

HCIL PAPERS 1990

The enclosed Papers are written by way of trying to arrive at an HCIL response to a number of current topics.

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HAMPSHIRE CENTRE FOR INDEPENDENT LIVING

Independent Living.

What is it?

Why do we need it?

What can we do to promote it?

Independent Living is the term used by many disabled people to express a general concept, within which is implied a further definition in respect of the particular issue of assistance with daily living.

The general objective is that of personal autonomy or self direction in a world whose attitudes and structures would enable physically and intellectually impaired people to enjoy equal opportunity with their able-bodied peers.

The particular issue which currently receives most attention, and so is most closely associated with the phrase, is that of control over the Personal Assistants required to overcome individual physical and/or intellectual limitations. Indeed it has been suggested that the degree of control granted is a direct measure of the quality of "independent living".

In this country, which is only in the very earliest stages of the enfranchisement of disabled people, the present focus of attention is control over the assistance necessary in tasks associated with every day life, i.e. getting up, going to bed, personal hygiene, eating, shopping, cooking and cleaning.

The major issues facing disabled people in this area relate to who decides how much Personal Assistance is required, who chooses the Personal Assistant, who decides what the Personal Assistant does, and when and how it is done.

The question of what a Personal Assistant does, that is, the purpose of Personal Assistance, is particularly relevant as it is directly concerned with current statutory attention being given to Assessments and the role of Case Managers. Regarding this, it is essential that disabled people articulate clearly their wish for equal opportunity and that this should be the purpose of any enabling.

Demands for Assistance at "work and play" are already being made by disabled people and this should be expected. Life is more than eating

and sleeping, despite the fact that the statutory authorities seem to perceive these as the only needs to be considered.

Disabled people see the new battle ground as the struggle between the narrow definition of "independent living" imposed by the servants of society and that of our own broader concept of "independent living" as the enabling of equal opportunities. The right to Personal Assistance and control over it is seen by disabled people as being the way to enable equal opportunity.

The major problem that disabled people face is the fact that society has no view of them as fellow human beings aspiring to and expecting equal opportunity, having in the past, and to a large extent today, left this responsibility to the goodwill of family and friends with the state giving them only the meagrest of encouragement and support.

To complicate this we have a history of the misguided intervention of well-meaning individuals and voluntary institutions whose original "love for their neighbour" has resulted in them gaining and exercising power on behalf of the disadvantaged people they purport to "love" and interpreting their "love" by determining the lives of the "loved ones". A contradiction of the biblical injunction which directs Christians to help people to be what they want to be and not what we want them to be: "love your brother as yourself" .

Also, we cannot ignore the role of medical and social welfare professionals over the years. These have been entrusted by society to act in our best interest which has resulted in their exercising extreme power, defining and determining our lives whilst also fulfilling the role of gatekeepers to society's limited benevolence.

This background results in a society incapable of facing up to what is involved in enabling equal opportunities for disabled people. It allows government to appear most enlightened when in fact they are backward in the extreme. Meanwhile a better understanding of their fellows gets no nearer.

Major solutions require greater public awareness of the aspirations of disabled people and a commitment to enabling true equal opportunity from cradle to grave. In particular the cost implications need to be discussed in the broadest possible terms so that society can make an informed decision. Such public debate is preferable to the present

situation where politicians say they are doing "so much for us" when in fact disabled people experience very little change in their lives.

Parallel to public education and debate disabled people need to be given the opportunity to develop the skills necessary to take control of their lives.

Strategies to this end require establishment. These will include training opportunities, peer counselling, the ready availability of information and advice as well as the personal assistance to use it.

The role of organisations of disabled people should be to promote general policies that move us towards our ultimate goal as well as encouraging specific initiatives that progress this aim.

At a practical level we need to demonstrate that disabled people, when given the opportunity, can and have developed appropriate responses to their needs and have achieved levels of personal autonomy that confound received wisdom.

Whilst these recommendations may appear vague it is necessary to realise that what we are proposing is a frame-work within which the wealth of ingenuity and imagination of our fellow human beings can flourish as each person designs for him or herself independent living", as he or she works out his or her personal aspirations within the context of the real world, which, in exchange for this privilege it affords all citizens, demands the exercise of responsibility and citizenship. True equal opportunity, enabling the exercise of personal attributes in furtherance of personal responsibility and collective dependence.

Our job is to establish the framework - not to define the individual outcome. We must not fall prey to the crime of which we accuse today's establishment.

Additional Points:

I There is some grudging acceptance by society of a need for physical assistance where physical impairment results in the loss of function. However people with hidden impairments or fluctuating functional abilities are considered far less favourably. Worse still, assistance of an intellectual nature is barely considered at all. We need to be saying that all are equally deserving of society's enabling.

II Some disabled people feel that we should not share our ideas with social welfare charities and professional people, as this enables them to re-interpret them and maintain the dependency relationship. However understandable this view may be, we are interdependent and what is important is that disabled people retain the initiative.

Consumer Consultation

Consumer consultation: What does it mean and how should it happen?

Hampshire Social Services recently published a consultation document on the future of services for disabled people. The paper was called "Positive Partnerships"¹ thus implying that an essential feature of future policy would be the active consultation of disabled people. This is in keeping with the spirit of recent national developments such as Section 10 of the Disabled Persons Act of 1986.

It is important for disabled people to consider among themselves what they think the process of consultation should involve and the purpose of writing this paper is to start the debate.

The reason for consultation: The ultimate objective of services must be to enable equal opportunity for disabled people, any other purpose is a denial of our humanity. It is only the disabled person who can satisfactorily define his or her needs in terms of the enabling of equal opportunity. This is the basis of demanding consultation and it is the purpose of consultation.

Consulting the individual and consulting the group: We are quite confident about what must happen when we are discussing matters at the individual level. The problems come when the process of consultation seeks to address broader issues, such as service priorities, which means gaining the opinions of disabled people in general. Just as we believe that we must control what happens in our own lives, so too we think that all disabled people must be enabled to be part of any broader decision making. It is how we arrive at the latter that presents a challenge to us all.

¹ Partnerships are usually between equals. This is not what disabled people usually experience. Indeed one could argue that had the local government's Social Services genuinely intended to implement a partnership with disabled people the document would have been composed of blank pages with policy to be jointly compiled from the start.

First to clarify the more straightforward matter of consultation within the life of the individual.

At the individual level: consultation means each of us being fully in control of what happens in our lives. That is, we should determine and control the services that we require. For example, if we are to receive care attendant help, (a local government in-home lay "care" service) then we should be in control of who comes, when they come, how often they come, how long they come for and what they do.

Some people think that this level of control will only come about when individual disabled people control the money that is spent on meeting their needs. That is, each is given the money. At the extreme they suggest that society should abandon all the statutory "disability" establishment and divide the resulting money up amongst "the disabled". However this scenario is unlikely to come about nor would such a measure be sufficient in itself. Instead we must look for a commitment by the local government Social Services to accepting our right to determine our own priorities and services in each of our lives. This must mean an actual transfer of power from the statutory service providers to the individual.

Now to look at the matter of "consulting disabled people" as a group.

Collective consultation: It is when we move from the individual to the collective that deciding what consultation means becomes more complicated. In these instances it is easier to say what we believe it is not.

For example, consultation is not pulling one disabled person out of the hat and expecting him or her to speak for all disabled people on all subjects, or even on any particular subject.

Nor does it mean calling a single meeting and inviting half a dozen disabled people to speak their mind and responding on that basis.

Nor does it mean inviting opinions from various "pressure groups" or are we satisfied with a "market research exercise", or a "survey of clients needs".

These are all selective processes determined by the service provider and fail to incorporate two most important aspects, universality and interaction. That is, consultation open to all and, an expectation that

participants in the consultative process will "grow" as a result of the experience.

So how can a statutory service provider begin to exercise something approaching genuine consumer consultation, and what do we, disabled people, think should happen?

Consultation within a specific service: We suggest that one can begin in situations where a specific service is involved. It is easier to identify the clientele and to regard them as the constituent available for consultation.

For example, a Day Centre. Local steps have already been taken to enable people in Day Centres to elect User committees to represent their interests. In a similar fashion HCIL have long campaigned for Users of Care Attendants services to be enabled to meet together regularly and to act collectively to represent their common interests.

In this fashion it is possible to arrive at a more satisfactory way of consulting users within specific services. However this process does not accommodate the interests of those people who do not use those services. Nor does this brief description give sufficient emphasis to what we regard as an essential parallel programme: offering the users the opportunity to gain the skills necessary to participate in such processes. Nor have we mentioned the potential for the development of "cliques" in such small groupings and the need to ensure good democratic methods of operating.²

So, how does one go about giving all disabled people the opportunity to be involved in consultation?

General consultation: The local government of Hampshire is dividing its Social Services into four Districts and these Districts are themselves being further divided into Areas. These Areas will have an Area Manager who will, by and large, be responsible for deciding the services in his or her area.

² Some people suggest that in every sphere of life we have to give something in order to gain something and that within services to disabled people the same should apply. Namely that consultation should be a compulsory process both ways. That is, participation in the consultation process should be a condition for receiving services.

This idea sounds alien to our voluntary culture but the proposers suggest that it is a way of ensuring that power cliques do not develop to manipulate the process. Perhaps the solution is worse than the problem; perhaps the problem is exaggerated. Whatever, we need to recognise the danger and ensure that it is minimised.

We suggest that each Area Manager should organise meetings to which ALL disabled people in the Area are invited and enabled to attend. That means arranging the meetings, the transport, the personal assistance to enable attendance and all other facilities such as signers, etc. At these meetings issues of common interest with regard to service provision would be discussed prior to people having an opportunity to express their opinions, possibly by a postal vote.

Such meetings would occur regularly and could lead to the election of local committees who, in turn, might elect representatives to a higher level.

But this will not happen overnight. We must be in no doubt that developing consultation will be a long process requiring a lot of patience and perseverance. We are dealing with a proportion of the population whose history is of not being consulted and of not being involved. To turn this around will take time, resources, and commitment.

Furthermore this consultation must be more than merely a process of gaining consumer support for the Social Services chosen actions. Consultation implies the ability to change a course of action and to influence decisions. We must therefore expect to see genuine power being given to this process.

The intention of the above outline is to ensure that every disabled person in Hampshire has the opportunity to learn about, contribute to, and be part of deciding what services are provided for their benefit in their Area.

Many service planning and delivery decisions have resource implications, local and national political decisions control the extent to which these are satisfied. By inference we are talking about the process of politicising disabled people. We consider this to be a most important step if we are to go on to put our case to the general public.

Additional points:

I. Only a minority of disabled people actually use local government Social Services. Disabled people are concerned about much broader issues: such as information, education, transport, employment, housing, recreation etc. That is why regional organisations of disabled people are coming into being and should receive financial encouragement.

II. Many people in the group we are discussing lack the skills needed to act in the manner we are assuming as necessary for participation. We should recognise this fact and ensure that learning opportunities are provided, as well as making sure the consultation process is relevant to all.

III. Apathy must not be allowed to be taken as endorsing either the status quo or negating the above proposals. Apathy is a disinterest in both, equally, and we should remember why disabled people have especial reason to be apathetic.

IV. As already mentioned, it is important to insist on processes that seek to ensure democratic practices.

V. Finally some people may wonder why disabled people, who elsewhere seek integration etc, are not prepared to let the normal democratic process represent their interest? Why are we asking for something special when it comes to consultation? Why should we be treated any differently from other groups in society?

The answer must be that in the ideal world disabled people's interests could and should be represented through the normal process. Eventually, if and when genuine integration takes place, we have to believe this will happen. That one day disabled people will be so much a part of everyday life that society will value them and as a matter of course respect the enabling of equal opportunity.

In the meantime we have to say that the democratic process does not represent our interests. It does not take much to see that the average councillor, whether district or county, has little or no understanding of disabled people's everyday experience nor their aspirations. At the national level one's experiences indicate that MPs, Ministers and senior civil servants are equally ignorant. The interests of disabled people are not adequately understood or represented.

We believe that in these circumstances it is quite legitimate to seek for "special interest" representation in order to ensure that the will of this group of people is taken into account. There are both gender and race precedents for such an argument and we see this issue as being of that magnitude of importance.

Summary:

I. Consultation at the individual level means giving each person the power to decide what happens in his or her life.

II. Collective consultation in specific service groups can happen and should be encouraged and enabled.

III. Collective consultation within a Social Services Area can and should take place.

IV. Consultation means:

- i. All being enabled to participate, both practically and intellectually.
- ii It is a long slow process requiring persistence, that is, years of invitation and enabling.
- iii It must have real power, it must be seen to achieve the changes democratically arrived at.

V. The formation of a broadly based genuinely representative organisation of disabled people needs to be encouraged at the local government level in order that this can influence local issues beyond the Social Services.

VI. Throughout all these developments we should expect to see a number of processes going on:

- i Disabled people should be gaining control of what happens in their lives.
- ii Disabled people should increasingly experience equal opportunities.
- iii Specialist, segregated, paternalistic, and dependency creating structures should be abandoned.

Assessment

Introduction: It is clear from the Government White Paper "Caring for people" that the assessment of individual needs by local government Social Services forms an important part of the future national strategy in Community Care. Just who will carry out this assessment and what criteria it will be based on remain unclear, so too are the areas of consumer rights and statutory obligations. (That is, how the 1986 , Disabled Persons Act relates to this general topic and in particular the philosophical purposes that underlie the definition of "needs".)

Rather than trying to second guess developments perhaps we, disabled people, should say what we want and how it should be done.

Context: It is important to place this debate in context, that is of a people who have been conditioned to being grateful recipients of meagre services grudgingly given; people who are seen as "problems", "burdens" to family and society; people whose existence society barely recognises and makes little effort to accommodate. We need to develop a strategy that takes into account this cultural conditioning if we are to change the ways of determining services. In particular we should not imagine that disabled people will become knowledgeable, discerning, assertive self assessors, overnight.

Purpose of assessment: The internationally agreed directive (United Nations) is that nations must enable their disabled citizens to enjoy equal opportunity and that these disabled people must have the principal role in defining and implementing this policy.

What is equal opportunity: I would say that it is enabling the opportunity to exercise life's choices. What are life's choices? These are the opportunities and responsibilities usually available to people as they go through life.

Method of assessment: Self-identification and self assessment should be the principle. That is, the individual decides what he or she needs in life and how he or she is best enabled to achieve this.

The possibility of further development and changes have to be part of any programme to account for changes due to growth, physical, experiential or intellectual changes, and deteriorating conditions or other changing circumstances.

Implementing the result: Once the needs have been identified, probably in terms of hours of personal assistance per week and/or a specific aid, the means of meeting these needs should be discussed. The most straightforward is that of a financial grant.

Costs: The matter of costs are a reality both to the individual and society. These must be known in order that the individual should be able to make the compromises that may be necessary and that such public knowledge would lead to a better informed electorate who could make their views felt at the political level.

Responsibility: Society would need to be able to come to terms with the probability of people making mistakes.

Advocacy, information, advice, training, counselling, etc: We recognise that there is a need for advocacy and education opportunities in order that informed choices can be made and to enable people to use the funding. This applies before, during and after any assessment.

Until such time as there is true integration from cradle to grave one should expect the provision of these additional facilities in order to balance the cultural conditioning and deprivation identified earlier.

Measuring Outcomes: we need to identify intended outcomes so that we can measure the degree of success in achieving our basic purpose of enabling equal opportunity. For example: are disabled children attending ordinary schools; are disabled people obtaining age/intellect appropriate employment; are disabled people offered normal transport options; are disabled people able to participate in standard social activities? We can identify and measure success within these categories.

There already exist comparisons and the measurable outcome should be to see these comparisons less unfavourably balanced in future. For example the national Office of Census and Population Studies identified unemployment among disabled people at 69%. If equal opportunity policies are effective we should expect to see a change in that imbalance.

That this monitoring needs to avoid unnecessary bureaucracy goes without saying.

Meeting Assistance Needs

The purpose of writing this paper is to demonstrate that disabled people have an abundance of ideas on the matter of meeting assistance needs. These ideas need airing in order to encourage further initiatives and to reassert our intellectual copyright.

The Personal Assistant Model: It could be said that in England the first fruit of the search for autonomy was the Self Operated Care Scheme (SOCS) model for personal assistance pioneered by HCIL:

"The basic principle involved is that a grant is paid to individuals who then employ their own personal assistants in their own homes. It has proved to be the most successful form of community based personal assistance. The person with the disability is completely in control and, within the limits of finance granted, can set their own times of assistance. It is the person who needs the assistance who directly pays the wages to the assistant, and who is responsible for finding assistants, and for dismissing them if inadequate.

The great advantage of this scheme is that the routine is decided by the disabled person, which truly enables them to lead a life of their own choosing.

In practice the scheme has transformed people's lives, opening up new horizons for those who previously might have had to stay in institutional care. This scheme has been successful precisely because it has been designed not through the calculations of professionals but by people with disabilities. The scheme leads to true integration in the community."

(Simon Brisenden, A Charter for Personal Care, 1985.)

However, since the earliest days HCIL have recognized that some disabled people do not relish the Personal Assistant option. The administrative tasks involved can be daunting and time consuming. With this in mind we have set out to indicate alternatives and are now taking this opportunity to document some of these.

In proposing the following options we must stress that society's only valid purpose in providing assistance to disabled people is in order to fulfil an obligation to enable equal opportunity. By and large it is for the individual disabled person to determine what equal opportunity means in his or her life. With this in mind we must ensure the prime role of the

disabled person in defining this and insist on him or her having control of both the planning and the practice of the service. This principle must be part of drawing up any agreement or contract between the parties. Such a contract would ensure that roles and responsibilities were clearly identified with the ultimate control remaining with the User of the service.

Another reason for insisting on such arrangements is to try and ensure that we do not replicate past service power structures that prescribe "solutions". We need guide-lines that build-in a controlling voice for the group or individual directly involved. The purpose being to promote personal growth and less dependence in order to break out of the "grateful recipient" trap, and the "institutional" trap.

This paper does not go into the detail of the agreement or contract which we suggest should exist between the parties in the options proposed. We leave these to later deliberation which we feel must involve an advocacy role from an organisation of disabled people.

Ideally the financing of all options would be through the user. An arrangement which we feel preserves the ideal balance of power.

Third Party Model: In 1986 HCIL put forward a pilot scheme for a named individual. This person did not wish to be involved in recruiting, scheduling and paying staff but did want to have a veto on who was employed and to have local responsibility to direct staff in his home. Our proposal suggested a shared management arrangement with a third party. The third party would undertake much of the administrative work - hiring, scheduling, paying and firing - at the direction of the User .We demonstrated that a financial management addition could be built into the funding to enable the third party to meet these costs.

The arrangement envisaged drawing I up agreements as to procedures and areas of responsibility in order to ensure that no misunderstandings occurred and that every eventuality was catered for . In addition, how use of a remotely operated local telephone "help-line" could ensure independent 24 hour back-up.

HCIL suggested that an existing local government agency already supplying in-home services could be paid to take on this project as a separate activity. In, order to implement the plan the subject needed re-housing so as to be able to, accommodate live-in assistance unfortunately neither the housing nor the Personal Assistance funding

were forth-coming and two years later the individual was admitted to a Residential Home.

We are not proud of this outcome.

Buying Into a Care Attendant Scheme: More recently HCIL has been encouraging local care attendant schemes to take on the role of managing Independent Living Fund (ILF)² assistance for people requesting such an option.

We note that such developments are occurring in different parts of the country and that they are contemplated in Hampshire. However we are concerned that not enough thought has been given to the details of the arrangements between the parties, which should, we think, be like contracts.

We suggest that agreements and procedures must be drawn up between the local Care Attendant Scheme Organiser and the individual user in order to ensure that there is a common understanding between all the parties regarding the terms and conditions of the arrangement. This agreement needs to clarify areas of responsibility, giving the user control over who comes into his or her home, what they do and when, insofar as this is acceptable to the Care Attendant Organiser. These guidelines need to be established at the outset.

We would encourage any disabled person considering such an arrangement to seek advice before finalising any agreement.

The "Dutch Fokus" Model: We have begun discussions with a local residential home about the possibility of participating in a "Dutch Fokus" type scheme. The Home plans to house some of its residents in individual bungalows in an integrated development being planned in a local village. It is proposed to provide assistance to these bungalows from a central staff building. Each bungalow being connected directly to the central office by a communication device.

We have suggested that such a scheme could and perhaps should be extended to include other people living locally.

Again, we think it is essential that agreements or contracts are drawn up in order that participant's interests are ensured and that they have a clear understanding of the arrangement they are entering into.

Working Together: Along with other organisations we have been looking into ways of enabling disabled people to work together to confront some of the more difficult aspects of recruiting, using and paying staff.

Recruiting: HCIL in co-operation with the Options Trust is already well into a one year pilot project on recruiting through a non-profit agency.

Using: We are trying to encourage people to consider employing co-operatively at a local level. We are aware of a few informal arrangements, that is, people living in the same road sharing staff. Such arrangements require a lot of mutual trust.

On the staff side "care" staff in Wallsal, encouraged by the Local Authority, have come together to form a Care Co-operative. Also members of the Derbyshire Coalition of Disabled People have experimented with a care co-operative involving personal assistants and disabled people.

Paying: The possibility of paying co-operatively, a pay-roll co-operative, is also feasible. That is, disabled people co-operating to fulfil their financial and legal obligations. The advantages would be that expertise could be shared to the benefit of all, particularly people not familiar with PAYE, etc.,. Such a local arrangement would help communications with the Inland Revenue.

(May we stress that in proposing co-operative solutions we mean genuine co-operatives, that is, all concerned compulsorily having an equal share in the decision making. We do not mean one group of disabled people becoming service providers to others, this is something quite different.)

Conclusion: We feel that all these options could and should be developed given time, some direction and encouragement. The major obstacle to their growth is the absence of adequate funding for the "organising" or management costs involved. HCIL have always argued most vigorously for a financial management addition to the staff salary element of any "personal assistance" funding- say, wages plus 20%. This recognises a cost that is an essential feature of any Private or Local Government provision.

Given the meeting of "management" costs we are confident that disabled people's ingenuity and imagination will result in the above and many more "community care" options being developed.

Additional Comments:

We must add more about organisations of disabled people becoming service providers. We recognise this development as a possibility and are happy to see examples coming into being. However we must be under no illusions about the nature of service provision and we must seek to ensure the development of balancing structures that will act in the interests of consumers, just as we do with any other service provider. We see this as increasingly important as more and more service provision is "contracted out".

II Two options not considered in the Paper for obvious but very different reasons:

- i The individual purchase of personal assistance services from a private agency.
- ii A local or regional private care agency winning the sole right to provide care to a specific client group.

III In England the Self Operated Care Scheme (SOCS) option was pioneered by HCIL in Hampshire. The Focus scheme was pioneered by Prof Bratgard in Sweden. The Care Attendant Scheme was proposed by Noel Crane in Coven- try. The co-operative recruiting and paying of staff was pioneered by STIL in Stockholm. All are disabled people or organisations of disabled people.

IV Private & Non-Profit agencies providing services must cater for (insure against) such eventualities as bankruptcy and so ensure that they can preserve the consumers interests at all times.

1) Local government funded non-profit in-home "care" (salary only) agencies designed to provide lay domiciliary assistance for the "main carer", sometimes called "family relief".

2) The ILF is a government financed and administered charity that, after a financial, physical, psychological and intellectual means test will, in certain circumstances, provide a regular payment to the individual for the purchase of assistance with "care" - (salary only) that is, help with

personal physical requirements (washing, dressing, toileting, etc.,) and domestic assistance (cooking, cleaning, laundry, etc.) only.

The ILF has nothing to do with enabling disabled people's understanding of independent living and is unacceptable because it fails to address the issue of equal opportunity. That it is a "state charity" is doubly insulting.

Respite Care

We need to address the subject of Respite Care as it receives increasing emphasis from local government Social Services as a valued feature of community care provision. We should recognise that this is the result of a very effective carers lobby who are well organised and have significant influence in public policy and planning decisions as well as considerable public understanding and sympathy. The implications are that this overburdened, manipulated, abused, self-sacrificing section of the population desperately need a break from their overbearing, demanding, ungrateful and manipulative dependants. We should not hide from the fact that means us, disabled people. The carers lobby is successfully playing on public prejudice and public guilt to our disadvantage.

There are also political pressures. Some saying that care should be provided by the family and charity. Others saying that the family needs help from the state and that the politicians know best how to provide that help.

Even among the "pension" pressure groups there are differences. One argues for an adequate "carers income" whilst the other advocates sufficient income in order that the disabled person can make independent provisions for him or herself.

When discussing Respite Care it is most important for us to state quite categorically that the focus of attention should be the disabled person and that our wish would be that person is enabled to enjoy equal opportunity with their able-bodied peers. That is: equal opportunity to exercise responsibilities and to take advantage of whatever society has to offer.

In addition we recognize that before disabled people can be fully integrated there need to be significant changes in public attitudes and the physical structures within society. Given that is our objective it follows that we expect to see disabled people enabled to sustain their

lives in the same way as able bodied people are. That is to say that we do not expect them to be dependant on the goodwill and sacrifices of anyone else for their survival.

It is not disabled people's wish to be burdens to anyone. It is not their choice to have to rely on the charity of friends and families for their daily necessities. That is the condition that society imposes on them. Given free will and the ability to exercise that free will most adult disabled people would choose to respect and value the relationships that they enjoy with their friends and family rather than compromise that by imposing demands that exceed natural bounds. It is important to show quite clearly what our wishes are and where the present blame lies for the position we are forced into.

This preamble is necessary in order to demonstrate that talk of respite care in any official capacity is basically an acknowledgement of failure by society to enable the sustaining of a stable, situation. It is most important to nail that flag to the mast so that whenever and wherever we see the term "respite care" we propagate the clear understanding that this represents an admission of failure. Respite care is another term for crisis management and we would not expect crises to occur if satisfactory provisions were made to ensure that the disabled person was enabled to enjoy secure and adequate support. Crisis management should not be the basis of a nation's social, welfare provision.

As we have stated earlier, disabled people have the long term objective of full integration into society and equal opportunity. In the meantime, as we hope to show below, there are shorter term objectives that recognise the grossly inadequate nature of our present circumstances and try to work within these.

Primarily we should look for policies that provide for sufficient input to ensure that there is no overburdening or unwelcome dependency. We recognise that this requires planning, forethought and financing, which we believe should be largely driven by the wishes of the active participants. Just how these wishes are arrived at is an important consideration and whilst we recognise the importance of consulting both parties we insist that those of the adult disabled person must predominate.

The issue of Respite Care will continue to rear its ugly head and we are forced to recognise that some "carers" will demand this facility most

vigorously in large and well organized numbers. We need to show that there are viable alternatives.

Insofar as people with physical impairments are concerned, we suggest the following. In doing so we recognize that it is important that other facilities are developed alongside these suggested below, facilities and services which provide the opportunity of essential advice, counselling, information and continuing support to individual disabled people in order to enable them to develop their sense of self worth and the ability to make decisions and take control of their lives.

First: we need to repeat that there should be the possibility for sufficient input into a given situation in order to ensure, as far as possible, that a crisis and hence the need for respite, does not occur. This can be achieved via a state pension or disability income specifically intended for the purchase of personal assistance and sufficient to meet individual need.

Second: where a situation is agreed by both parties liable to stress or break- down adequate measures could be taken by considering likely future developments with those concerned. Possible responses should be part of mutually agreed forward planning. For example if an 18 year old severely disabled person is living with ageing parents one can see that there is going to be a need for a change sooner or later. That possibility should be openly contemplated in advance of any crisis.

That is to say long term responses to crisis could be prepared for in advance. This makes economic sense. Crisis intervention is invariably expensive.

Third: In the event of the need for immediate relief it may be helpful to have already drawn up plans for an intervention team. That is, contingency plans drawn up at the direction of the parties concerned for the rapid deployment of local lay personal assistance, so maintaining the disabled person in their present accommodation.

This idea sounds attractive but in practice it would require very thorough

preparation and maintenance, people are always busy when you need them! If the disabled person is already receiving publicly financed personal assistance from a source other than family or friends (as we suggest should be available) then this response could simply be an expansion of that existing support.

Fourth: If the previous options are not sufficient and a physical separation is required, then, again, we would urge the development of contingency plans for a local facility (hotel/guest house), based on lay care or fostering, that can, be used on a temporary basis. We would reiterate however that the long term objectives must be to support a stable situation. Experience teaches that "temporary" solutions often become permanent.

Further Comments:

I. "Disabled Holidays": The idea of "caring relatives" having to divest themselves of their responsibility at regular intervals in order to survive is disquieting. That this should result in the disabled person concerned taking an enforced "holiday" at an invariably distant residential facility is further cause for concern. Such actions postpone rather than remedy what is clearly an unstable situation.

II. The building and staffing of Respite Care facilities reduces the resources available to support disabled people in their own homes.

III. Society is ambivalent. On the one hand society says it cares and is concerned for disabled people and it recognises their stature as equal human beings. As in the United Nations declaration of human rights that specifically includes disabled people. Also the UN statement that governments should ensure provisions that enable equal opportunities for disabled people and that disabled people should be instrumental in defining what this means and how it is brought about. Witness too the general social welfare developments in this country since 1948 and the Community Care rhetoric of the past decade. Not to mention Telethon and the many other charities.

These are all examples that demonstrate society's awareness of our disadvantaged circumstances and the often very generous albeit misguided response.

On the other hand the fact of the matter is disabled people do not enjoy equal opportunity. By and large they are not consulted in the matters

that affect their lives. The vast majority are cared for by relatives or friends at great personal, physical and fiscal cost to all concerned. Disabled people are both financially and in every other respect significantly more disadvantaged than virtually any other portion of the population. As a group in society it has been shown that they are generally poorer, less well educated, more likely to be unemployed, suffer ill health, be mal-nourished, suffer the most medical and \ dental neglect and physical and sexual abuse.

Worse than that, society says it cares, but then proceeds to determine what this means: how it should care, for whom it should care, and how much care should be provided, leaving its officers, (that is either statutory officers or those of the various charities that act in this field), the unenviable task of making these awkward decisions in the face of the knowledge that they are barely scratching the surface of need.

It is this contrast between society saying it does care and the daily experience of disabled people that needs to be drawn out into the open. Disabled people do not see this as a caring society in terms of present day expectations. It is the absence of a genuine commitment, despite all the fine words, that forces the dependency situation highlighted at the start of this paper and it is a consequence of this reluctant dependency that results in the temporary relief being demanded by those forced by these circumstances to provide care. Hence the carers lobby for respite care.

See also "*Day Centres*".

Notes

1 Insofar as people with learning difficulties are concerned it can and has been shown by *People First* and others that non-institutional policies along the lines suggested can be developed based on the principles of normalisation.

2 It is unclear how present government legislation, in particular Section 3 (*Assessment by Local Authorities of Needs of Disabled Persons*), Section 4 (*Services under Section 2 of the 1970 Act: duty to consider needs of disabled persons*) and Section 8 (*Duty of Local Authority to take into account Abilities of Carer*) of Disabled Persons (*Services, Consultation & Representation*) Act 1986 will fit into this discussion when fully implemented. Given society's past record there is not much room for optimism. Remember 1981, the International Year of

Disabled People, whose slogan was: Integration, Participation and Education!)

Day Centres.

Introduction. We need to say something about Day Centres because they exist, a lot of people attend them and they are seen by the carers' lobby and many social welfare professionals as being an essential ingredient of community care.

In our response we should be sensitive to the very real insecurities of the present users of these facilities many of whom see them as an acceptable alternative to their usual confinement at home. We believe that our unexplained opposition to Day Centres alarms the people who use and value them for the facilities offered such as fellowship, cheap meals etc. We should recognise the insecurities generated by our remarks and seek to address these.

Our response will be within the context of disabled people's wish for a fully integrated society that is sensitive to the needs of physically impaired people and people who require assistance with learning opportunities and work. We are looking for a world which accommodates our needs and includes us in the mainstream, that is normal, integrated options and it is in this context that we judge the provisions made.

In looking at Day Centres it is necessary to identify the functions served and in each instance to show that it possible with time, energy and commitment to promote viable alternatives We should note that in implementing these alternatives people will have be prepared to combat prejudice against disabled people as well as overcome the physical obstacles prevalent in todays world.

What is the said purpose of the Day Centre?

1. **Respite care.** A Day Centre is seen as somewhere disabled people are sent in order to give their "main carer" a break. For our response to this please see our paper on Respite Care.

2. **Education.** A Day Centre is seen as a place where physically impaired people and people with learning difficulties go in order to receive training. We should note what kind of training is intended and respond to this.

a. If it is academic education, that is an exam course, literary or numeracy skills, language, art, technology, etc., then these needs should be met through mainstream options. Such courses already exist and people should be enabled to attend these. It is not economically or humanly acceptable that such opportunities be provided in special, segregated facilities.

b. If it is work training such as technical skills, office skills etc., again, such mainstream courses exist and disabled people should be enabled to attend these mainstream courses and their performances at them should be facilitated by the provision of staff or Personal Assistants if necessary.

There is no need for special facilities in segregated buildings. Such provision is an extra expense. Places such as IT Centres have demonstrated that an integrated training centre can function satisfactorily.

c. If the training is of a so-called "independent living"/ rehabilitation nature then we would suggest that this sort of training has been proved to be best accomplished in the situation in which it is intended to apply. Learning how to make a cup of tea in a Rehabilitation Centre rather than the home the person lives in is shown to be of little value. Such lessons are of greatest benefit within the setting of the intended residence.

Courses such as assertiveness training, how to be a better self-advocate, learning how to use the system, learning to budget, how to plan the week's meals, how to ensure that you can contact the emergency services and other support services etc., already exist in mainstream sources under the title of Personal Development, Home Economics, Using Community Information Services, etc.

We would make one slight addition to that remark and that is to say that education of life skills in terms of coping or managing with the various intellectual exercises that need to be performed in order to survive in the community can and perhaps even should be provided in a setting outside peoples' homes and although this could be done in mainstream setting such as an Further Education College, it is the sort of exercise that one might see in a Centre for Independent Living (CIL) where peer experience is the essential ingredient.

More specialist topics such as gaining and using independent living funding, recruiting, employing and managing Personal Assistants and other such training courses, often of a more individual peer counselling nature, may be better suited to the specialist setting of a CIL, though the only thing that sets the venue apart would be that is where the "experts" were and there is no reason why these shouldn't operate out of mainstream facilities if that was possible.

There are some courses which take place in specialist settings simply because that is where the target audiences are, such as how to run elections and choose representatives, how to work in committees, how to understand minutes, etc. These courses are intended to enable the participants to gain the skills thought necessary to become more involved in the management of these facilities (such as a Day Centre). As such they are valuable, assuming that at the end of the day the active participants will be able to exercise real power and perhaps close the Day Centre.

3. Physiotherapy/treatment. Some Day Centres provide remedial facilities where exercises on specialist apparatus or experience of new aids can be gained. We suggest that these facilities should be within mainstream facilities seeking to serve the same ends and that they should not be set apart. By and large it seems to us that the sorts of treatments and facilities required would be seen as being in common with a much larger patient group and in those circumstances they should be provided in common or normal settings, just as we believe medical and dental treatments should be.

4. Social Intercourse. This is a real function as witnessed by many Day Centre Users comments that they feel isolated at home and value the opportunity to get out and meet with people experiencing the same sort of difficulties as themselves. However we need to point out that social isolation is not peculiar to people with physical impairments and that personal immobility is a consequence of inaccessible transport and premises as well as low income and insufficient personal assistants to enable alternative options being taken up, such as attendance at normal social functions in pubs, clubs, churches, etc.

It is our opinion that local government could be encouraged to do all they can to help overcome the structural barriers to social intercourse and enable people to mix with their fellows in normal settings by promoting better access etc.

Having said that we should recognise that isolation is a genuine problem and that loneliness seems to be the Western Societies' disease of the late 20th century .The fact is that more and more people live more and more isolated lives. This is indeed a social problem that deserves attention.

5. Cheap Meals or canteen. A Day Centre as a substitute to local government provision of a door to door cooked meals delivery , "meals on wheels", etc. This is using the Centre to alleviate poverty and/or a lack of personal assistants in the home. We realise that this is a valued service at present and that in proposing alternatives we need to stand out very firmly for options that recognise current poverty and limited availability of personal assistants. A more accurate use of resources would suggest that a realistic income and better provision of personal assistants in the home would obviate this need.

6. Information. Many Day Centres are both an informal and a formal source of information for disabled people in that they meet people who are encountering the same sorts of problems as themselves and there is a mutual sharing, also some Centres operate a limited advice/information service.

These purposes can and should be satisfied by funding local organisations of disabled people, newsletters and other means of information gathering and dissemination. Such developments would cater for many more disabled people than attend Day Centres. Furthermore such developments would come naturally out of steps to involve all disabled people in the local government process of service planning and delivery discussed in the paper on Consultation.

In addition we feel that much more could be done to provide local mainstream information sources such as the Citizens Advice Bureaus with the resources they need to be able to help people use the information that is available to them.

7. Work. All aspects of work opportunities in Day Centres and sheltered workshops have long since been shown as being very unsatisfactory. Integrated work options are a realistic and viable alternative. ICAN projects and others have demonstrated that given time, energy and commitment as well as the availability of personal assistants it is possible to place people with learning difficulties and physically impaired people in mainstream work situations. Such steps require imagination

and the co-operation of employers. This must be the way forward for a civilised society.

However, we do appreciate that at present disabled people do not enjoy equal opportunities and that paid employment poses problems for disabled people with regard to their state pensions and funding for Personal Assistants, and that this raises other issues which must be addressed if disabled people are to become genuine partners in the workplace. Briefly we believe that income to enable equal opportunity should be as of right and unaffected by any other income. The latter should then be subject to the same tax etc. that applies in society at large.

Conclusion: Day Centres are a continuing financial liability, they need maintenance, staffing, heating, lighting, etc. They represent capital tied up in an inflexible manner. We propose a more flexible, more individual response. Options that are tied to a person and not to a place.

These alternatives are not easily achieved, they require a profound change in the attitudes of many of our institutions, businesses and individuals as well as the physical characteristics of our environment. For example, in promoting integrated employment options we are expecting co-operation from management as well as fellow workers, not just in their attitudes but also in the physical environment of the work place as well as the availability of suitable transport to the premises. All of these will require changes. They are not easy options but they represent the only humane and realistic way forward if we are to build a better society and to take seriously the endeavour of enabling equal opportunity for disabled people and regarding them as equally human.

These alternatives are founded in the belief that they encourage growth of confidence and knowledge within the individual thereby promoting independence. Such developments will have short term benefits and long term implications. Not least as facilities are increasingly made more accessible, so enabling future generations to enjoy more integration and giving society greater opportunity to get to know physically impaired people and people with learning difficulties as equally human and equally deserving of the same opportunities as those enjoyed by their peers. This is a legacy that we owe to our children and something worth doing, rather than preserving costly institutions and practises that do little or nothing to advance human understanding.

