous possibilities which the INCARE Personal Assistance Service offers.

Leaders indicate that they utilize the PAS in a number of different settings including at home (15) in the study place (9), workplace (11), residential (4) and the social and recreational environment (14). The settings in which the PAS is utilised reflects directly the type and variety of work the P A may be involved in. Leaders utilise their P A for personal care tasks (21), general domestic duties (16), educational related activities such as note taking, assistance at lectures, typing, etc. (9), workplace related duties such as assistance to and from work, phoning, typing, interpreting at meetings etc. (9). Assistance with driving was most frequently cited in the 'other' category, each leader as 'employer' decides the hours and days which the PA works. Together the leader and PA draw up a weekly, fortnightly or monthly schedule, depending on each individual's situation.

There exists an endless amount of potential in arranging "the 'when', 'where' and 'how' of the assistance -week on week off, three days on and three days off, etc as well as sleep overs and live-in arrangements. The majority of the administration associated with the employment of a PA's dealt with centrally, including financial matters. All the leaders are aware of the requirements and ensure that they are meeting their 'employer' obligations.

#### **4.4 Pre-INCARE**

Using the 'with-without' criterion in order to gain a full appreciation of the impact of the programme, the research first focused on an examination of what life was like for the leaders prior to the establishment of the INCARE programme, the type of assistance they had and their opinion of statutory and voluntary services they availed of, if any.

Life for the majority of leaders, before the emergence of the PAS was described as one consisting of dependency, reliance on family and friends, planned out and structured with little, if anything done spontaneously. Few leaders had the opportunity to be self-determining or having a choice over what was done, when and by whom. Each leader's story resounds of the universality of the lack of control of their own life and the following extracts help to paint a general picture of what life was like then; "Life for me consisted of depending on family to take me everywhere and to do everything for me. I didn't have any independence because it wasn't up to me where I went or what I did." "I was living with my sister and her two children and before that with another sister: I was completely dependent on them for everything." "I lived in institutions, my autonomy, individuality and personality

were ignored. It was too difficult to challenge an individual if they were violating my rights." "Prior to INCARE, I would have got out of bed, but based on the local services agenda, as to when a home help could come or not come. The home help had their own agenda about me. It was always things that they thought needed to be done, rather than the things that I wanted to do, and nobody lives on that basis. We write down in our minds all the golden rules we are going to stick by, and you're not up ten minutes when you've already forgotten them and that's the way life should be. But for people with disabilities it is different. All these roles were reinforced every second of every day, every day of every year: This is where we get the huge passive dependency from."

It also became apparent that some leaders were unable to participate in any meaningful way in social or economic life. Inactivity and boredom characterised their world; "I was at home all day doing nothing" "I was stuck in the one spot, I had the telephone and read a lot" "I was depressed I had nothing to do and didn't see any escape from a life of emptiness"

Furthermore, it emerged that many leaders were forced to think in terms of 'living independently' whether in school, residential care or at home. The focus of service providers reinforced this notion that they should be able to do everything on their own, regardless of the time or energy involved. The rehabilitation experts and professionals who knew what was best for them, were training disabled people to do things alone; "push yourself, try harder, exercise, don't get lazy, use your manual chair," were all too common phrases heard by leaders.

Leaders therefore felt "trapped" by this perception of what it is to be independent, they had to do everything on their own -which was neither practical nor appropriate. Prior to the development of the INCARE programme leaders relied on a variety of and more than one source of assistance, but as is evidenced from Table 4, the majority relied on informal and unpaid assistance of family and friends, while others availed of the services of the Cheshire Homes and a small number availed of the Health Board's home help service and the Irish Wheelchair Association's Home Care Attendant Scheme.

Table 4: Type of Assistance pre-INCARE Programme Type No. of Leaders Family 14 Friends 9 Partner 1 Colleagues 2 IW A Home Care Attendant 2 Residential Care 6 Home Help 4 Public Health Nurse 1 Private PA 1 Child Care Worker 1 No Assistance 2

#### **4.5 Leader Opinion of Statutory and Non-Statutory Service Provision**

Overall, leaders expressed greater or lesser degrees of dissatisfaction/satisfaction with existing service provision. Criticisms centered around their unsuitability and inadequacies for people with significant physical disabilities. Leaders saw the increasing amount of community-based services catering for the more 'able disabled' i.e. people who are less significantly disabled and do not require assistance with the activities of everyday living. Therefore, services focused on the living independently model. It was also believed that

people with disabilities have no control over services provided in the disability field. However, one of the strongest criticisms lobbied was of the lack of understanding among service providers and of their attitude 'they think they know what is best for us': "I felt that they didn't understand the difficulties I was going through. I had to do with what I had and that didn't care once you had someone to take care of you " "The people in the positions of power and who make the decisions do not really understand." "Their attitude is all wrong. They don't know what they are talking about, and don't listen to what I have to say." One leader who explains the reasons behind the inadequacies and unsuitability of services, reflects an opinion held by many of the leaders; "In general the services being provided for disabled people are for them and not in conjunction with them. Disabled people do not seem to have any part in sitting down around the table and working out what is best for them. The services are decided upon by able-bodied people and brought through by able-bodied people. "

Therefore, what is very often missing from the existing system is the knowledge and expertise that people with disabilities have gained through their own experiences of disability. This appears to be the greatest shortfall as seen by leaders. According to one leader, the lack of knowledge is compensated for in a patronising fashion. which in turn further segregates and isolates people with disabilities.

Moreover, leaders argue it is the 'system' that is wrong. It produces more and more dependency, reinforces segregation and isolation and invests in 'bricks and mortar', not individuals. This has been a result of the lack of involvement of people with disabilities in the truest sense in the planning, development and execution of services. Some leaders expressed very strong opinions on existing services provision and they experienced total degradation, humiliation and were treated in an "infantile manner"

One leader explains the feeling thus; "I felt like a beggar, asking for this or that " Another leader described the existing services as "a joke" because of their complete lack of suitability for him. One leader felt very strong about the current residential care provision and saying, "I could not stand residential care for the rest of my life".

On the other hand some leaders expressed a general satisfaction with the services they availed of, and attributed success to the commitment and level of understanding of the individual workers involved, ranging from the home helpers, the public health nurses to the occupational and physio therapists. It is also important to note that the leaders made it clear that they did not want to create a separatist or a 'them and us' mentality with existing service providers, which they argue does not make for true inclusion. Instead, they want to become an integral part of the whole process and to be involved in all decision making which affects their lives.

#### **4.6 Impact of die INCARE Programme**

The programme has had a considerable impact at a number of levels. The success of the programme in achieving its aim of 'independent living' is clearly evident from an examination of the impact it has had, and becomes even more apparent with a comparison of life without and with a personal assistant.

#### **4.6.1 Impact on the Individual**

Each individual leader's account illustrates that the programme has had an enormous impact at the individual level, enabling people with a disability, for the first time, to take control of their own lives, to exert choices and to be self-determining. Comparing the situations before and after the development of the PAS, the leaders are no longer 'dependent' on family, friends or colleagues to meet their personal care needs; they no longer have someone else deciding what is best for them, taking away responsibility, protecting and ultimately controlling their lives.

The leaders, unlike the previous scenario, feel no longer under a compulsion to ask for assistance; it is now a right. The personal assistance service is provided as a commodity and not on the basis of charity or altruism. One leader sums up the enormous change which ensued "We're talking about the difference between living and existing." People with a disability are finally getting an opportunity to make the move out of the passive dependent culture and associated apathy, which has characterised their life to date. They are now beginning to take pride and value themselves as full and equal citizens in society.

Furthermore, they are starting to live life like everyone else, the ultimate goal of the philosophy of independent living. They are achieving what is second nature for most people and taken for granted by the majority of the population - independence. It has also allowed for the dignity of risk and the possibility of failure: "... it has taken the fear out of being independent. I can fail and feel free to try again in any aspect of independence..." Depending on the leaders' previous life experiences, circumstances and levels of dependence and independence, the programme has accordingly impacted to a greater or lesser extent. Leaders indicated that their quality of life and type of lifestyle, through the provision of personal assistance has changed and been enhanced considerably.

The following are only a selection of the leaders' responses to the question 'How has the INCARE PAS impacted on your life as an individual?', but nevertheless are reflective of the overall replies: "It gives me so many more opportunities to do things that I want to do and couldn't have done otherwise. It gives me choice and control of my own life. I am not physically or mentally dependent anymore. I can do things now and hopefully I don't fail, but if I do, so what, I'll try again - everyone should have the right to fail." "I'm a new woman, my confidence and personal development is on an upward drive." "It has had an enormous impact on my life. I'm out there living now." "It makes me able to realise some of the things I have only dreamt about or wished for. I am a much stronger person. I am more secure in myself, I see myself as having a role and a future. I see myself as someone who is

contributing and can contribute more to society. I now have real potential as distinct to being someone who is at the receiving end of something, more dependent and more of a burden." The PAS has allowed for the achievement of some 'unique' and personal opportunities for leaders including moving out of home to their own apartments and becoming involved in other disability issues, the Forum of People with Disabilities and disability politics in general. Furthermore many people with disabilities are now able to participate in the social life of the community and to go out socially. While these are unique opportunities for people with disabilities, they are no different to the life experiences of the greater majority of the population.

Furthermore, the personal assistant has also had a significant impact on leaders' relationships with their families, friends and colleagues. Leaders reported that the P A service has taken a lot of pressure off family and friends. It has allowed for the development of healthier and better relationships, with more freedom, independence and free time for both parties involved, enabling them to do what they want to do. It has also allowed for the development of one's individuality where the person with a disability is no longer seen as an object of pity or frustration but as a person, as someone who is out looking to achieve and succeed. It has also made leaders feel better about themselves because they do not have to constantly ask family or friends "to give me a hand, to do this and that or go here and there."

Some leaders discussing the impact of the PAS on their relationship with family members indicated their initial and inevitable protectiveness and their reluctance to let go. However, once the families realised the service did work successfully, the families themselves began to reap the benefits of increased independence. Personal assistance has also enabled leaders to be less reliant on colleagues at work. Those leaders who are in employment describe how the PAS has made things much easier for them and has allowed for the development of a "different relationship" with their colleagues. They are now getting used to the idea of having Personal Assistants in the workplace and have come to accept and value it. Where it is impossible to quantify, it is equally difficult to convey in qualitative terms the impact the programme has had on individuals' lives. One leader discussing the impact on his life explains the dilemma; "The impact has been huge but it is very difficult to discuss it without getting carried away about it and getting excited. There is simply no comparison. "

#### **4.6.2 Vocational Impact**

Not only has the INCARE programme enabled people with disabilities to be self-determining and in control of their own lives but it also has had a critical influence in enabling leaders to develop themselves vocationally -accessing further mainstream education, training to gain the necessary skills to enter the labour market and to actively participate in the workforce. Leaders as people with significant physical disabilities are most discriminated against in terms of education, training or employment: they come last at the end of a long line,

because of their need for assistance creates the risk of segregation, isolation and exclusion. Through the use of a personal assistance service, people with significant disabilities can become productive members and contribute in a meaningful way to society. They become an 'exchequer gain' rather than an 'exchequer drain'.

Table 5 illustrates present occupational status of the 23 INCARE Leaders. Table 5 - Leaders Occupational Status STATUS % Studying 27.5 Training 18 Employed 50 Unemployed 5

Education 27.5% (6) leaders are attending college and pursuing different courses, one in second level education and five at third level. Of these 6 leaders, three have, as a result of the PAS started in college and indicated that they would not otherwise have been able to attend. All leaders undertaking educational courses use personal assistance in the study place.

Training 18% of INCARE leaders are at present involved in some form of training, including computer applications and programming and community development training.

Employment Of the 50% of leaders who are in employment 45% of them have as a result of the personal assistant service been enabled to take up positions of employment, while 55% indicated the service has in part, enabled them to maintain existing employment.

All leaders indicated that they use personal assistance in the workplace. One leader explains, "I worked before the personal assistant service but to have a PA during work makes it a lot easier". Another says "I took up a job in Dublin, I wanted to see what life was like in the big bad world." Some leaders regret the lack of existence of a PAS when they were younger. "If I had a PA at 18/19 I would have got a degree and I'd surely be earning a living at something. I've always been ambitious"

Alongside providing opportunities for education, training and employment, some leaders reported other ways in which the PAS enabled them to prepare vocationally or professionally. Examples cited by leaders include: "The PA opens a lot of doors for me and gives me more scope and options. I've done a number of night classes and various computer courses. Without a PA, it would have been a lot more difficult" "Writing is my life and not having a PA held me back intellectually and hindered my progress. What would take me 3 to 4 hours to do, I could do in one hour with a PA. My PA can now write for me and I will dictate. It is much quicker and I can push my mind and thought processes to move much quicker. I have now prepared my novel to a stage which is presentable to my literary agent."

#### **4.6.3 Macro Impact**

While it is not possible here, due to limitations of time and resources to carry out a complete and in-depth analysis of the macro impact of the INCARE programme on policy and service provision, it is possible to make some observations and comment upon them. It is clear that independent living is on the service providers' agenda and is very much in

fashion in the world of disability. However one of the main concerns at present is the lack of any true understanding of what independent living really is and as a result, there exists the risk of the dilution of the principles of the philosophy.

Possibly one of the most important and noteworthy effects of the programme has been the break-through in the well-established institutional approach to providing care, especially for people with significant disabilities. Independent living proves that alternatives to institutional care can and do work where the patient role is dropped and the consumer role assumed, with consumer control, peer consultancy and self-help at the centre.

As a new form of service delivery the INCARE programme has shifted the emphasis away from the current rehabilitation model where the individual with a disability is trained by experts and professionals to do everything for ..him/herself and then he/she will be considered 'normal' and 'able' to fit in. Very often this 'living independently' approach is confused with the independent living model. The INCARE programme is beginning to reverse this trend. emphasising instead, quality of life with assistance -assistance which must necessarily be consumer controlled.

People with disabilities, by successfully managing and controlling the service, directly challenge the existing approach to service provision, where there has been no room for consumer input. The INCARE programme is at the 'cutting edge' of disability in asking questions about and challenging the existing 'system'. It is also not possible in this context to measure the effect the programme is having on public attitudes and awareness. This aspect of the programme in itself requires a separate analysis and evaluation. However, a number of outcomes have been noted.

By promoting through action, of a new and positive image of disability and through a process of re-education, public attitudes are beginning to change from seeing people with disabilities as pitiful objects of charity to individuals who are equal and have the same rights as everyone else. Because of their increased participation in social and economic life, people with disabilities are becoming more and more visible in the streets, in school, in college, in the work place and in the social environment. This, in turn, is affecting public attitudes and creating awareness of the numerous environmental and architectural barriers which face disabled people on a day to day basis.

There is a gradual shift away from viewing disability as an individual problem towards a societal acceptance and responsibility of viewing it in the wider environmental context. In terms of overall impact, the programme has also begun to influence more and more people with a disability. Through empowerment of individual leaders involved in the INCARE programme, other people with disabilities are becoming aware of the options and alternatives. There is a raising of the individual and collective conscience and subsequently a movement out of the passive dependency culture. There is an increasing solidarity among all disabled people in their struggle to achieve independence and equality. The INCARE

programme is creating choices and options. Independent living is not intended to suit everyone; there will always be people who will want to choose other alternatives. Yet the ever-increasing demand for personal assistance illustrates that the disability movement is effecting change.

Disabled people are equipping themselves with one of the most important tools of power - knowledge. 'Self-help' approach is a practical manifestation of and central to the disability movement itself. People with significant disabilities will no longer tolerate existence at the margins yet want no more than everyone else determination, control and self respect.

#### **4.7 Disadvantages and limiting Factors of the Programme**

As with anything new or innovative, there will be initial and other problems encountered and limiting factors to deal with. The INCARE programme, as the first of its type in Ireland promoting a completely new form of service delivery, has had and continues to have problems. But the action-research 'learn by doing' approach allows for constant re-evaluation and implementation of change where deemed necessary. It was found, during the course of the research, that one of the main problems was leaders lack of experience and knowledge of independent living.

Because of their systematic and continuous exclusion from social and economic life, people with significant physical disabilities were never afforded the opportunity to participate, and subsequently lack the confidence necessary to assume control. Instead, the 'cosy prison' of special education, special training and residential care has meant that they were always in, as one leader calls it, a "safe environment", where everything was decided for them, where they had no choice, no responsibility and, most importantly no control of their own lives.

Moving away from this safe environment was difficult and overcoming the fear involved presented many challenges to the leaders involved. As many of the leaders pointed out, assuming newly found responsibility and control of your own life, is not an easy task. Individual leaders encountered specific problems including finding the 'right' personal assistant, lack of compatibility between leader and PA, personality clashes and being able to keep the PA for one year only. The latter is due to the nature of the FAs Job Training Scheme, which lasts for one year. The FAS training allowance, which is 'topped up' by EU Horizon funds, is relatively low, which in turn restricts and limits the number and type of people who are attracted to and remain in the job. It was difficult to attract suitable males PA's and PA'S who were willing to do 'overnight stays', in part due to the lack of financial reward. Those with only one PA, especially those in college, found it restrictive and could use more PA hours than the 35 available. With only one PA, it was difficult to find a replacement when the P A needed time off or was sick. It was also felt by some leaders that participation on the programme was time consuming taking up a lot time, especially the training aspect. One leader found the time factor a main disadvantage; "... as a disabled person you hardly have time to live. By the time you organise everything to attend

meetings, it doesn't give you much chance to enjoy life. The whole package can nearly end up taking your freedom from you because you have so many commitments."

Furthermore some leaders found that using personal assistance in itself was a disadvantage, having to guard their privacy and autonomy and learn to create space for themselves and their PA. Another disadvantage identified by leaders is that although they should be seen as 'the employer' very often the PA thinks it is 'the office' who employs them. However, the reality is that leaders are not in the legal sense the employer. They are participants on a training programme.

As the leaders do not have direct control over the financial resources it was felt by some that they did not have ultimate control. The following examples explain leaders' predicaments: "The payment issue can be restraining. It is outside my control, more or less. If I have a question about my PA I have to ask the office." "Even though I give my PA the cheque at the end of the week, my PA thinks it's the office who is employing her." The training programme for the PA's also presented some problems at the early stages. Again, the majority of the problems encountered were due to the 'newness' of the programme.

Following a review of the first two modules, the leaders expressed concerns over the fact that PA training has begun to move away from the independent living model; the leaders themselves did not have direct control over the amount and type of training which had taken place. They were not involved directly in the preparation of the training weekends. Furthermore, both leaders and PA's felt that the use of outside guest speakers/professional was not appropriate, as many of them were operating from a different perspective and philosophy to that of independent living. To overcome this a number of changes took place in the method and type of delivery of PA training.

Leaders, through the Training Advisory Group are now directly involved in all policy decisions and implementation of the training programme. One leader, talking about the pressure which the programme has placed on him and other leaders, sees it as a disadvantage. He says: "We have to run so fast to stand still. We're not just developing a PAS, we're developing a whole way of life. We're the pioneers and that carries a huge amount of weight in terms of commitment and responsibility. You have to develop a political awareness. Every action has to start with you, be developed by you and finish with you. The other real disadvantage is that, because we're doing something that hasn't been done before, it is very threatening. We're operating something which needs money up front, that's a huge disadvantage. When we spend money we don't spend it on buildings or on anything tangible or physically visible. It's always very difficult to justify in relation to the existing system, what we're doing." Other more general disadvantages and limiting factors identified by the leaders include the insecurities of the programme and being unable to make long-term plans in relation to independent living. Not knowing what the future holds raised many questions for leaders: "Will I be able to finish college; Will I be able to continue

in my job; will I have to give up my flat and return home or to residential care,. will I have to give up the lifestyle I now enjoy?"

A further disadvantage is the job insecurity for the personal assistants following the completion of their training. With no recognition of their occupation in the wider context, PA's lack job security and are unable to plan their future careers. Whilst some of the disadvantages arise out of the 'newness' of the programme, many of them are as a result of its 'pilot' nature and will remain until the personal assistant service is mainstreamed and regularized as a consumer controlled service, which enables and empowers people with significant physical disabilities to achieve independent living.

The leaders, some with almost two years experience of the PAS, have throughout that time gained a wealth of knowledge and know-how in relation to the management of a PA and the achievement of independent living. Once over the initial problems, leaders have learnt from their experiences what to do and equally importantly, what not to do. Through training and peer consultancy leaders are able to share the fruits of their experience, advise and educate each other.

## **5. CONCLUSION**

### **5.1 Main Conclusions**

Using the philosophy of independent living as the framework of analysis, this report represents an attempt to systematically describe and analyse the INCARE programme, the impact it has and the extent to which it has achieved its aim of independent living. Through the 'action-research' approach the INCARE programme has proved that a personal assistance service is what makes independent living a reality for people with significant physical disabilities.

Furthermore, as the research findings indicate, the development of a consumer controlled PAS is an essential element to the achievement of social and economic inclusion of people with significant physical disabilities. Yet personal assistance is only one of the elements necessary for active labour force preparation and participation. Numerous other social, economic, attitudinal and architectural barriers must be changed before people with significant disabilities are included in all areas of life. Like many of its predecessors in Europe and the United States, the success of the programme is based on the grass-roots development and self help approach and putting people with disabilities first. They are not longer talked 'about' or 'for' on an agenda set by others -they are taking a leading role in services which affect their lives.

Personal assistance as a tool of empowerment has meant that leaders are not only achieving independence, they are becoming contributors to society, as workers, tax payers and active citizens. By an examination of life before and after the INCARE programme, the report also serves to highlight the huge changes and improvement in quality of life

experienced by the majority of leaders and the enormous and positive influence it has had on their lives, despite the problems and limiting factors encountered. The examination of current statutory provision illustrates that at present in Ireland it is not possible, through use of existing services alone, to achieve independent living. There are numerous shortcomings.

Administrative and legal constraints, professional practice and attitudes and the lack of knowledge reinforced by complete absence of consumer involvement have prevented the development of the independent living approach and philosophy in Irish disability policy. The outcome has been that existing services do not enable people with significant physical disabilities to have the choice to live in the community with all the necessary back-up and support~ they do not allow people with disabilities to be self-determining, exert control, take responsibility or make decisions on his/her own behalf. As a result people with disabilities remain 'passive' dependents in need of 'care'. They are viewed only as a burden on society and its resources. Dependency is a huge cost, and as a study on independent living in the US concludes: "Keeping disabled people in dependency is costing many times more than would helping them to independence. To do nothing on the basis that our ability to respond to the problem is constrained by the inflation is to feed that inflation and further reduce our capacity to solve the problem of disability. The costs of not eliminating the dependency will vastly exceed the costs of spending to make the disabled independent"(Bowe, 1980: 203)

The success of the INCARE programme in allowing leaders to control how their support needs are met, provides a good model of the empowerment of disabled people by demonstrating that, given genuine choice and adequate resources, disabled people are able to exercise control over their own lives and reduce for themselves their enforced dependency on inadequate services. This report suggests that the development of personal assistance is not just morally desirable and professionally appropriate but also offers the possibility of providing more cost effective and efficient services.

As a study on personal assistance services by the Greenwich Association of Disabled People has illustrated, it is possible to conclude increased efficiency and effectiveness is achieved through switching from the over production of welfare services that people don't want or need, and the underproduction of those that they do, to a situation where the services that are produced and purchased by statutory providers are precisely the services that users want and need. (Oliver and Zarb, 1994)

Similarly, the INCARE personal assistance programme is one which consumers want and need. An examination of the national and international scene illustrates that PA 's have proved their worth over and over. In some countries they have become an integral part of statutory services, in others they remain outside their realm - depending on the model adopted, the method and delivery of services and the philosophical underpinnings of social policy within the particular country. In order to further promote the development of

personal assistance at statutory level, in 1993 the United Nations in their Standard Rules on the Equalisation of Opportunities for Persons with Disabilities declared the following: "States should support the development and provision of personal assistance programmes and interpretation services especially for persons with severe and/or multiple disabilities. Such programmes would increase the level of participation of persons with disabilities in every day life, at home, at work, in school and during leisure-time activities". "Personal assistance programmes should be designed in such a way that the person with disabilities using the programmes have a decisive influence on the way in which the programmes are delivered" (preconditions for Equal Participation Rule 4 paragraph 6& 7)

The Standard Rules, while supporting the development of a personal assistance services, also advocates the all important consumer involvement.

## **5.2 Consumer Control**

Apart from the peer consultancy, one of the most outstanding and unique features of the programme has been the issue of consumer control. It has been central to the INCARE programme and the development of a model personal ,assistance service. Consumer involvement per se represents a new departure not only for disability but social policy in Ireland.

But a first step in controlling and assuming responsibilities for one's own life is to control one's own assistance. In this context, as the report has shown, the disabled person must be trained to take on the role of both 'employer' and 'trainer'. The person with a disability is therefore able to decide the where, what, when and how of his/her own assistance, the type or level of help he/she requires, the hiring, evaluation, appraisal and firing (if necessary) of his/her own personal assistants.

The emphasis on consumerism provides for the development of "Consumer control gives people with disabilities a chance to grow as individuals and to learn how to be independent. Until I joined the programme I found that people were making decisions for me down to when I went to bed; got up, studied, to when I went to the toilet. But the PAS has given me the chance to be independent in mind and body, to make my own decisions and accept the consequences. The programme has taught me and others how to be an individual." Clients of the Independent Living Fund (ILF) in Britain who 'buy in' personal assistance have had similar experiences of consumer control: As Kestenbaum (1993: 35) explains: "For many applicants the Independent Living Fund (ILF) was not just making up for unavailable statutory services, it was the preferred option from a disabled person's point of view. The provision of cash makes the important difference between having one's personal life controlled by others and exercising choices and control for oneself Money has enabled ILF clients not only to avoid going into residential care, but also to determine for themselves the help they require and how and when they want it to be provided. Interviews with ILF clients showed that, contrary to much received professional wisdom, many of even the most

severely disabled people can successfully manage their own care." The 'consumer control' approach to services for people with disabilities directly reflects the overall thrust of the 'consumer first' philosophy of the recently published Health Strategy, Shaping a Healthier Future, A Strategy for Effective Health Care in the 1990's in which the Minister states: "The Strategy firmly places the consumer first and sets out proposals for improved participation in the planning and evaluation of services." Furthermore, the Strategy's main theme of the reorientation of the system by reshaping the way services are planned and delivered is a new departure, and opens up the opportunity for consumer involvement.

But most importantly, the new Health Strategy is central to the lives of disabled people because "the primary and unifying focus of all efforts" is not only to improve peoples' health, but is also to enhance the 'quality of life' and to have a 'social' as well as a health gain. The shift in emphasis is necessary if independent living is to become a reality for people with a significant physical disability, as independent living is all about quality of life, with assistance. all about quality of life with assistance. The Health Strategy presents a real and exciting challenge to the existing system, provides an opportunity for long term change and a shift in emphasis towards consumerism.

### **5.3 The Expanding Role of Personal Assistants**

One of the conclusions of the report and illustrated by the research findings is that the role of personal assistant varies extensively in the type and setting of work depending on the individual leader's requirements. The role of the P A has expanded considerably from the original perception. The assistance is not compartmentalised into time locked and neat packages. It is as flexible as is required and involves assistance in all aspects of one's life.

The work of the PA is valued highly and the leaders in the CIL are continuing their efforts to gain acknowledgment and increase the status of the 'personal assistant'. The CIL have recognized the importance of good quality consumer controlled and certified training for PA's. the PA's themselves have taken steps in this regard by forming their own organization both to increase awareness and create job opportunities for themselves both in Ireland and abroad. The personal assistant as a new category of personnel in Ireland continues to challenge the institutional approach of providing 'care' and instead focuses on 'assistance' in the community environment.

### **5.4 The Future**

While the INCARE programme, as a practical manifestation of the independent living movement, has been instrumental in terms of breaking new ground, challenging dependency and empowering people with disabilities, there is still a long way to go. Its future presents a huge challenge to Irish society as a whole, service providers, policy makers and people with a disability. The pilot phase of the programme is now drawing to a close and the future remains insecure. There is no longer a need to pilot the service. The

programme has proved its worth and the time has now come when people with disabilities must be invested in and not viewed as a burden. The first move has been made out of the passive dependency culture by a small group of people, who working against the odds have achieved the aim of independent living.

Yet the struggle is no where near its end. Instead it is only the start of a very long process to come. But disabled people are individually and more importantly, collectively, at the strongest they ever have been within themselves and are demanding their rights as equal citizens and as one leader puts it: "The situation is that we as people with disabilities have much greater expectations. It is no longer acceptable that we be institutionalized, isolated, segregated and treated as special. It is no longer acceptable that we're left outside of life, housing, buses, trains, school, college or work. My expectations for the future are great. So many people with disabilities are starting to say 'I want'.

Therefore on the one hand, leaders are embracing a fighting spirit, and an enthusiasm for life and collective responsibility. They are determined not to let the PAS go. On the other hand, the stark reality of a retrograde step back to a life of dependency and institutionalization is still fresh in the minds of many of the leaders. A future without the PA is discussed in very negative terms, including 'moving back', 'relying upon' and 'merely existing' again. Apart from being unable to go to school, college or to work, leaders' reflections on their future without a personal assistant capture it all: "I would probably retreat back into my depression. I don't want to think about it because I can't face life without a PA. S

So what would be the point in merely existing?" "Residential care would be my last and only resort. I would rather die in a way than go into residential care, because I've been in some pretty awful places." "Institutional care is the last thing I want. I don't see any life beyond that point." "I would become a vegetable".

## **5.5 Final Remarks**

It is hoped that this report has captured some of the spirit and unbridled enthusiasm which has characterized the programme since its instigation. The energy, willingness and enthusiasm of both leaders and personal assistants made the programme into what it is. INCARE is about and by people with disabilities: the passion which they bring to the programme is invaluable. Unfortunately, it is outside the scope of this report to discuss the processes and detailed day-to-day workings of the INCARE programme and identify the CIL staff and numerous other people who supported and made the programme happen. It would take many more pages to even begin to capture the 'action' and activities of the CIL and the workings of the INCARE programme over the past two years.

Finally, as the philosophy and paradigm suggest, disability must to be seen as part of the whole society's common experience and not as a separate and problematic issue.

Responsibility for the problems of disability must not stop at the person with the disability. It is everyone's responsibility, and requires an all encompassing response. Disabled people must be viewed as and intrinsic part of the social structure of society. Inclusive, as opposed to existing exclusionary and separatist policies is where their future must lie. While the INCARE programme is only the 'tip of the iceberg' in the bigger independent living picture, its leaders are becoming a strong political and economic force and an important voice for many people with disabilities. Independent living is what people with disabilities want: it is not just a passing 'fad', it is here to stay.

Policy makers and service providers cannot and should not ignore that fact. The CIL has succeeded in starting to break down some of the numerous environmental barriers to the achievement of independent living and challenge the passive dependency culture. Most noticeably, it is continuing to empower and invest in people with disabilities as individuals.

As one leader so succinctly puts it; "Twelve months ago, there was no light at the end of the tunnel: now the tunnel is wider and the light is brighter. The world is at my feet. It's up to me to make it happen"

## **6. Recommendations**

(i) Establish an Independent living Fund (ILF) for the purpose of the provision of funding for a consumer controlled personal assistance service for people with disabilities who require assistance.

(ii) Maintain, through the Independent Living Fund, the existing INCARE programme funding for 50 PA'S for 25 Leaders Cost of a Trained Personal Assistant £7,500 P A Salary Per Annum £15,000 Leader Coordinator £15,000 PA Coordinator Cost of a Trainee Personal Assistant £4,800 Trainee Allowance £2,000 Training Costs Meeting training costs requires partnership between FAS, Department of Social Welfare/Department of Health/National Rehabilitation Board.

(iii) Establish service brokerage as the preferred method of delivery of the personal assistance service initially, rather than a direct payment system.

(iv) Support the development of good quality training to enable people with a disability to fully utilise the ILF, to achieve independent living and active participation.

(v) Recognise the role and status of the new category of personnel - the Personal Assistant. Acknowledge the value and importance of their work through appropriate certification and remuneration.

(vi) Any organisation (statutory or non- statutory) which uses the phrase 'independent living' must only utilise it in terms of the philosophy of the independent living movement and ensure there occurs no dilution or distortion of the essential elements of the philosophy.

(vii) Statutory and non-statutory bodies must promote active and real participation by

people with a disability and to involve them in policy decisions and service provision which affect their lives.

(viii) Spending on disability should be monitored to ensure that it is not spent on reinforcing segregation, isolation and dependency.

(ix) Invest in people with a disability as individuals rather than view them as a burden on society and its resources.

(x) All research agencies should promote and engage in participatory and emancipatory research by people with disabilities to be used in informing and influencing future policy developments in the field of disability .

### **Appendix 1**

CIL International Affairs The Center for Independent Living from the outset, recognised the essential importance of establishing and maintaining contacts at international level. It established an 'International Cell' which is very active and has successfully initiated and maintained links with similar groups and individuals both in Europe and the United States, involved in the world-wide independent living movement. The CIL seek not only to draw from the experience and expertise of other nations, but also to influence the world agenda in the area of disability.

Prior to and during its development, the INCARE programme had a number of key advisors including people from the United States, Yugoslavia, Britain, the Netherlands and Sweden. All the advisors have one thing in common, they are people with a disability who themselves use personal assistance. In this way, the INCARE programme remains true to the independent living movement.

The CIL have also established an International Working Group on Disabilities with the aim of accelerating progress in the area of disability and made up in the main, of people with disabilities. It has strong international links and the Working Group addresses four main areas; legislation, exchange programmes, European funding and the international symposium. Plans are currently underway for the symposium with the theme, 'Visibility: Investment not Burden' In the two years of its existence, the programme has created a tremendous trans-European impact and has developed a prototype PAS for countries all over Europe.

The INCARE leaders have been involved in the exchange of experience and sharing expertise with countries including, The Czech and Slovak Republics, Denmark, England, France Spain, Portugal and Italy. Some of these countries are in the process of developing independent living and personal assistance programmes, others are looking to the INCARE programme to revitalise their own ideas and approaches. The transnational element of the Horizon programme also enabled the CIL to establish links with German counterparts, The Center for

The Promotion of Employment of Persons with Disabilities (Zentrum fur Selbstbestimmtes Leben Behinderter e.V.) which involved the exchange of information and two-way study visits to share experiences and expertise.

On December 3 1993. International mid European Day of Disabled People, people with disabilities in Ireland were represented in the first ever European Disabled Parliament by four of the INCARE Leaders. CIL leaders have also participated in a number of international and European Conferences, and presented a paper entitled 'Personal Assistance Services -A New Approach' at the Rehabilitation International 6th European Regional Conference held in Budapest in September 1994. Because of the important transnational interest the Centre for Independent Living are initiating plans to establish a European Centre of Excellence on Disability Studies in Dublin. The Centre's primary objective will be to promote research in the field of disability and the relevant policy areas, to promote new forms of disability research, set a new agenda, advance a European perspective on independent living and exchange information, ideas and expertise in the field of disability. Ireland is uniquely suited to be the location of the Centre and would be meeting demand at an international level which has in part been created by the success of the INCARE programme.

## Appendix II

### The Personal Assistant Perspective of the INCARE Programme

Rosaleen Doherty

#### OVERALL IMPRESSIONS

The group of Personal Assistants who graduated in August 1994 were the first of their type in Ireland. As with anything which is being developed for the first time, there will be unanticipated problems and issues arising from both the PA and leader perspective. Therefore, the development of the INCARE personal assistant service was a learning experience for everyone and set a precedent for future personal assistance services in Ireland. For some of those people who have gone through the year long training course and are now qualified Personal Assistants there is an emptiness: while the demand for personal assistants still exists, the funds are not available to employ us in a full time capacity. However, to speak on a personal level, I have gained a lot of experience, knowledge and job fulfillment, throughout the year long training and work as a PA.

#### THE ROLE OF THE PERSONAL ASSISTANT

Our main role as a personal assistant is to enable the leader to exercise choice and control in their own independent and individual lives. The range of work varies, personal assistants may work in the leader's home, at the leader's workplace/study place, in the social setting or it could be a combination of all three. The personal assistant works a thirty five hour week and when he/she works varies with each leader. The job of personal assistant is not a

regular one and a PA may have to work unsociable hours which can be very demanding of your own social life. An essential part of being a personal assistant is that he/she must understand the philosophy of independent living and work from the perspective at all times. They must act in a manner which respect the dignity, confidentiality, privacy and autonomy of the person they are working for. They should strive not to hold any prejudice against race, religion or gender. At the same time, it is very important for us as personal assistants to remember to live our own lives because sometimes without realizing it, we may tend to live around our employers and let our own slip away.

## THE TRAINING PROGRAMME

Many of us have gained through the training programme, an insight into the world of disability and disability issues. With training we find ourselves communicating with the world around us with more ease. The year long training course was a combination of on-the-job and classroom based training. The classroom based training held on weekends was demanding and many PA's felt that after working all week they were entitled to time off. Apart from the actual training, the most beneficial aspect of the training weekends was spending time with other personal assistants having the time to talk, share experiences and realise that they were not in this alone. I think that apart from the communications module the first aid training was valuable. The modules were very well presented, interesting and enjoyable. Most of the PA's were eager to learn and gained further knowledge to enhance their skills. Some were nervous at the beginning because it had been a considerable amount of time since we were in a classroom situation. For those of us who may not be very experienced in household maintenance the training in this area was quite relevant, but for future it should be made optional as not all Personal Assistants may need this training for their work..

## CERTIFICATION

Certification for our training is important because it brings value to our work, our careers and our future as personal assistants. The type of certification we receive is equally as important and should in future reflect the type of work we do and the philosophy form which we work. (\*Rosaleen Doherty is one of the Personal Assistants who graduated in August 1994. She is currently employed as a PA by a CIL Leader)

## APPENDIX III

List of Reports and Submissions Produced by tile Center for Independent Living

CIL (1993) Publicity Pack (contains copies of all press coverage of the CIL and individual leaders}

CIL (1994) Preliminary Report on the Research Ending of the INCARE Personal Assistance Programme, unpublished.

CIL (1994) Response to 'Shaping A Healthier Future -A Strategy for Effective Health Care in the 1990's, unpublished.

CIL (1994) Response to the Green Paper on European Social Policy, unpublished.

CIL (1994) Submission to the Commission on the Status of People with Disabilities October, 1994, unpublished. (Outlines CIL's stance on the different issues raised by the Commission)

CIL (1994) Training Programme Specification for the Certificate in Social Studies (Disability Studies), unpublished. (The TPS details the new leader training programme, its aims, objectives, modular breakdown, etc.)

CIL (1994) Report on the Impact of the INCARE Personal Assistance Service on the Employment, Education and Training Opportunities for People with a Significant Physical Disability, unpublished.

Halligan, N. (1994) Training Development Plan/or Personal Assistants, CIL, unpublished. (This report presents the plan for future training for Personal Assistants based on a listening survey with leaders and PA's )

INCARE (1994) Six Monthly Activity Report, July -December 1993 INCARE (1994) Six Monthly Activity Report, January -June 1994 INCARE (1994) Six Monthly Activity Report, January -July 1994 (These three reports describe in detail the activities of the INCARE programme from its inception)

McGettrick, G. (1994) Independent Living CIL, unpublished. (This short paper describes the independent living movement, the independent living philosophy and the independent living research paradigm)

Naughton, M., McGettrick, G. and Rajkov, G. (1994) Personal Assistance Services -A New Approach, Research Paper presented at the Rehabilitation International 6th European Regional Conference, Budapest, September 1994. (This paper outlines the CIL's approach to personal assistance services, the importance of the need for good quality training for personal assistants, the recognition of the role and status of the PA and their role in the Disability Movement.)

Toomey, J. (1994) Listening Survey of Mature Leaders, CIL unpublished (This report outlines the results of the listening survey on the training needs of leaders)

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