

Margaret Webb.

---

# Equal Status

*a blueprint for action*

---

104034



Submission to the  
Commission on the Status of  
People with Disabilities

*by*

**N:3**

National Rehabilitation Board

---

October 1994

# Order of contents

Nº 3

	Page
NRB's Mission Statement	vi
• The context of this submission	1
• Introduction	3
 General strategies to equalise the status of people with disabilities	 7
• Disability proofing as an element of comprehensive equality proofing	8
- Women with disabilities	9
- Disability and ageing	10
• Access to the physical environment and to information	12
- Physical environment	12
- Access to information	13
- Access services	16
• Equal participation and representation	18
• Equal opportunities policy and practice as key criteria for funding	22
• Anti-discrimination legislation	23
- Current legislative position	24
- Key features of specific anti-discrimination legislation dealing with people with disabilities	25
- Implementation	26
• Comprehensive approaches to disability equality training	27
 Specific strategies to equalise the status of people with disabilities in some key areas	 29
• Education	30
- Current situation of young people with disabilities	30
- General strategies to equalise status in education	31
- Specific strategies to equalise status in education	34
- Pre-school education	34
- Primary and post-primary education	35

---

- Control	83
- Impact	83
- General strategies to equalise status in the arts, culture and the media	84
- Specific strategies to equalise status in the arts, culture and the media	86
- Arts	86
- Culture	87
- Media	87
• Justice	89
• Religion	91
• Sexuality and relationships	92
- Sexual health	94
• Conclusion	96

## The context of this submission

### N.3

NRB's submission to the Commission on the Status of People with Disabilities should be seen in the context of NRB's statutory functions.

NRB was set up under the National Rehabilitation Board (Establishment) Order 1967. This legislation delineated NRB's functions as follows:

- with the consent of the Minister, to supervise or operate or arrange for the operation of services (hereinafter referred to as "the services") for the welfare of persons who are disabled as a result of physical defect or injury, mental handicap or mental illness. The services shall be regarded as including:
  - the co-ordination of the work of voluntary bodies engaged in the provision of rehabilitation and training services for disabled persons
  - the giving of medical treatment to disabled persons
  - the provision of a service for the assessment of disability and the giving of vocational guidance to disabled persons
  - the training of disabled persons for employment suitable to their condition of health
  - the provision of a service for the placement of disabled persons in employment
  - the making of arrangements with other bodies for training disabled persons
- with the approval of the Minister, to co-operate with or assist companies or associations formed for the purpose of performing functions similar to any or all of the functions of the Board, and to enter into such contracts or agreements as may facilitate the provision of the services
- with the approval of the Minister, to do all things necessary, either directly or in co-operation with other bodies, for the making available of a service for the provision of prostheses and appliances including artificial limbs and hearing aids
- to furnish advice, information and assistance in relation to any aspect of the services to the Minister, or to any Health Authority
- with the approval of the Minister, to organise and provide courses of training in the treatment, training or placement in employment of disabled persons
- with the approval of the Minister, to provide courses of training for students of occupational therapy.

While NRB has devolved some of its original functions to others over the years, the organisation has also been given responsibility through the Department of Health for the management and monitoring of EU funding in the area of specialised vocational training for people with disabilities, for the

# Introduction

## NRB

People with disabilities in Ireland today are in many ways excluded, set apart, stigmatised and undervalued. They are marginalised by a society organised primarily by non-disabled people, based largely on specious assumptions about “average” human beings and responding to approximations of their needs. They are rarely consulted in the formulation of policy or practice which affects them and, when they are, their low status means that they are less likely to be believed or heard than non-disabled “experts”.

The prevailing medical model of disability locates their exclusion in the individuality of each person’s disability. It also promotes the notion of “hierarchies of oppression” in which some disabled people are seen to be more pathetic or deserving than others. NRB, on the other hand, is concerned in this submission to consider solutions to the current low status of people with disabilities through an understanding that it is Irish society itself which disables and disadvantages its disabled citizens by means of its current structures, policies and practices. This submission will name and offer solutions to this pervasive discrimination, which is to be found at all levels of Irish society and is as prevalent in services and structures aimed directly at people with disabilities as in those catering for the population as a whole.

People with disabilities are under-represented in all areas of Irish life, leading to the perpetuation of popular belief in their inability to be proactive citizens in charge of their own destinies. This belief is used in turn to legitimate exclusion, often through the double-edged strategy of “protection” and so the cycle of marginalisation - and its consequences of passivity, low self-esteem and low status - continues. A series of affirmative action measures is needed at every level of Irish society in order to equalise both opportunity and outcome for people with disabilities. In this submission NRB will detail many examples of the kind of affirmative action measures which can really make a difference to the participation of disabled people in Irish society.

This submission takes the view that while the social and economic needs of people with disabilities may require particular responses, those needs are no different from those of other citizens. The caring model of service delivery to people with disabilities as a category of people with special needs has enabled Irish society to deal with disability primarily as an issue of welfare, while substantially ignoring it as an issue of civil rights and equality of opportunity. This submission will advocate for a clear and unequivocal recognition of the right of people with disabilities to equality of treatment and opportunity in Irish socio-economic life.

specific measures to equalise the status of people with disabilities in each.

It is recognised that the areas covered and solutions proposed are not exhaustive but rather provide a starting-point for the elimination of discriminatory structures, policy and practice from Irish society. The general strategies are to be taken as read in the discussion of specific sectors.

---

# General strategies to equalise the status of people with disabilities

---

**The solution to the current low status of people with disabilities lies primarily in the whole-hearted adoption of a series of general strategies to be applied across every sector of Irish society.**

These concern:

◆  
Disability proofing as an element of comprehensive equality proofing

◆  
Access to the physical environment and to information

◆  
Equal participation and representation

◆  
Equal opportunities policy and practice as key criteria for funding

◆  
Anti-discrimination legislation

◆  
Comprehensive approaches to disability equality training.

---



NRB recommends that, as a matter of urgency, the Commission on the Status of People with Disabilities communicates with NESF:

- to ensure that a disability dimension constitutes a central plank of NESF's deliberations
- to establish a two-way flow of information that will facilitate the development of a coherent approach to equality proofing in Ireland.

While it is crucial to include disability proofing as a key element in an overall equality proofing strategy, it is also vital to recognise that, by itself, disability proofing will not impact on the status of all disabled people equally. There are other core axes of exclusion which impact differently on individual people with disabilities, including considerations of class, income, race, ethnic origin and gender orientation. While not underestimating the importance of these (income and gender orientation are to some extent explored in the sections on income support and sexuality respectively) this submission will draw particular attention to two other vital axes of exclusion: gender and age.

## Women with disabilities

There is at present no comprehensive information on the situation of women with disabilities in Ireland but research in the US, Canada and the UK shows that women with disabilities are more isolated from the larger socio-economic system than men with disabilities, with low average participation rates deriving from the fact that they are women, that they have a disability and, significantly, that they are women with a disability. Additional consequences are seen to derive from the fact that they are both female and disabled, consequences which would not necessarily become evident if the focus was placed on their status as women, or on their status as people with disabilities.

This means that without disability proofing, policies and practices enacted to equalise opportunity and outcome for all women will impact less strongly on disabled than non-disabled women. Without the particular consideration of the situation of women with disabilities, there is a real danger that the recommendations of the Commission on the Status of People with Disabilities will, in addressing the requirements of disabled people as a whole, impact less strongly on women than on men with disabilities, particularly as to date the bulk of research and discussion on disability and exclusion has centred on models of involvement in the labour market and modes of economic and social discrimination as identified by disabled men.





NRB recommends that, as well as considering the impact on older people with disabilities of its report and recommendations, the Commission on the Status of People with Disabilities should advocate a programme of positive action to ensure that the obstacles which only older people with disabilities face are dismantled and that older people with disabilities can participate in Irish society on an equal basis. Some specific solutions to the exclusion and marginalisation of older people with disabilities are included in the examination of specific sectors of Irish life later in this submission.

- recently-introduced health, safety and welfare legislation be monitored to ensure that people with disabilities are not excluded unnecessarily on the grounds of safety
- standards for the accessibility of the external environment be developed collaboratively between people with disabilities and sector experts and made mandatory through the introduction, enforcement and monitoring of appropriate legislation
- training on access issues, including information and access service issues, be included compulsorily on all vocational training courses, including in-service and continuing training, for design and building management professionals such as planners, architects, engineers, fire/safety officers, interior designers, product designers, building managers and all allied service providers
- specialist courses on access issues be developed, and that people with disabilities particularly be encouraged to take them up
- a system of mandatory access certificates, covering physical access, access to information within the building (e.g. audible and visual fire warnings, loop systems etc) and building management systems, similar to the system of fire certificates, be developed, implemented via legislation, enforced and monitored
- the provision of accessible, adjacent parking spaces to agreed standards becomes mandatory via legislation, enforced and monitored, for all buildings in public use where parking is provided
- it becomes an offence to bar a guide dog from any premises
- standards of access, design and safety be continually updated in line with international best practice.

## Access to information

Among the factors concerning access to information which currently exclude people with disabilities are the lack of provision of information in formats other than print, excluding blind and other non-print-literate people such as people with learning disabilities: lack of visual information systems in stations, queuing systems, emergency warnings in buildings etc. excluding deaf and hearing-impaired people: the location, promotion and availability of information generally: the clarity of information given: the rarity of helpline services and the lack of text telephones and other telephone devices for the deaf (TDDs).

- technology and equipment for accessing information in alternative formats should be made widely available to people who at present do not have access to it for financial or other reasons (for example, reading machines, audio equipment, adapted computers)
- education in using computer technology to access information should be provided to all people with disabilities, including older people
- information-giving organisations should be networked to the greatest possible extent, to minimise the necessity to consult a multiplicity of sources to access information
- in all public places signs should be simple, clear and uniform. Standards to ensure this should be developed, implemented via legislation, enforced and monitored
- information should be disseminated to people with disabilities in rural areas through a multiplicity of methods, including mobile libraries and banks, parish centres, information days, local radio stations
- helplines, using both freefone and 1-850 systems, should be funded to become more widely available and funding or other mechanisms should be developed to ensure the universal availability of text telephones and TDDs in businesses, organisations etc, along with their promotion among people with disabilities
- TV and radio should be used more widely to give information in the context of public service broadcasting, including the increased use of subtitling and live-action sign interpretation (see also media section, page 87)
- the specific information needs and requirements of women and older people with disabilities should be addressed and resourced, along with the information needs and requirements of newly-disabled people.

There are several key issues relating to disabled people's access to vital information, particularly about their own personal affairs.



NRB recommends that:

- people with disabilities be granted access to medical and other formal records which relate to them, be granted the right to information about medical, assessment and other procedures which they may have to undergo and be consulted concerning the flow of information about themselves to carers and other family members

- organisations should be required to train an agreed proportion of staff in sign language, in the same way that they must have safety committees etc.
- frontline and other staff in organisations should develop skills in helping those who need it, including people with learning disabilities, through complicated procedures
- consideration of the needs and requirements of people with hidden disabilities should become part of the procedure of disability proofing and the development of equal opportunities policies and practices.

NRB recommends that the Equal Status legislation currently in preparation and any subsequent anti-discrimination legislation dealing specifically with disability issues (see page 23) address all the above access issues, with provision for their full enforcement and monitoring. Total accessibility of services and information should become a central criterion in the allocation of state funding (see page 22).

Pending general improvement in the accessibility of buildings, services and information, the wide and creative promotion and advertising of information and facilities will be critical if take-up is to be encouraged and confidence built up.

voluntary, to establish regular, workable and effective consultative procedures. Particularly important is the involvement of people with disabilities in the decision-making procedures of services and structures aimed specifically at them

- advocacy structures should be properly funded and resourced if they are to develop. Resourcing for participation is the most important tool in ensuring equal representation
- mentoring and co-operative work-sharing strategies should be used to ensure that a wide range of disabled people develop the skills necessary to be effective staff and board members
- a system should be developed and resourced, drawn up in collaboration with disabled people, to enable groups of people with disabilities to learn skills for participation, negotiation and representation and to develop appropriate models of self-help and organisation, along the lines of the Department of Social Welfare's Community Development Programme and schemes to support local women's initiatives. Specific attention should be paid to the development of these skills in particularly marginalised people with disabilities, such as people living in residential and institutional settings, older people, disabled Travellers etc
- appropriate proportions of existing funds for self-development and organisation, such as the schemes currently administered by the Combat Poverty Agency and the Department of Social Welfare, should be allocated to projects of disabled people. Accessibility and openness at all levels to the participation of people with disabilities should become a key criterion in the eligibility for funding of all projects in these schemes (see next section)
- a system should be developed to support the co-ordinated development of local access groups
- organisations providing services specifically aimed at people with disabilities should involve disabled people, including women and older people, to a meaningful level on their boards of management
- education and training in self-advocacy and participation skills should form a central part of all curricula aimed specifically at people with disabilities in education (formal, continuing and second-chance) and training (formal, whether ESF-funded or not, and informal) so that all people with disabilities, including older people, can be involved to the greatest extent possible

**NRB in this submission has already argued that equality proofing, total accessibility and measures to ensure equal participation and representation are the cornerstones of developing a truly inclusive Ireland for people with disabilities. Three approaches to underpinning these practices are:**

- **equal opportunities policy and practice as key criteria for funding**
- **anti-discrimination legislation**
- **comprehensive disability equality training.**

## Anti-discrimination legislation

### N:3

The strategies advocated so far by NRB in this submission can work effectively on their own, given the political will. They would, however, be strengthened immeasurably, in both practical and symbolic terms, by the introduction, adoption, enforcement over an agreed timescale and well-resourced monitoring of anti-discrimination legislation.

It is the increasing experience of a wide range of societies that a legislative base is necessary if minority groups, including people with disabilities, are to be enabled fully to participate in society. This is recognised by, among other structures, the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities and the EU White Paper on European Social Policy, which advocates the revision of EU Treaties at the earliest opportunity to introduce a specific reference to combating discrimination on the grounds, among others, of disability. The Government's commitment, in its Programme for a Partnership Government, to the introduction of an Equal Status bill and the extension of existing employment equality legislation to cover people with disabilities, among other groups, is a reassuring sign of Ireland's willingness to tackle these fundamental issues.



**NRB recommends that the comprehensive legislation promised in the Programme for a Partnership Government be introduced, adopted and enforced in the shortest possible timeframe, with well-resourced and comprehensive monitoring systems.**

It is, however, part of international experience that the complexity of issues confronting people with disabilities is such that separate legislation dealing with their position is also necessary and that it is not sufficient simply to include them as a category in general equality or anti-discrimination provisions.

Furthermore, if such legislation is to be effective, it must be grounded in and reflect the distinctive cultural and historical realities which have formed the society for which it is designed. The Brehon Laws provide ancient but still relevant examples. It would be neither sufficient nor sensible simply to adopt legislation designed for other societies with their distinctive cultural and historical roots. While learning from all of these and from the examples of best practice around the world, the legislation which will be most effective in Irish society is that which best reflects the values which inform this society, especially in its sense of what is fair, just and right in dealing with those who are disadvantaged.

declarations of rights in the abstract, as in the Constitution, are of themselves of limited practical, everyday value without the strengthening of specific legislation.



NRB recommends that:

- existing legislation be examined to determine its impact on people with disabilities, with a view to amending legislation where necessary to ensure that the rights, equal opportunities and participation of disabled people are enhanced to the greatest extent possible
- that anti-discrimination legislation dealing with the specific situation of people with disabilities, as detailed below, be introduced, adopted and enforced in the shortest possible timeframe, with well-resourced and comprehensive monitoring systems.

## Key features of specific anti-discrimination legislation dealing with people with disabilities

Since the aim of legislation is to improve the position of people with disabilities in Irish society and to increase their participation in it, the law must be both negative and positive in its construction and its effect. It must both outlaw discrimination and harassment perpetuated against people with disabilities and promote good practice in the equalisation of opportunity and outcome for them.

The legislation must also be specific about those actions and omissions which must be taken or avoided in order to comply with the law and which will form the basis for any prosecution taken for an offence under the law.

Given that the focus for legislation will be on promoting the maximum participation in society of people with disabilities, the definition of disability used in the legislation must be related to a person's functioning in society rather than to narrowly-based medical definitions.

The legislation must cover the full range of circumstances covered by this submission, including, among others, access, information, accommodation, education, training, employment, income support and social security, culture, recreation and sports, family life, personal integrity and justice. Crucially, it must be formulated in such a way as to end the daily exclusion of people with disabilities from participation on a myriad of levels and on an equally wide range of specious grounds, ranging from "fire hazards" to the inconvenience of non-disabled people.



# Comprehensive approaches to disability equality training

## N:8

The experience of introducing legislation in relation to gender equality and health and safety has shown the necessity for new legislation to be accompanied by a sustained and adequately-funded campaign to educate both those on whose behalf the law is introduced and those who are bound to its observance.

Such a programme of education and awareness is as crucial to the success of any new legislation as the vigorous pursuit of offenders under the law. A process of awareness → understanding → commitment enhances the culture and society within which legislation is to be enacted. To the extent that disabled people are not immune to the effects of the pervasive negative attitudes that surround them, people with disabilities frequently internalise their own oppression. Education for self-advocacy (see page 19) and counselling responses (see page 74) provide important responses to this issue, but generalised disability awareness/equality training will also do much to counteract the effects of a long history of marginalisation and exclusion. Neither goodwill nor legislation can, on their own, bring about attitudinal shifts in people with disabilities or the population at large.



NRB recommends that:

- disability equality training designed in collaboration with people with disabilities and provided by and/or with their active participation, should become universally available, in:
  - all school curricula, including those aimed specifically at people with disabilities
  - all training courses, whether mainstream or specialised, ESF-funded or not
  - all existing and future equality training courses and modules
  - all teacher training courses, including in-service training
  - all training, including in-service training, of, among others, medical and paramedical professionals, social welfare workers, lawyers, judges, gardai, probation officers, prison officers, managers, supervisors, religious, trainers (both specialised and mainstream), trade union officials, community workers, housing officers, transport staff, building and design professionals of all types, counsellors, therapists, arts administrators, media personnel, frontline staff of all kinds etc.

---

# Specific strategies to equalise the status of people with disabilities in some key sectors

---

NRB in this submission has already argued for the implementation of a number of general strategies aimed at equalising the status of people with disabilities at all levels and across all sectors of Irish society. While of themselves they will bring about enormous shifts towards true equality in Irish society, there is a need for the development of additional specific strategies in key sectors. Many of these strategies involve affirmative action programmes geared to the particular circumstances of individual sectors. In considering these, the universal application of the general strategies is to be taken as read.



The sectors and specific strategies detailed below are not to be understood as exhaustive. Indeed, the consideration of sectors and the formulation of proposals for specific strategies are seriously hampered by the lack of focussed research in some areas and the apparent total lack of consideration of disability issues in others. The sectors and specific strategies which are considered in this submission, however, together constitute some of the most significant and pressing areas requiring attention. Their order in this submission is not to be taken as representing a hierarchy of importance.

---

isolation from family and community can deprive the individual of close emotional relationships for substantial periods of time and prevent the learning of lifeskills which can be transmitted through such relationships. This arrangement also denies non-disabled age peers the opportunity to experience young people with disabilities in the community and leaves a vacuum in which fantasies and prejudice (which highlight the difference and inequality of young people with disabilities) are allowed to flourish.

Furthermore, these students with disabilities are often “cared for” in a way that controls their behaviour and negates their independence. For instance, provision of special transport to and from school and supervised visits to the toilet can deny these young people the opportunity to challenge authority and try out behaviours which are a central part of growing up.

In mainstream schools which have been geared to provide for students with disabilities, provision of special school transport for students with disabilities often means that such students are removed from school just when extra-curricular activities are about to begin. The effect of this is to deny an opportunity for socialisation as well as an opportunity to explore new areas of learning which are different from the set school curriculum.

The impact is to create a subgroup of potentially socially inadequate young people who are different and less equal. This has come about through the idea that young people with disabilities need to be protected, and that this is best done by making special provision for them. Such special provision consistently segregates young people with disabilities both from their age peers and from mainstream society.

## General strategies to equalise status in education

There are a number of key strategies applying to all levels of education which, when implemented, will do much to equalise the status of people with disabilities in the sector and will ensure a far greater level of equalised outcome in students’ future lives. Throughout this section the term “personal supports” is taken to mean equipment, personal assistance, teachers’ aides, remedial and extra tuition, transport etc.



NRB recommends that:

- the forthcoming Education Act should cover all levels of education, both formal and informal, including pre-school, primary, post-primary, third level, adult, continuing and second-chance education, and should assert unequivocally:
  - the right of all children to an education

- the forthcoming Education Act should specify that psychological and other assessments of students with disabilities are the responsibility of the Department of Education. Such assessments should be comprehensive and holistic in approach, be followed up by the implementation of appropriate plans and be regularly monitored and reviewed
- clear, unbiased information on educational assessment, procedures, choices and recommendations should be made available in appropriate settings and formats to the parents of disabled children of school-going age
- students with disabilities should be enabled to remain with their classes to the greatest extent possible, with time away for special activities being kept to a minimum
- provision of extra time to complete papers in public examinations, the use of computers and other necessary equipment etc should become standardised and delivered as a right to students with disabilities
- educational material should be reviewed so that stereotyped images of disability and people with disabilities are removed. New materials need to be developed in which girls, women and older people with disabilities figure positively and frequently
- since the current debate on equality of opportunity in education for girls and boys has not impinged in any significant way on the debate on equality of opportunity in education for disabled students (e.g. it is not mentioned in the SERC Report), this issue should be researched and policy and practice amended accordingly
- sexuality and relationships education for young people with disabilities and all young people should show equality in relationships of disabled and non-disabled people, both male and female
- students with disabilities at all levels of education should have ready and well-publicised access in appropriate formats and settings to
  - confidential advice and counselling
  - assistance from an independent advocate
  - a complaints procedure with an independent element
- the demands of certain groups of disabled people for specialised provision (e.g. profoundly deaf people, Travellers) should be met in ways which promote social inclusion and cohesiveness, e.g. through location within mainstream educational settings

### **Primary and Post-Primary Education**

These form the core of disabled people's educational experiences. Since they together form the only mandatory education in Ireland, they merit particular attention.



NRB recommends that:

- there should be greater representation of pupils with disabilities in mainstream primary and post-primary schools, promoted by appropriate monitoring, incentives and sanctions
- specialised education for pupils with disabilities should be clearly divided into primary and post-primary sections, with appropriate curricula, services and supports
- pupils with disabilities in both mainstream and special schools should have ready access to required services such as physiotherapy, educational speech therapy and occupational therapy
- measures to reduce class size and increase remedial teaching and other classroom resources should be stepped up if young people with disabilities are to benefit fully from inclusive education
- sign language should form part of all curricula and teacher training should take this into account
- programmes in schools to combat bullying should deal specifically with the issue of disability
- education for leisure skills, social and political education and personal development programmes should be included in all curricula
- young people with disabilities in all educational settings should be given the opportunity to meet for peer support and with appropriate disabled role-models
- segregated schools should be required to develop an open door approach, involving resource and outreach work, short courses for young people with disabilities and teachers etc.
- in all second-level schools, a teacher should be assigned special responsibility for monitoring the equal participation of students with disabilities.

### **Support to Parents of Children with Disabilities**

Parents of children with disabilities require and deserve support and guidance at every stage of their children's progress. As well as the information and unbiased assistance advocated above (see page 33), NRB recommends that:



- supportive training programmes be provided throughout the country for parents of children with disabilities, focussing on ability and its development, rather than problems and their solution and emphasising social rather than medical constructions of disability, underpinned by an approach stressing rights, responsibilities and choices
- support groups for parents of young people with disabilities, based on principles of self-help, self-advocacy and mutual support, be set up at local level throughout the country.

The recommendations in this section should be read in conjunction with the General Strategies to Equalise the Status of People with Disabilities (pages 7 - 28).

- training centres providing training to people with disabilities should be appropriately accredited in accordance with the NRB Standard for Vocational Training
- existing quota schemes, such as the provision of 50 apprenticeship places reserved for people with disabilities, should be expanded further, promoted and monitored
- in order to facilitate the provision of supports such as braille materials, adapted equipment, sign interpretation, personal assistance etc, mainstream training agencies should build an element for this into their budgets from the beginning
- pre-training courses should be developed to facilitate the entry of people with disabilities to mainstream training programmes
- flexible, modular and part-time courses available in mainstream training should be made more widespread and accessible to people with disabilities
- the discriminatory ceiling of 10% of marginalised groups, including people with disabilities, eligible to participate in the VTOS programme should be removed
- the system and network of on-the-job training promised in the Programme for Competitiveness and Work (1994), should be made available to people with disabilities
- the potential for accreditation of prior learning as a mainstream certification option should be examined
- all trainers in mainstream settings should receive training in working effectively with people with disabilities
- a policy of equalising opportunities and outcomes for women with disabilities in training should be adopted.

## Strategies to equalise status in specialised training



NRB recommends that:

- nationally-recognised certification of training should be available on all vocational training programmes provided in special training centres

- a policy of equalising opportunities and outcomes for women with disabilities in training should be adopted.

The recommendations in this section should be read in conjunction with the General Strategies to Equalise the Status of People with Disabilities (pages 7 - 28).



there precarious and means that people may be unwilling to challenge the system, particularly where representation or facility for collective bargaining is absent (see page 20).

## General strategies to equalise status in employment



NRB recommends that:

- the Employment Equality Act (1977) be revised and extended to cover people with disabilities, as promised in the Programme for a Partnership Government and the Programme for Competitiveness and Work
- at each step of the employment process - recruitment advertising, selection interviewing, provision of working conditions and opportunities for further training and promotion - it should be unlawful for an employer, by act or omission to cause a person to be disadvantaged because of having a disability. Employers should also have a legal responsibility demonstrably to take all reasonable steps to facilitate a person with a disability in respect of the above issues. Legislation should state what would be acceptable as proof of reasonable steps, with corresponding sanctions for failure to adopt such measures
- the 3% quota in the public service should be enshrined in legislation, monitored and enforced with appropriate sanctions. Monitoring systems should be designed to give information on the positions and grades of people with disabilities employed in the public sector, with a view to putting in place structures to ensure that such employees do not remain clustered in lower grades
- a similar quota should be introduced in the private sector, enshrined in legislation, monitored and enforced with appropriate sanctions
- in any job selection process, only medical tests which are essential to the tasks involved in the job should be applied
- health, safety and welfare legislation (see page 13) and insurance provisions (see financial services section, page 56) should be monitored to ensure that they are not used as mechanisms for excluding people with disabilities

- the Employment Service targetted at long-term unemployed people, as advocated by NESF (Report 4, 1994) should, if introduced, be made available to people with disabilities, including the provision of:
  - personal and practical support
  - information on job vacancies and training opportunities
  - advocacy and active job placement
  - expert knowledge of the labour marketand should be demand-driven, i.e. responding to the requirements of unemployed people, rather than the availability of existing schemes
- all workers in the proposed Employment Service should receive disability equality training and be competent in working with people with disabilities. Every effort should be made to recruit people with disabilities to work in the Service
- such specialised services aimed specifically at people with disabilities as might be provided by the Employment Service should be accessed via mainstream routes and in mainstream settings
- people with disabilities should have access to both mainstream and specialised enterprise development and self-employment courses, with access courses to these being provided where necessary
- centres for the unemployed should promote their openness to the full participation of people with disabilities
- a prestigious national award scheme for employers instituting best practice in the employment of people with disabilities should be considered
- following a successful UK pilot programme, a disability leave scheme, enabling workers to retain their jobs during periods of e.g. hospitalisation, temporary relapse or retraining, should be piloted, monitored and evaluated
- the eligibility of people with disabilities to benefit from mainstream employment support programmes and employment schemes aimed at the long-term unemployed should be built in from the start
- all barriers currently operating in the benefits system which inhibit people with disabilities from taking up employment should be removed, equalising disabled people's right to take up casual and temporary job opportunities

- consideration should be given to dropping the use of the term “sheltered” altogether
- organisations providing training or work aimed specifically at people with disabilities should do so in such a way as to avoid confusion between the role of “trainee” and “worker”
- such organisations should:
  - pay the going rate for the kind of work offered, using employment support payments to make up any deficits in a disabled worker’s productivity, rather than using DPMA with top-up payments
  - provide for the participation of people with disabilities in decision-making on policy and practice
- the social firm concept should be continued and developed, with sufficient lead-in and set-up timescales and funding
- all business enterprises receiving any state funding, regardless of their charitable status, should be required to publish annual audited accounts to allow the State to monitor its investment.

The recommendations in this section should be read in conjunction with the General Strategies to Equalise the Status of People with Disabilities (pages 7-28).

- **development and coverage of allowances:** the development of allowances and benefits has been ad hoc. The current system of benefits results, for example, in people with severe disabilities which restrict their independence and mobility receiving less in allowances than mobile, independent people with other disability types. Some people fall through the net, being ineligible for state support and not having private health insurance
- **social insurance applies only to people in employment:** people who acquire a disability in the course of employment receive significantly higher allowances than people who have been disabled from birth or who became disabled while not in insured employment e.g. women working in the home
- **compensation based on the tort system:** existing compensation for disability acquired as a result of an accident or occupational hazard is granted under the tort system, which requires that somebody be considered at fault for the disability. If nobody can be demonstrated to be at fault, no compensation can be obtained.

The end result, for many of the people with disabilities surveyed, was abject poverty:

- overall, two thirds of the participants did not have enough money to cover their costs
- some (30%) managed by borrowing to meet everyday costs, and most (63%) borrowed to meet once-off costs
- over a fifth of the participants (23%) said that they were always in debt and a third (33.3%) were sometimes in debt
- almost half of the participants (46.7%) described their standard of living as poor or very poor.

In addition, the complexities of the system lend themselves to opacity and a dearth of clear information. Differing eligibility criteria and payments arrangements result in claimants being involved in multiple sets of negotiations. The discretionary nature of many allowances and the frequently reported lack of adequate explanation for the refusal of allowances mean that many people with disabilities feel they are relying on the subjective judgements of others for their financial well-being.

## General strategies to equalise status in income support

Piecemeal change in the system has been shown to be inadequate and has in some ways contributed to the current inequitable situation.

What this submission advocates is a fundamental review and reorganisation

However, some costs are not calculable or compensated financially. In 1987 the Australian Office of Disability, in collaboration with disabled people and their advocates, identified these as:

- lack of privacy and independence
- lack of access to buildings and public transport
- lack of educational, training, employment and recreational opportunities
- lack of information
- emotional costs - fighting prejudice, frustration, effort required to be taken seriously, health worries, fear and insecurity
- costs in terms of family relationships, e.g. the emotional cost of family separation where a disabled child or adult is in residential care
- cost in terms of social relationships - loss of community participation, disruption of social networks, isolation and prejudice, loss of social opportunities.

These non-financial costs will be mitigated by the implementation of strategies detailed elsewhere in this submission.

NRB recommends that:

- the research, implementation via legislation, enforcement, monitoring and evaluation of the above strategies be addressed
- allowances paid to carers should be disentangled from those paid to people with disabilities, in order to facilitate the development, implementation via legislation, enforcement and monitoring of policy and practice which supports carers without reinforcing the dependency of people with disabilities or impacting on their independent living
- all people with disabilities, including older people and those with learning disabilities and/or mental health difficulties, should be enabled to maintain control over their own money to the greatest extent possible, backed up by an independent system of citizens' advocacy where necessary (see page 20). Where payments are made to a third party, claimants themselves should be enabled to choose whether the allowance is paid to a family member, a personal friend or a professional and there should be a statutory responsibility to ensure that the client is not exploited.

- as promised in the Programme for Competitiveness and Work, the social welfare system, including those elements delivered through the Department of Health, should be examined to ensure that obstacles to the entry and re-entry of claimants into education, training and gainful employment are removed
- claimants of disability-related benefits administered by the Department of Social Welfare should retain their benefit entitlement if they opt for education or segregated training. At present they are entitled to no disability-related social welfare or health benefit, including RMA
- the recommendations of the report on social welfare sickness benefit claims and appeals cited above should be implemented in order to simplify the system, make it fairer and ensure the access to full information of both claimants and decision-makers
- the complex and discretionary system of supplementary welfare allowances should be clarified and made more transparent. Community welfare officers administering the system should receive specific training to support them in dealing with disabled claimants
- free travel passes allocated to recipients of disability-related benefits should include a companion pass, where required
- all income support measures and associated rules and regulations should be reviewed in terms of their impact on single and married women with disabilities and then equalised to the highest standard, ensuring that women receive benefits as individuals. Income support should be paid in their own right to married or cohabiting women working in the home at the time of disability onset.

DPMA as it applies to people with disabilities in training is considered elsewhere in this submission (see page 40).

repayment of costs arising from the purchase of “medical and surgical appliances” (technical aids and equipment), included in the legislation but never enacted, should be clarified and addressed (see also page 75)

- the Drug Cost Subsidisation Scheme should be promoted and extended as a more customer-focussed alternative to the Drugs Refund Scheme for regular claimants
- the Long Term Illness Card scheme should be reviewed in order to provide drugs, medication and technical aids and equipment to all people with disabilities free of charge, irrespective of disability type, income, employment status, gender or age and to extend entitlement to people with mental illness over the age of sixteen
- the Long Term Illness Card and medical card schemes should be monitored by an independent body to ensure that items and services are not disallowed for entitlement because of cuts caused by cashflow problems in Health Boards.

The recommendations in this section should be read in conjunction with the General Strategies to Equalise the Status of People with Disabilities (pages 7 - 28).

- insurance companies should not refuse to quote for car insurance for drivers with disabilities and should examine their loadings in the light of accurate, up-to-date information (at present, for example, it is understood that the largest motor insurance company in Ireland is loading disabled drivers' car insurance by 20-30%)
- the rule by which medical insurance companies disallow members from claiming for expenses which arise from their disabilities for a set period (generally five years for in-patient services and six months for out-patient services) should cease
- exclusion clauses in hospital cash plans and other insurance schemes which effectively debar people with disabilities from ever claiming for practically anything, should be eliminated on the grounds of discrimination
- the subjective and discretionary procedures used to determine the eligibility of people with disabilities for local authority loans should be replaced with standardised, transparent criteria and promoted to people with disabilities
- the practice of excluding people with disabilities from places otherwise open to the public should be stopped. Public liability and fire insurance do not mention people with disabilities as such, so exclusions made on this basis are discriminatory interpretations of the management procedures required to comply with regulations
- insurance and banking organisations should agree a clear mechanism for the investigation of complaints from people with disabilities through their respective Ombudsman services and supported by an advisory group which includes people with disabilities. This should not affect disabled people's right to take court action through any forthcoming anti-discrimination legislation (see page 23)
- as well as disability equality training, specific training in disability issues should be provided to actuaries and underwriters, along with frontline staff and decision-makers in the financial sector.

The recommendations in this section should be read in conjunction with the General Strategies to Equalise the Status of People with Disabilities (pages 7 - 28).





NRB recommends that:

- legislation should be introduced, enforced and monitored to ensure that all public transport, including taxis, becomes accessible to all disabled people in a given enforced timescale
- as elsewhere in Europe, specially-designated exchequer funding should be made available to ensure that this comes about, and total funding should be made conditional on targets being met (see section on funding, page 22)
- a Taxi Card system, whereby people with disabilities have the right to a set number of taxi journeys in a given period at a cheap rate, should be investigated with a view to the possibility of introducing it throughout the country
- adapted hire cars with hand controls should become available throughout the country
- the very welcome Transport Improvements Scheme, funded by the Department of Health, which provides lifts for buses owned by voluntary organisations should be extended to facilitate the purchase of new vehicles.

The recommendations in this section should be read in conjunction with the General Strategies to Equalise the Status of People with Disabilities (pages 7 - 28).

## Existing housing

People with disabilities who require adaptations to their homes to enable them to function independently can apply to their local authority for a grant, through the Disabled Persons' Housing Grant Scheme, of up to £8000 or two-thirds of the cost of adaptation, whichever is the lower. The local authority pays the full cost if the person with a disability lives in public housing.

There are many inequities in the current system, including levels of payment, delays, lack of standardisation etc. Half of the participants in the Costs of Disability survey (see page 48) described adaptations to their homes which would make life easier for them but 75% of these people could not raise the money to make these adaptations. Some 30% had carried out adaptations to their homes. In most cases, they financed the adaptations themselves.



NRB recommends that:

- the Disabled Persons Housing Grant scheme be overhauled to ensure that
  - standards, procedures, levels of grant, supports and regulations, including assessment procedures and speed of response, are equalised to the best available practice, as determined in collaboration with people with disabilities
  - the full costs of adaptation, including architects' fees and other professional charges, are covered
  - heating and through-floor lifts become eligible for grant aid
  - the delays caused by waiting for tax-clearance certificates from suppliers and builders are eliminated
  - the right of people with disabilities to further housing adaptations caused by changing circumstances is copperfastened
  - in the absence of 100% grants, clear entitlement to borrow from local authorities (as for House Improvement Loans) should be established and 100% funding provided in circumstances of particular hardship
  - all criteria, regulations, procedures etc are made transparent and are communicated clearly and appropriately to all applicants
  - the eligibility of people with sensory impairments and serious mental health difficulties to apply for the scheme is clarified and standardised throughout the country
- where the experience of disability results in disabled people having to move from unadaptable housing, often to more expensive accommodation, grant aid should be provided, possibly through an extension of the Disabled Persons Housing Grant Scheme, to cover the extra costs incurred.

## Voluntary housing associations

This innovative development is very welcome and should be increased to have a greater impact in meeting the housing needs of people with disabilities.



NRB recommends that:

- Capital Assistance funding to voluntary housing associations should be increased, with specifically-designated grants being made available to offset any extra costs involved in providing accessible or adaptable accommodation
- approved voluntary housing associations should also be able to qualify for grants for the conversion and/or adaptation of existing houses where the payment of Capital Funding assistance under any other Scheme is not involved, or where Capital Assistance has not been paid within the previous five years
- people with disabilities should be supported to develop their own voluntary housing associations.

The recommendations in this section should be read in conjunction with the General Strategies to Equalise the Status of People with Disabilities (pages 7 - 28).

sense of participation, there is no sense of involvement" (*Making Connections*, NRB CSW). While residents' committees are becoming more common they are by no means universal, particularly outside smaller centres or those catering for people with physical disabilities only.

Central to the debate about quality of provision must be the understanding that residential and institutional care settings are disabled people's homes and the level of support and assistance they require does not mitigate this fundamental fact. The exercise of rights, policies and practices must stem from this understanding if people with disabilities living in institutional and residential care are to achieve a desirable quality of life.



NRB recommends that:

- resources allocated to residential and institutional care should be targetted in such a way as to replace large-scale institutions with smaller-scale options, including adult foster care, supported independent living units, sheltered housing, minimally-supervised and high support hostels and group homes, small-scale "retirement villages" and small residential centres. These options should be available throughout the country. All residential and institutional care options should be sited in local communities and centres of population to maximise potential for integration and community involvement
- increasingly, as new options become available, residential care options should be offered as that, affording the maximum level of choice to potential residents and enabling existing residents to change their living arrangements
- older disabled people living in institutions and residential care should not be excluded from opportunities to restart life in the open community simply on the grounds that it is too late to endeavour this "at their age"
- equally, people with disabilities should have protection from removal out of an institution on grounds of administrative necessity or financial retrenchment, if this is against their will or if adequate care and support outside are not available
- disabled people whose housing has been linked to sheltered work/employment should not on retirement be required to leave that housing until there is alternative accommodation offered which meets their preference as far as is practicable

- a study on the appropriateness of residential placements should be carried out as soon as possible
- a survey of the views of those living in residential and institutional settings should be conducted
- as well as disability equality training, staff in residential and institutional care settings should receive specific training on working with disabled people. Job titles such as “house supervisor” and “head of care” should give way to staffing structures which reflect the domestic nature of residential care
- existing legislation on nursing homes might be reviewed to consider its possible broader application.

The recommendations in this section should be read in conjunction with the General Strategies to Equalise the Status of People with Disabilities (pages 7 - 28).

Essentially, disability is a health issue, but not exclusively so. As advocated elsewhere in this submission, many issues concerning people with disabilities should be mainstreamed. At the same time, service delivery within the health sector should become increasingly focussed on meeting the requirements of disabled people as customers. In this context the recent Department of Health strategy document, *Shaping a healthier future*, has much to offer.

## General strategies to equalise status in health and personal support services

Focussing on disabled people as customers central to the provision of health and personal support services will serve to improve significantly the current dynamic and relieve the tension in the system which exists between people with disabilities, carers and society at large. Many services ostensibly aimed at people with disabilities are traditionally constructed as being methods of “giving carers a break”, which reduces acceptability by denying the humanity of both disabled people and those who live with them, ignoring the dynamic and collaborative nature of all human relationships. The “burden of care” felt so acutely by many carers and people with disabilities, causing tension and difficulty in otherwise healthy personal relationships, can be mitigated to a large extent by the provision of coherent community-based health and personal support services aimed appropriately at disabled people and/or carers.

For example, users of personal assistance services (see below) no longer have to rely on family members to assist them in personal care, mobility etc. This has the effect of normalising family and personal relationships to the level generally enjoyed by non-disabled people. It also changes the dynamic with respect to the demand for services such as respite care, since intense dependency is reduced and responsibilities shared. The need for emergency services reduces because planning is facilitated and crises can be averted. People with disabilities, including older people, and those living with them are afforded the opportunity to live the lives of their choice.

Customer focus on people with disabilities in health and personal support services involves such elements as:

- consultation at all stages of planning and execution of services, including involvement in all case conferences concerning them and the support of advocates where appropriate
- real options and choices, constructed in such a way as to enhance the independence and dignity of service users and those who live with them
- flexibility, taking account of the changing nature of disabled people’s needs, relationships, life states, desires and requirements, irrespective of the progressive or static nature of any given disability

- a comprehensive programme of capital funding should be implemented to make all hospitals, health centres, clinics and surgeries, their transport and the services and information they provide, accessible to all people with disabilities. Among the services which should, as a matter of priority, be made fully accessible to people with disabilities are screening, vaccination and maternity services and alcohol and drug abuse programmes. The service needs of people with mental health difficulties and other disabilities who are homeless should receive particular attention
- disabled people's primary disability should not be used as a reason for refusing or delaying treatment indefinitely, whether or not the treatment is related to the primary disability. Decisions concerning older people should be guided by the recognition of the positive relationship between independence and health and of the danger of underestimating the potential of older disabled people
- particular professional training should focus on the prevention and aggravation of disability among older people, and on the diagnosis of conditions, such as depression, which are difficult to recognise in old age
- active medical and functional rehabilitation should be made available to elderly disabled people, whatever their disability, on the same terms as they are provided for younger people with disabilities. The notion that rehabilitation is not appropriate to certain disabilities, or to disabilities newly incurred in old age, should be discarded
- people with disabilities should be fully informed about how treatment might impact on their disability, likelihood of outcome, experimental nature of treatment etc, including being told when these factors are unknown
- people with disabilities should be given the right to refuse to participate in teaching, research, clinical trials and experimental treatment
- formal guidelines for the disclosing of the fact of a disability should be developed in collaboration with people with disabilities. For example, nobody should overhear their diagnosis before it is formally revealed, nobody should be alone during or after hearing the news, unless that is their expressed wish, and information should be repeated and elaborated as many times as it is requested. Health service staff should receive particular training and support in this area. Information in accessible formats on relevant support services should be supplied to newly diagnosed people and those who live with them

Some voluntary organisations have developed successful home care assistance and home support schemes which provide a more flexible approach to meeting the daily requirements of people with disabilities. Home care attendants usually receive training, attend to the personal needs of people with disabilities and may be available during anti-social hours and at short notice at times of particular stress. However, they are not available throughout the country, they may be limited to the membership or customers of particular organisations and the schemes are frequently reliant on short-term funding and/or temporary employment schemes.

Both services can be essential in maintaining the independence of people with disabilities.

NRB recommends that:

- the present home help service be extended to provide a more comprehensive service, including assistance with personal care where required, and delivered to all people with disabilities who require it, irrespective of who else is living with the disabled person. Realistic rates of pay based on the responsibilities and skills involved should be offered and training given
- service delivery should not be predicated on the ages of children living at home. Under no circumstances should children be required to act as care assistants
- a specific sum should be allocated by Health Boards for more intensive work with people with disabilities at times of particular need or crisis, along the lines of the Homemaker service run by the Eastern Health Board.

### **Personal assistants**

This recent development, pioneered by the Centre for Independent Living, involves the employment of personal assistants for a set number of hours per week by people with significant physical disabilities. This service benefits people with disabilities who want to live independently, pursue a career or education but cannot do so without a high level of support.

The relationship between the person with the disability and the PA is one of employer/employee. The PA is chosen by the disabled person and works exclusively for his/her employer who determines the level, type and timing of assistance required. The system enables the development of self-determination for people with disabilities and facilitates them to join in the activities of their choice.



## Technical Aids and Equipment

For many people with disabilities technical aids and equipment, whether as low-tech as grab-rails or as high-tech as environmental control systems, make all the difference between dependence and independence in their daily lives. The Health Act (1970) mandates health boards to provide medical card holders with “medical and surgical appliances”, which theoretically means that they must be supplied with whatever they require in this area free of charge. The same Act allows for the refund of part of the cost of medical and surgical appliances to people who do not have medical cards through what is known as the Drugs Refund Scheme (see also page 54), but this part of the legislation has never been enacted. Another section of the Act enables health boards to supply medical and surgical appliances free of charge to holders of the Long Term Illness Card (see also page 55).

There are many shortcomings in the system, all of which result in people with disabilities having to spend large sums of money or do without the technical aids and equipment that would make their lives easier. These include:

- “medical and surgical appliances” are not defined in the legislation. The terminology is restrictive and outmoded. The term “medical and surgical appliances” fails to reflect the extensive range of new technology and assistive devices that is now available, particularly in the areas of personal care, mobility, lifting, communication and information technology. Narrow interpretation of the existing term may be used by health boards which are undergoing periods of financial restraint as a justification for refusal to supply certain items
- the lack of definition leads to varying interpretation throughout the country, with lack of standardisation being reflected in inequitable provision to people with disabilities
- lack of adequate resourcing means that more expensive basic equipment, such as electric wheelchairs, may not be supplied, or delays and waiting lists may be operated. Items may or may not be available without explanation
- the discretionary nature of provision under the Long-Term Illness Card scheme gives rise to many inadequacies and inequities in terms of provision to people living in different parts of the country
- there is a lack of resources for the repair of equipment, leading to delays which impact heavily on the people with disabilities who rely for their independence on such items as wheelchairs and communication aids being in working order
- assessment procedures vary from area to area and are particularly problematic where there is no community-based occupational therapy service
- since there are no standard procedures for the inclusion of technical aids on health boards’ product lists, nor standard procedures for updating, it can be very hard for people with disabilities on low incomes to access new products. In reality, availability and choice for

### **Day Activity Centres**

For disabled people whose specific disability prevents them from working or availing of education or training opportunities (e.g. people with acute mental health difficulties, people with head injuries etc) and for those who do not wish to access these opportunities (e.g. some older people with disabilities) day activity centres may provide social and occupational variety and a stepping-stone towards independence and inclusion. Conversely, the lack of day activity centres can condemn people with disabilities to a life of inactivity, isolation and under-achievement.

However, day activity centres are unevenly distributed throughout the country and access to the service for some people with disabilities, especially those with dementia, acute mental health difficulties and challenging behaviour, can be both limited and problematic. The development of day activity centres is often limited by reliance on short-term public funding and precarious fund-raising income. Lack of transport restricts catchment areas and numbers attending. Staffing may rely on the availability of FAS and other temporary work schemes. Service users who would prefer a longer time commitment may be restricted to attending on only one or two days a week.



NRB recommends that:

- the provision of day activity centres throughout the country be reviewed, with the intention of providing an equitable and adequate service for all people with disabilities who request it. It should remain independent of day hospital and training provision, particularly for people with mental health difficulties
- people with disabilities who attend day activity centres should be encouraged to become involved in running them. Training in self-advocacy skills, social and political education, personal development and sexuality and relationships education should be offered
- links should be developed between day activity centres and local leisure facilities and community activities, in order to facilitate the maximum level of active participation and inclusion by people with disabilities using the centres
- involvement in day activity centres should stem from requests from people with disabilities to join.

The recommendations in this section should be read in conjunction with the General Strategies to Equalise the Status of People with Disabilities (pages 7 - 28).

- anomalies and inconsistencies concerning insurance should be tackled at the highest level (see financial services section, page 56)
- lottery funding for sports and leisure facilities should be made contingent on access and openness to people with disabilities
- local authorities and other leisure planners and managers should include the specific requirements of older people with disabilities in their strategies and plans
- education in leisure activities and development should be included in all curricula in education, whether formal or informal, and training aimed at people with disabilities
- strong links should be developed between segregated clubs, training courses etc. and mainstream leisure groups of all types
- since research shows that boys and men are more likely to be encouraged to take risks and to be involved in outside activities, particular attention should be paid to ensuring that girls and women with disabilities are facilitated in leisure activities
- pilot schemes introducing the Canadian concept of “leisure buddying”, whereby a person with a disability can link up with another person, disabled or non-disabled, who shares their leisure interest, in order to develop or try out the activity with support, should be evaluated
- the Building Regulations Technical Guidance Manual on accessibility should be amended to put equal emphasis on accessibility for participants in sports stadia etc. as on spectators
- national, regional and local sporting and youth work organisations should incorporate the topic of leisure and involving people with disabilities into their training programmes for administrators, coaches, youth workers, community and outreach workers, officers etc
- coverage by the media of sports and leisure events involving people with disabilities should be undertaken by relevant journalists, rather than by health correspondents (see media section, page 87)
- retirement planning courses should be made available to people with disabilities who are due for retirement from sheltered work/employment

## Arts, culture and the media

### N:B

The social perception of art and culture is undergoing significant change at present. Issues regarding popular participation, freedom of expression and economic control have profound implications, not least for the involvement (and perception) of people with disabilities. While disabled people have always been involved in the arts in Ireland (Carolan and Joyce, for example), this aspect of their experience has traditionally been minimised or hidden. Now a new generation of artists has emerged whose work is informed directly by their experience (e.g. Mary Duffy, Corban Walker), as well as evidence of increasing interest from the growing community arts sector in involving people with disabilities. The right of people with disabilities to find their own voice is the foundation for policy on their involvement in the cultural life of the nation in general and within the arts in particular.

Meanwhile, in recent years there has been growing recognition of the fact that arts and culture are no longer the realm solely of wealthy dilettantes but also offer real job opportunities, whether as creative, administrative, technical or support staff. According to recent figures there are 60,000 full-time equivalent jobs in the "cultural industries". The music business alone generated £20.2m in 1992 and the audio-visual sector is growing by 15% per annum. This growth provides opportunities for people with disabilities in terms of both creative contributions and financial benefit.

Against this welcome expansion in creative opportunities must be set the long-standing stereotyping and negative imagery associated with disability and human difference. The media and the arts have often powerfully reinforced images of the marginalisation, dependence and hopelessness of people with disabilities. The right, therefore, to participate in cultural activities must go hand-in-hand with a challenge to negative portrayals from people with disabilities themselves, particularly of the pejorative images frequently used for fund-raising purposes which serve to emphasise dependency and exclusion.

To date much discussion of disability and the arts has been considered primarily in the context of art therapy. While the arts undoubtedly have therapeutic value for everybody, a clear distinction must be made between therapeutic techniques and the creative process per se. The right to expression includes the right to recognition. A solely therapeutic focus tends to minimise the full recognition of the work of art as a product of individual creative expression and locates creativity and ownership in the (usually non-disabled) therapist or therapeutic process. Organisations providing services specifically aimed at people with disabilities have tended to see the arts in therapeutic terms, as the province of the gifted or as an expendable and undervalued leisure pastime. To date there has been more interest in

representation are crucial to the development of the process of participation, leading to a fruitful interface between the arts and people with disabilities, whether as practitioners and/or consumers. Access means not just ramps but also, among other things, signed performances, equal opportunities policies, ticket price concessions, colour contrast, audio description, clear information and signage, disability equality training, especially for front-of-house staff, traineeships, outreach work and, above all, imagination.

### **Expression**

All people have the capacity for creative expression and the right to free expression is crucial to finding one's own voice. To speak, to create without fear of ridicule or neglect, to assert one's own voice are all central to the creative process. Environments must be created in which the creative voice can be facilitated and heard. The design and provision of options, techniques and new technologies have much to contribute to this facilitative process (e.g. the Drake Project which uses advanced technology to enable people with significant physical disabilities to compose and perform music). Access to creative writing and other formal and informal arts courses is important in developing confidence in self-expression.

### **Control**

Throughout the arts a major issue is the control of the artistic product after its creation. The writer surrenders the book to the publisher, the playwright to the director and the painter to the gallery manager. People with disabilities are often particularly vulnerable in this regard. There are examples of works of art being accredited to an institution rather than to the individuals who created them. Asserting ownership is part of the process of self-empowerment.

### **Impact**

Marginalising and excluding policies and practices in the arts, along with stereotypical imagery and the invisibility of "real" people with disabilities, have a profound impact not only on disabled people themselves but also on the non-disabled population, which absorbs a therefore unreal world from the media and a distorted symbolic language from the arts and culture generally. Examples include people with disabilities being portrayed:

- in paintings, as characters in plays and films etc, as simplified symbols of, for example, lack, loss, innocence or evil rather than as complex, "real" people
- in newspaper reports, fundraising campaigns etc, as passive recipients rather than as significant actors in their own destinies.

- pricing policies in theatres, concert halls etc should be amended to offer tickets in accessible parts of venues at the cheapest price in the house to e.g. wheelchair-users. The widest possible choice of seating location should be offered
- as well as disability equality training, disability studies should be included on the curricula of all arts and media training courses, e.g. arts administration, film production, literature, fine arts, journalism, PR etc
- the concept of “leisure buddying” should be introduced to enable people with disabilities to attend e.g. evening classes in creative subjects (see also page 79)
- pilot schemes introducing the concept of “arts escorts”, whereby people with disabilities who need assistance or company to attend performances can arrange for someone to go with them, should be introduced and evaluated in contrasting locations and contexts (e.g. organised by venues, by local authority arts officers, by festival committees) with a view to developing the system throughout the country, as in the Artslink system (UK)
- work created by artists with disabilities should be credited to them and not to the institutions they may attend
- organisations providing services specifically aimed at people with disabilities should find ways of increasing the involvement of arts and cultural dimensions in their work, by, for example, encouraging the emergence of cultural expression specific to disabled people
- through anti-discrimination legislation or other means, it should become an offence to exclude people from artistic or cultural activities because of their disabilities or because supports or access are not provided.

## Culture



NRB recommends that:

- general disability awareness campaigns aimed at increasing public awareness about disability issues and the need for the inclusion of people with disabilities in all aspects of Ireland's cultural life, should be developed, implemented and monitored at both national and local levels, involving extensive and creative use of the media and community resources. Approaches should be developed by a campaign team, comprising people with disabilities, media, PR and advertising experts and health promotion specialists. The campaign should use a multiplicity of approaches and include imagery of all aspects of Irish life, including popular culture such as GAA, pubs, night-clubs, rock concerts etc. The campaign should take a long-term view combined with an incremental strategy (as in, for example, the drink-driving campaign) and be resourced appropriately (minimum five years)
- an oral history project with people with disabilities should be instituted by a relevant body such as the Folklore Commission or the Department of Folklore at UCD, partly with a view to radio/TV programming, as in the recent series on Channel Four (UK, 1993)
- resources allocated to the celebration of specific cultures in Ireland (e.g. Travellers, Irish speakers) should be extended to cover and encourage the celebration of disability cultures.

## Media

At the end of the twentieth century, the pervasive power of the media to influence opinions and perceptions cannot be over-estimated.



NRB recommends that:

- the disabling impact of inappropriate language and imagery should be ended by the introduction, enforcement and monitoring of a stylebook on disability issues throughout the media, with the approval and explicit support of journalists, sub-editors, editors, producers etc and their representative bodies
- a media watchdog body should be established and resourced to examine and monitor all media and be empowered to take appropriate action
- disability studies should form part of PR training courses

# Justice

## N:8

Disability issues as they relate to justice and the legal system in Ireland are invisible, unresearched and unrecorded. For example, no statistical information is available from the Department of Justice regarding offenders or prisoners with disabilities, the incidence of mental health difficulties caused or enhanced by imprisonment or the incidence of crime committed against disabled people. The Department of Justice's recently-published Five Year Plan on the Management of Offenders does not refer to people with disabilities.

At the same time, research from the US, UK, Canada and elsewhere, points to the vulnerability of people with disabilities to street crime and sexual and physical abuse. Harassment (in the workplace and at home), verbal abuse and neglect often go unreported.

Disability also impacts strongly on the less dramatic area of family law. For example, where a marriage partner becomes significantly disabled there is a very high risk of marital breakdown, which in turn leads to many other difficulties involving maintenance payments, custody etc.

Some of these circumstances can only be mitigated effectively by changes in self-esteem and culture, the removal of stigma and other general shifts in the attitudes prevailing in society. Others will be addressed by anti-discrimination legislation. However, specific actions are required in several areas.



**NRB recommends that:**

- the Department of Justice should review and research the interface between people with disabilities and the judicial system, including consideration of:
  - the vulnerability of people with disabilities as victims of crime and how this can be addressed
  - the vulnerability of people with disabilities as perpetrators of crime and how this can be addressed
  - issues relating to people with disabilities as witnesses and jurors
  - the need for pre-trial court familiarisation and in-trial personal advocacy so that people with disabilities can understand and follow court proceedings
  - in the case of people with learning disabilities, the recognition of the difference between chronological age and that determined by psychometric testing, with its implications for admissions of guilt, ability to withstand questioning and capability of pleading



## Religion

### **N:3**

Religion plays an important role in the lives of the majority of Irish people, including people with disabilities. Yet at present religious practice is not always welcoming or respectful of people with disabilities. Places of worship are frequently inaccessible, services may be conducted in ways which exclude or marginalise people with disabilities, information is not generally provided in accessible formats, clergy are largely ill-informed on disability issues, and rituals and parish work may exclude or marginalise disabled people. As religion forms an integral part of the culture within Irish society and in the building of local communities, people with disabilities are in effect often segregated and excluded from active participation within their locality, contributing further to their social isolation.



NRB recommends that:

- religious authorities should eliminate all practices that discriminate against people with disabilities
- disability equality training should play a key role in the formation and on-going training of all religious personnel
- religious personnel, especially those working at local level, should develop religious and community practice which is inclusive of people with disabilities, encouraging their active participation and ending their marginalisation as objects of charity
- disability awareness should become part of the core curriculum in religious education programmes.

The recommendations in this section should be read in conjunction with the General Strategies to Equalise the Status of People with Disabilities (pages 7 - 28).

Society has many laws and conventions restricting and defining “proper” sexual relations, marriage and so on. The application of differential rules to their sexual lives has major implications for people with disabilities.

The constraints imposed by society make people with disabilities sexually vulnerable and all too easily at risk from abuse and exploitation. Yet this in itself can lead to further marginalisation, rejection and exclusion through well-meaning protection measures. What is needed is to break the cycle by supporting the right of people with disabilities to own and express their sexuality in their own way, subject to the laws of the country, including through a homosexual or lesbian orientation, with or without a partner.



NRB recommends that:

- mainstream services relating to sexual relationships should be made easily accessible for people with disabilities. Relationship and psychosexual counselling and treatment services, pre-marriage services, the provision of sexual aids, STD clinics, Rape Crisis Centres, family planning, well woman centres and refuges, among others, should be made more accessible to people with disabilities in terms of their services and information. Peer counselling and support should form an integral part of this provision
- people with disabilities living in residential and institutional settings should not be denied the opportunity to become involved in close or sexual partnerships or to express their sexuality
- inappropriate intervention in the personal lives of people with disabilities should stop. Too frequently, in specialised services expression of sexuality and marriage for people with disabilities is seen as a prize to be earned or the province only of those who can be “independent”, rather than an expression of personhood
- support systems, aimed at assisting people with disabilities in relationships and marriages, should be developed. Since these can be meaningless unless service personnel internalise positive attitudes towards such measures, training is of paramount importance, along with the involvement of disabled role-models and peer supporters
- sexuality and relationships education for young people should become available to all young people, regardless of where they are being educated or trained, and should show equality in relationships of both disabled and non-disabled people, both male and female (see page 33)

- genetic counselling should be made freely available throughout the country. Prospective and actual parents of children with disabilities should be afforded the opportunity to meet people with disabilities and their families to receive a rounded view of what the experience of disability might be like
- given the sensitivities involved, both sides in the abortion debate should refrain from using the matter of whether or not a foetus has a disability as a circumstance in rationalising either the pro- or anti-abortion argument. The attitudes of both sides to disability issues frequently offend disabled people
- research into the field of human genome analysis as it impacts on people with disabilities should be conducted to ensure that emerging reproductive technologies do not lead to new ways of devaluing, stigmatising and disempowering people with disabilities, including by over-emphasising the desirability of “perfect” babies.

The recommendations in this section should be read in conjunction with the General Strategies to Equalise the Status of People with Disabilities (pages 7 - 28).

## Conclusion

**N:B**

NRB acknowledges that many of the recommendations made in this submission could have important implications for non-governmental and governmental organisations, including NRB itself. While we have attempted in this submission to put the interests of people with disabilities first, it would be essential at the appropriate time to give serious consideration to the possible effects of implementing the submission's recommendations.

Through its mission statement, quoted at the beginning of the submission, through its published Strategic Plan 1992-94, and particularly through its actions during the last few years, it should be clear that NRB has already moved its orientation, within the constraints of its 1967 Establishment Order, in the general direction outlined in this submission.

Legislative change would be required to enable NRB to take the kind of substantive steps which our recommendations call for. NRB looks forward to having that opportunity.

- programmes aimed at preventing abuse and presented to people with disabilities must be geared directly to their experience e.g. a programme which suggests that one should kick an assailant on the shin and then run away is of little relevance to a person with a physical disability, whereas discussion of the potential for abuse by enablers and professional staff may be very apt
- given the growing evidence of the sexual abuse of people with disabilities in Ireland and elsewhere, often citing very high levels of abuse, the Department of Health should introduce guidelines, such as those submitted by NRB, for the investigation of allegations of the sexual abuse of all disabled people, and not just people with learning disabilities as recommended in the report of the Kilkenny incest case. People with other disabilities, including significant physical disabilities, sensory impairments and mental health difficulties are also at risk
- policies and staff guidelines on sexual matters in segregated centres should be translated into individual service-level contracts between people with disabilities and the management of the centre so that rights are safeguarded
- people with disabilities who have children should be provided with the supports they need for successful parenting
- restrictions on adoption and fostering by people with disabilities, made on the grounds of disability alone, are discriminatory and should be removed.

### **Sexual health**

As important as the right to sexual expression is the right to access services dealing with sexual health.



NRB recommends that:

- the issue of the sterilisation of and contraception for people, generally women, with disabilities without informed consent should be explored and clarified, possibly in the context of the forthcoming national plan on women's health being drawn up at present by the Department of Health. In addition, an independent citizens' advocacy scheme should be used to support disabled people's rights to their own bodies
- people with disabilities should be offered the full range of contraceptive options

## Sexuality and relationships

### **N:8**

The myths and fears which lie at the heart of contemporary belief systems about sexuality have a profound influence on the lives of people with disabilities, the kinds of sexual relations people with disabilities may have and whether, in fact, they may express their sexuality at all. The sexual expression and the development of a sexual identity of people with disabilities is frequently subject to the control of others, either directly or indirectly, through society's delineations of acceptable sexual expression or what is attractive.

It is widely accepted that sexuality is culturally defined as well as being a natural force. What is acceptable and valued is conditioned by social position and status. In a society in which status is determined largely by the exercise of economic power and social influence, people with disabilities are disadvantaged in terms of their right to express their sexuality. While there is no agreed view of what constitutes the appropriate sexual behaviour of people with disabilities, society's rules of acceptable behaviour for non-disabled people appear to be different from those rules which are applied to people with disabilities: this creates inequality.

Underpinning this inequality are issues of protection and control, along with unarticulated fears concerning fertility which distantly echo the eugenics debate. The main religions in Ireland portray sexuality as a gift and there is also a close association with the notion of procreation and the "giving of life". For many non-disabled people, the sexuality of people with disabilities, far from being a gift, is a liability because of its association with procreation. To avoid confronting this, the sexuality of people with disabilities has been largely ignored. Where avoidance is not possible, arbitrary controls are applied. While these are often presented as being for the physical protection of people with disabilities, they also work to protect society from the possibility of a person with a disability becoming a parent.

In dealing with sexual values, generally expressed in terms of the "naturalness" of sexual feelings or behaviours, each individual brings with them their own subjective views, experiences and fears to any discussion on the topic e.g. discussions on homosexuality give rise to anxieties and expressions of prejudice from heterosexual men. In the light of this, and as a consequence of rigid thinking in society about sexual matters, it is easy to see why certain fears and myths about sexuality are projected on to people who are different in some way, leading to damaging stereotypes. These are ways of shutting out that which is problematic or uncomfortable, disempowering people with disabilities and denying their personhood at the same time.

- the population of people with disabilities in prison and the extent to which their requirements and rights are comprehended and fulfilled
- the treatment of prisoners who develop mental health difficulties and other disabilities while in custody
- in order to prevent abuse of all types, people with disabilities should receive appropriate information, particularly about personal rights, self-defence training and assertiveness training, through formal and informal education and training settings
- a code of practice on the protection from harassment of people with disabilities should be developed, introduced via legislation, enforced and monitored, along the lines of the *Code of Practice on Measures to Protect the Dignity of Women and Men at Work* (Employment Equality Agency, 1994)
- research is needed into the impact of disability on marital breakdown and the many difficulties that result from it for disabled people, with a view to ensuring that their requirements are dealt with equitably in any forthcoming legislation, codes of practice etc
- in order to ensure the greater protection of people with disabilities, the system of protection orders should be extended to everyone, irrespective of marital status or living situation
- the concept and implications of “fit parenthood” should be examined to ensure that discriminatory practices are not perpetuated against people with disabilities
- the particular situations of women and older people with disabilities require focussed attention.

The recommendations in this section should be read in conjunction with the General Strategies to Equalise the Status of People with Disabilities (pages 7 - 28).

- people with disabilities should be resourced to undergo training in lobbying, PR, handling the media etc
- the equivalent of the BBC Disability Programmes Unit should be established in RTE, involving radio as well as TV. The functions of such a unit should include the training and placement of people with disabilities throughout RTE, the making of programmes on disability issues (both series such as *Not So Different* and *In From the Margins* and once-off documentaries etc) and advising RTE and independent production units on disability issues
- the possibility of an annual theme week/season on TV/radio on disability issues should be negotiated with RTE, IRTC etc
- live subtitling should be introduced on news and other appropriate TV programmes, along with greater use of signing insets, both live and pre-recorded
- subtitling should be included as a criterion in RTE funding for independent productions and resourced accordingly
- TV and radio should, in the context of public service broadcasting, be used to supply information to people with disabilities (see page 15), including use of Aertel etc
- RTE should implement strategies to make people with disabilities, including women, more visible in its programming, as presenters, panelists, contestants, characters, audience members etc
- consideration should be given to the development of an award system honouring media personnel who promote better understanding of disability issues
- coverage by the media of events from demonstrations to access issues to art exhibitions involving people with disabilities should be undertaken by relevant journalists, rather than by health correspondents
- the Guidance Note on the Portrayal of Disabled Persons in Advertisements (1993) should be incorporated into the main body of the Code of Advertising Standards for Ireland and be stringently implemented and monitored by ASAI and the proposed media watchdog body.

The recommendations in this section should be read in conjunction with the General Strategies to Equalise the Status of People with Disabilities (pages 7-28).



## Specific strategies to equalise status in the arts, culture and the media

As well as the above general strategies, others specific to each sector are necessary if equal participation by disabled people is to be achieved.

### Arts



NRB recommends that:

- the Arts Council should initiate the development of informed policy in the field of arts and disability by setting up a “commission” on the model of The ACE/*Arts and the Ordinary* and *Making Youth Arts Work* strategies, involving meaningful consultation, focussed action research, realistic resourcing, implementation and follow-up
- at least until this “commission” reports (given that it may advocate alternative structures), the Arts Council should activate its existing policy and establish a sub-committee on the arts and disability
- as a matter of urgency, the Arts Council should update and implement its policy documents *To Enable* (1988) and *Code of Good Practice* (1985)
- since the Arts Council’s fund for improving physical accessibility to arts venues is, at £10,000 p.a., seriously inadequate, the fund should be:
  - increased in total
  - increased to 50% - 75% funding from the current 33%
  - advertised and promoted
- artist-in-residence schemes should be extended to ensure that:
  - disabled artists work as artists-in-residence in both inclusive and currently segregated settings
  - disabled people are prioritised as “students” of the schemes
  - all classes are held in accessible venues etc
- the use of disabled presenters, actors and performance artists on stage, radio and screen should be encouraged by the use of equal opportunities policy and practice at every level, including in theatres, acting schools, RTE and independent production units.

These and other dimensions of exclusion perpetuate cycles of oppression, both external and, in the case of people with disabilities, internalised. The fact that people with disabilities are not seen as participants in the arts has led to the view that people with disabilities are

- passive, rather than active
- not interested in arts and culture
- incapable, uncreative
- less than “normal”.

It has also deprived Irish artistic and cultural life of boundless talent, creativity and richness and has depleted the growth that comes from the inclusion of diversity.

## General strategies to equalise status in the arts, culture and the media

Many of the strategies already detailed in this submission - including total access, disability proofing, disability equality training, accessible transport - will, when implemented, do much to increase the participation of people with disabilities in the arts and culture. Given the dependence of most of the sector on subsidies and grant aid, the linking of eligibility for funding to the proven implementation of equal opportunities strategies benefiting people with disabilities (see page 32) would have a particularly important effect.



In addition, NRB recommends that:

- the Building Regulations Technical Guidance Manual on accessibility be amended to put as much emphasis on accessibility backstage and front-of-house in theatres, concert halls etc as on audience facilities (see also leisure section, page 78)
- specially-designated bursaries be offered by the Arts Council and other grant-making bodies to enable people with disabilities to participate in courses e.g. drama, sculpture, script-writing, journalism, arts administration, set design etc
- traineeships, pre-training, occupational familiarisation and access courses should be among the affirmative action strategies developed and implemented by arts organisations to ensure that opportunities for equal participation are activated
- unwaged people with disabilities should be included where venues offer pricing concessions

disability arts from mainstream arts organisations than from disability organisations.

With a few notable exceptions (e.g. PanPan Theatre, Look Beyond Dance Company, Muscular Dystrophy Ireland) concentration has been on visual arts (e.g. George McCutcheon, Stephen Walsh) and writing (e.g. Christopher Nolan, Davoren Hanna) rather than interpretative and performance arts, mirroring the invisibility of people with disabilities in the media and in the streets and, within that, the further exclusion of women and older people with disabilities. This may be because writing and visual arts are created alone in one's own space, while performance and interpretative arts require access to public spaces, collaboration with teams of people, auditions and career structures, particular education and training - all of which are made highly problematic at present for people with disabilities. Similarly, attendance at performances by others is frequently ruled out by inaccessibility, including the lack of audio-description, sign interpretation, loop systems etc, pricing and discriminatory policies (e.g. blind people or wheelchair-users must be accompanied by a non-disabled person etc).

## Defining parameters

There are four key dimensions in the relationship between disability and the arts, culture and the media:

- portrayal
- participation
- expression
- control

### **Portrayal**

In modern society the mass media are pervasive in their generation and perpetuation of powerful social and cultural images. For those with disabilities, the media often trivialise or marginalise their concerns. Images of difference, labelling and deviance are repeated and reinforced. Inappropriate language, inaccurate terminology and depictions of helplessness abound. Overall, portrayal is of dependence and powerlessness. As a result of this limited and negative portrayal, society's picture of the world is restricted and incomplete. Increased involvement of people with disabilities in the media and cultural activities will be an essential element of redressing this balance.

### **Participation**

Historically, the participation of people with disabilities in the arts and cultural activities has been restricted. Access, consultation and equal

- 
- **community development projects of all types should include a disability perspective.**

The recommendations in this section should be read in conjunction with the General Strategies to Equalise the Status of People with Disabilities (pages 7 - 28).

## Leisure

### N:8

NRB-2003

The policies and practices of exclusion - inaccessibility, lack of information, negative attitudes, inaccessible public transport etc - conspire to prevent people with disabilities from joining in sporting and other leisure activities. In addition, most sports and leisure centres at present have few facilities which cater for the particular requirements of people with disabilities. The more competitive sport becomes, and the greater the emphasis on winning, the more difficult it becomes for many disabled people to find a place with their peers.

Specious grounds such as "insurance risks" and "health and safety regulations" are frequently cited to keep people with disabilities out of pubs, clubs and other centres, while wheelchair-users may be allowed in on quiet days but not on busy ones as "they take up too much room". Such factors, together with lack of leisure education, result in low levels of participation. As a consequence, time and again research indicates that watching T.V. or listening to music or the radio occupy the main part of disabled people's leisure lives.

Difference in treatment promotes inequality by creating the impression that because people with disabilities are not a part of the mainstream social world they are unable to be part of that world. Limiting the social experiences of people with disabilities can create socially incompetent people who cannot find a place for themselves in the world at large and so become more withdrawn and isolated, with self-esteem further depleted.

In the absence of inclusion, separate leisure activities for people with disabilities have tended to be set up.

Many of the strategies already detailed in this submission would, if implemented, do much to increase the participation of people with disabilities in leisure activities. Specific strategies are also needed.



NRB recommends that:

- local authority funding for municipally-run or funded leisure facilities should be increased by central government and linked to their accessibility and concessionary pricing for people with disabilities. Specially-designated funds should be made available to purchase swimming pool hoists and other adaptive equipment
- playgrounds and other active leisure facilities at local level should be made accessible and welcoming to children with disabilities

people with disabilities may vary from total choice for those who can pay for the whole cost of their equipment to none for those who can pay nothing. Over half of the participants in the *Costs of Disability survey* (see page 48) had bought equipment, aids or furniture because of their disability, including hand controls for a car, hearing aids, wheelchairs, flashing doorbell signals, an intercom system and special utensils for kitchen use. The cost involved ranged from around £10 to £300. Some 70% of participants knew of equipment which would make life easier for them but almost all of these people could not afford to buy it.

A key weakness in the system at present is the fact that although legislation states that products must be supplied by the health boards free of charge to people with full eligibility, there is no requirement that products supplied must meet a certain standard or that users' particular needs and demands must be taken into account with regard to the equipment that is supplied. This results in differences between health boards in policy and practice. It also means that equipment supplied to people with disabilities may be unsuitable and remain unused, or may fail to resolve existing difficulties.

In addition, information for people with disabilities about technical aids and equipment, its features and availability and how to choose it, is hard to access, leading to people with disabilities struggling unnecessarily or spending large sums of money on inappropriate or even hazardous equipment. This situation may be partially resolved in 1995 when the Handynet European database on aids and equipment for people with disabilities becomes generally available and when NRB's Disability Resource Centre begins to develop a regional presence.



NRB recommends that:

- a full review of the service delivery system for technical aids and equipment be instigated immediately, with a view to addressing anomalies and inequities in the current system, eliminating waiting lists and setting and enforcing national standards
- clarification of the responsibility to inform people with disabilities about technical aids and equipment is required
- repairs to essential equipment should be carried out promptly
- anomalies and ambiguities in the provision of technical aids to people in hospital should be addressed.



NRB recommends that:

- a PA service be introduced as part of the comprehensive range of state-funded community-based support services, based on the results of the pilot programme recently completed
- the PA scheme should also be available to blind people (as readers, for example), to deaf people (as sign interpreters), deaf-blind people (as guide/companions) and people with mental health difficulties under the same conditions.

### **Counselling support services**

Throughout this submission attention has been drawn to the artificially limited life experience and low self-esteem of many people with disabilities as a result of their marginalisation and exclusion. Yet counselling support services to assist people with disabilities to develop coping strategies are all but absent, as is counselling support for those who live with or are related to people with disabilities. While physical and intellectual needs are addressed at every level in a multiplicity of ways throughout the life-cycle, emotional needs and general support systems are frequently ignored. What is required is a system of integrating counselling supports within the range of services provided for people with disabilities and those who live with them.



NRB recommends that:

- this area be researched and pilot schemes run with a view to introducing a set of appropriate service responses throughout the country, aimed at both people with disabilities and, crucially, those who live with them
- all professional staff working with people with disabilities and those who live with them should receive training in basic counselling skills
- disability equality training and training in disability issues pertaining to counselling policy and practice should be included in the professional formation of all psychotherapists, occupational guidance and other counsellors
- the range of occupational guidance and counselling resources currently available to people with disabilities should be reviewed and extended
- funding should be provided to train people with disabilities as peer counsellors.

- all health and personal support services should be comprehensively equality proofed (see page 8) to ensure equal access for both men and women
- women with disabilities should be included specifically in the national plan for women's health promised in the Department of Health's recent strategy document. All women's health services should be made accessible in every way to all women with disabilities
- recommendation 11.10.2 of the Report of the Second Commission on the Status of Women (1993), calling on the Department of Health to adopt and implement a specific mental health strategy geared to the monitoring, prevention and treatment of mental health difficulties as they affect women, should be implemented without delay. Psychiatric and mental health services should be examined to ensure that women who require them receive appropriate services.

## Specific strategies to equalise status in health and personal support services

As well as the general strategies detailed above, specific strategies are required in each of a number of health and personal support services in order to ensure equal status for people with disabilities both within service areas and in the community at large. This list is not to be taken as exhaustive.

### **Home help service and home care assistance schemes**

At present the home help service is aimed primarily at older people and provides only limited assistance to people with disabilities. The scheme as it currently exists is limited in terms of meeting the needs of people with disabilities in that:

- it is concerned with household tasks such as cleaning, cooking and laundry and does not address the personal care requirements of a significant proportion of service users
- it is not available during unsocial hours, which are often the times of greatest need
- criteria for the service vary throughout the country
- wage levels vary throughout the country but are generally low (as little as £1 an hour) and do not reflect the level of responsibility assumed by workers.



- innovation, taking into account increasing standards of service delivery, the development of new services and new models of best practice
- transparency, so that criteria for service eligibility, reasons for service withdrawal, available choices, changes in service availability, length of waiting lists and so on are clearly understood by and communicated to current and potential service users
- standardisation, so that service provision and criteria are equalised to the highest level throughout the country.



NRB recommends that:

- health and personal support services be refocussed to ensure planning and delivery in accordance with the principles listed above
- essential services which are currently discretionary should be made mandatory. Personal support services such as personal assistance and home help can make the difference between managing and not managing, continuing and giving up
- preventative strategies, such as those detailed in *Shaping a healthier future*, should be prioritised, and preventative measures within services should be strengthened in order to prevent the development of secondary disabilities and deterioration in existing conditions
- the reasons given by people with disabilities who refuse or opt out of services should be documented and used in service reviews
- each health board should allocate funds to be used each year to develop and test out new service responses to the changing requirements of people with disabilities, with a view to ensuring the dynamic development of services over time
- services such as pain management, which involve multi- disciplinary approaches centred on customer-identified needs, should be prioritised for development on a local basis
- all staff involved in the planning and delivery of health and personal support services, including administrative staff e.g. those involved in dealing with the provision of technical aids and equipment, should receive both disability equality training and training specifically geared to understanding the requirements of people with disabilities as they relate to their work
- a register of care workers should be established and maintained

## Health and personal support services

### N:8

Many people with disabilities have considerable contact with health services arising directly from their disability. In addition, since many disabled people are unemployed and dependent on benefit, the findings that unemployment and poverty lead to illness and that people from lower socio-economic groups make up a high proportion of those who experience psychological ill health and chronic illness, imply that people with disabilities are likely to use health services more than others, not simply because of their disability but also because they are unemployed and poor. The higher usage of the health services by unemployed people is attributed as much to the stress of being "on the scrap heap" as to the direct effects of poverty and deprivation (Nolan, 1992).

The issues surrounding this are:

- physical inaccessibility
- inaccessibility of information
- socio-economic class bias
- links which exist between health, class, poverty and disability.

Some 66% of the participants in the 1993 *Costs of Disability survey* (see page 48) had been to the doctor in the previous twelve months due to their disability. Over a third had spent time in hospital in the same period, while 40% had used three or more health-related services. Yet people with disabilities frequently argue that disability is not a health issue and, at the same time, disabled people, particularly women, are known to under-consume health services.

Unravelling this complexity involves recognising the following elements:

- the complex relationship between health, class, poverty and disability, as noted above, and their links to exclusion and low self-esteem
- the issue of many essentially social and community supports (e.g. personal assistance, home help) being perceived as health rather than social services, while other social supports (e.g. readers, sign interpretation services) may not be available
- the delivery of other services (e.g. training of people with disabilities) inappropriately through health organisations
- the poor quality of many disabled people's interface with medical and health services, generally resulting from, among other elements, physical inaccessibility, inaccessibility of information, poor communication, lack of transparency, lack of consultation procedures, lack of consideration of the particular needs of people with disabilities, preference for dealing with carers etc.

- resources should be allocated to ensuring that the physical layout of larger and older residential and institutional care centres is altered to afford maximum privacy to residents. Privacy should be afforded by staff by such common courtesies as knocking on the door before entering residents' rooms, making appointments etc
- national standards, drawn up in collaboration with people with disabilities, including people who live in these settings, governing residential and institutional care centres should be developed and implemented. These standards should include:
  - people voluntarily entering residential and institutional care settings should be given a written statement of their rights so that they are in a position to make informed choices
  - the rights of people who are detained involuntarily in institutional care should be made clear to them and protected, by use of an independent citizens' advocacy service where necessary
  - all residential and institutional care centres should have a mechanism whereby residents' views are heard, respected and taken into account and the parameters within which decisions can be made are explicit
  - independence should be fostered to the greatest extent possible. Residents should be enabled to choose and keep their own clothes, choose their own furnishings, decide their own daily routine and generally be enabled to make as many decisions about their own lives as they can
  - residents who require assistance with intimate personal care should be offered choice in who provides them with this service. Women should never be forced to accept such assistance from men without their expressed consent
  - residents should not be prevented from expressing their sexuality or from developing close or sexual partnerships (see sexuality and relationships section, page 92)
  - residents should have access to and control over their own money, including benefits and entitlements (see income support section, page 48), and the right to build up savings
  - inclusion and integration into local community activities should be developed to the greatest possible extent
  - assertiveness training, self-advocacy and personal development, social and political education, sexuality and relationships education and counselling should be made available to people with disabilities who live in residential and institutional care settings
  - living in residential or institutional care should not debar people with disabilities from accessing other services e.g. personal assistance, education, training etc

## Residential and institutional care

### N:3

While the majority of people with disabilities who live in residential and institutional care settings, apart from those compelled to do so by forced committal procedures, cannot be said to have been coerced, many do not do so by choice. Inability to cope alone, unavailability of suitable accommodation, inability of family to support and unavailability of home help services were the main reasons given for the forced move from the community into residential care in a recent survey of people with physical disabilities (*People First*, IWA, 1994). While most people with disabilities in residential settings live in places particularly aimed at people with their requirements, others are inappropriately placed e.g. young people with physical disabilities living among elderly people in general hospitals. This can have serious consequences in terms of dependency, quality of life and self-esteem.

Even where placement is seen to be appropriate, i.e. in centres offering services to people with a particular disability, best practice in independent living may be absent. Segregation and isolation, derived from an acute care model, can sometimes be extreme. Many institutions are large, physically isolated from centres of population and tend to import services and activities for residents rather than encouraging their inclusion in local communities on an equal basis. Sometimes topography brings its own problems e.g. a residential centre for people with significant physical disabilities on top of a steep hill, which means that residents cannot go to the shops in the village in which they live without assistance.

Large institutions, such as psychiatric hospitals, can be generally the most inflexible, with systems not geared to treating residents as individuals with unique personalities, preferences and requirements. Smaller living units, such as group homes etc, can allow much greater flexibility but this does not automatically happen, since institutional attitudes and procedures can be imported from the old institutional practices, particularly where staff are moved from hospital settings without adequate training, or the smaller units are "outgrowths" from a larger parent body (e.g. hospital) and share staff.

Privacy and personal choice are often at a premium in residential and institutional care. In many institutional and residential care settings times to get up, go to bed and even go to the toilet are fixed. Choice as to what to eat or wear may be absent, even in small-scale settings.

The involvement of residents in decision-making about their own homes is often minimal, especially in larger or high-support centres. A speaker at a conference on women and disability in Dublin in 1992 summed the situation up thus: "In residential care you are constantly compromising... there is no

---

## Rented accommodation



NRB recommends that:

- ways of providing reasonably-priced rented accommodation on short to medium-term lettings should be found
- the Landlord and Tenants Acts should be altered to ensure that an agreed proportion of flats for private letting be made physically accessible at the stage of conversion
- through anti-discrimination legislation or other means it should become an offence for a private landlord to refuse accommodation to a person or a family because the individual or a family member has a disability
- local authorities' criteria for priority on housing lists should become transparent and the system of "medical priority" be overhauled to ensure the inclusion of social factors.

## Housing

### N:3

Given their rate of unemployment, low average income level, inaccessible public transport etc. people with disabilities are more likely than non-disabled people to spend a large amount of time in their own homes. Many people with disabilities, however, live in accommodation which is inadequate for their needs or in which they are virtually imprisoned since they cannot gain access to even their neighbours' houses. Young disabled people's aspirations to leave home and live in a flat like their non-disabled peers is limited, not only by financial constraints but also because accessible flats are not generally available. This prevents young people with disabilities living a life of their choice and forces them to stay in the shelter of the family long after they may otherwise wish to.

### New housing

New homes built with flights of steps up to the front door represents visible evidence of the exclusion of many people with disabilities from housing choice.



#### NRB recommends

- the extension of the Building Regulations to include private dwellings
- the immediate implementation of the Department of the Environment's clear and detailed 1982 policy (NG/82 Construction Guidelines) that all new local authority home building should be of adaptable "lifetime homes". This would ultimately save the State money as adaptations would, by definition, be less extensive and people who currently have to remain in hospital until modifications are carried out would be discharged more quickly. This has the added bonus of allowing a person with a disability to return to a "normal environment" as soon as possible, and enabling older people who become disabled to remain in their own homes with the minimum of disruption. All new housing being "visitable" would do much to mitigate the social isolation of many people with physical disabilities
- a specified proportion of all new private housing developments should be of adaptable "lifetime homes"
- housing used by people with disabilities, especially women and older people, should be within easy reach of shops and other local facilities.

## Transport

### N:3

Access to transport is an essential requirement of modern living for people with disabilities, for whom the simplest of journeys can be a major undertaking. Access to transport is imperative, particularly as many disabled people cannot drive or cannot afford to. Some 70% of older people are believed to be heavily dependent on public transport. Despite their obvious need, people with disabilities continue to be denied adequate access to almost all modes of public transport within the State.

The current situation can be summarised as follows:

- **Rail:** some mainline trains have adapted spaces for wheelchairs but which trains is never clear; while all new rolling stock will be accessible, improvement is slow; many stations are inaccessible even when the trains are adequate; access for blind and deaf people is poor
- **City buses:** Buses purchased in Dublin in the last five years offer improved access to ambulant disabled people and people with sensory disabilities but exclude wheelchair users, while other Irish cities do not have even these improvements. Further changes are needed e.g. audible announcements of stops
- **Coaches:** highliners are extremely difficult to negotiate for people with ambulatory difficulties and are impossible for wheelchair users
- **Taxis:** Dublin is the only city to have wheelchair-accessible taxis, while cost prohibits regular use
- **Ferries:** the main ports and some ships are accessible but much more remains to be done
- **Air travel:** airports are on the whole accessible and open to improvements; aircraft themselves remain problematic.

Staff training and practice is an issue throughout the public transport system.

Lack of access to public transport for people with physical disabilities means that they are unable to leave their immediate environs without arranging for private transport or to pay for a taxi. This impacts on their ability to pursue education, attend training courses, work outside the home or live in the area of their choice. They cannot participate in social activities on the same basis as their non-disabled peers. They are prevented from going into the city to window-shop or browse. Lack of transport also deprives people with disabilities of the right to spontaneous action.

## Financial services

### N:3

Discrimination against people with disabilities appears to be general in the area of banking and insurance. Excessive and unexplained insurance loadings, extra medical tests and invasive questioning, delays in medical insurance cover and the use of “our insurance won’t let us” to exclude people with disabilities from places otherwise open to the public abound. Research detailing the extent of the issue is not available but many examples can be provided.

Anti-discrimination legislation, advocated elsewhere in this submission (see page 23), is essential in this area.



NRB recommends that:

- the area of financial services (banking, insurance, loans, hire purchase etc) should be researched with a view to eliminating discriminatory practices
- where a person with a disability can prove in the usual ways (appropriate level of income to meet repayments, security) that they can repay a proposed loan of whatever size there should be no requirement for a doctor’s certificate or other additional information that would not be required of a non-disabled person
- there should not be a requirement for people with disabilities to take out additional insurance for a loan where there already exists a mortgage on a property or other asset as security. The extra cost of (generally inappropriately loaded) insurance can make all the difference between ability and inability to repay a loan
- the loading of life insurance policies, particularly whole life and endowment policies, should be carefully examined to ensure fairness to disabled people. Disability does not always mean bad health and therefore should not always incur premium loading. Genuine loadings based on reliable risk factors should be used, if at all, and distinction should be made between disabilities on realistic terms, based on up-to-date mortality tables and actuarial information. At present such information appears to be out-of-date



## Strategies to equalise status in other entitlements

The issues of confusion, discretion and lack of clear information apply to many other entitlements which people with disabilities wish to access. As well as those detailed below, issues concerning housing (see page 60) and technical aids and equipment (see page 75) are considered elsewhere in this submission.



NRB recommends that:

- a disability leave scheme, enabling workers to retain their jobs during periods of hospitalisation, temporary relapse or retraining, should be piloted, and evaluated, with a view to working out a national system. The scheme places value on workers' skills and emphasises their retention rather than dismissal, early retirement or redundancy which ultimately cost more to both claimants and the State
- the Mobility Allowance should be reviewed, standardised, made transparent and, in common with all benefits and entitlements, promoted among people with disabilities. The present guidelines are generally restrictive, inequitable and assessed differently by AMOs in different areas. Any revised Mobility Allowance should also take into account the requirements of people with other mobility disabilities as well as full-time wheelchair-users
- the Motorised Transport Grant Scheme should be reviewed. At present the scheme involves a catch 22 situation, in that in order to access payment a person with a disability must require a car in order to access employment. However, having an income from employment generally eliminates people from the required means test, so they do not qualify for the grant. The scheme should be revised to ensure that it can benefit other disabled people e.g. those in education or training or who want to buy a car for reasons of general mobility, given the current inaccessibility of public transport and its absence from many rural areas
- a State-sponsored scheme, along the lines of that currently operated by the Disabled Drivers' Association, enabling physically disabled people who cannot drive to designate a particular car for a disabled passenger sticker, allowing parking in designated parking places, should be devised, implemented and monitored
- the Drugs Refund Scheme, which operates according to Section 59(2) of the Health Act (1970) and the Health Service Regulations (1972, 1991), should be reviewed to ensure a reduction of hardship on people with disabilities who require prescribed medication at times which do not correspond easily to the defined set period. Its relationship to the

## Interim strategies to equalise status in income support

Recognising that the radical strategies advocated above may take some time to implement, there are urgent changes required in the system of disability-related benefits which should be implemented without delay.



NRB recommends that:

- the ceiling on allowable earning from “rehabilitative employment” should be equalised to the level available to non-disabled people, including increases made if the claimant has dependants
- the practice of withdrawing DPMA from people with disabilities while they are in hospital or living in residential or institutional care should cease. A third of participants in NRB’s 1993 survey had spent some time in hospital in the previous year, leading to serious financial difficulty, since many of their regular costs of living - such as rent - had to be met during this time and they still needed to make purchases and pay for telephone calls while in hospital. The non-payment of DPMA to people in residential and institutional care suggests that they have no right to any income at all, reinforcing the notion of dependency, whereas with DPMA residents would be able to make a means-tested contribution towards their accommodation
- the discretionary medical assessment ascertaining which people with mental health difficulties are eligible for DPMA should be standardised, made transparent, enforced and monitored. At present in some Health Board areas DPMA is paid to people who have a psychotic illness, based on the report of a consultant psychiatrist. Frequently the assessment is made on the basis of the type of medication which a person may be receiving, which may result in being awarded or disallowed DPMA on the basis of medication rather than the functional impact of mental health difficulties. DPMA is generally not paid to people with mental illness who have difficulties which do not result in psychotic behaviour, yet their mental health difficulties may in fact limit their availability or suitability for employment
- benefit testing should cease. At present, under the provision of the Social Welfare Act (1992), where, for example, the husband or male partner is receiving disablement benefit and his wife or woman partner claims social assistance in her own right, both of their benefit incomes will be reduced, as a couple, so that the wife receives only what would be the equivalent of a dependant’s allowance

of disability-related benefits and entitlements, their calculation, assessment, delivery, administration and appeals systems. This requires a hard look at the principles underlying the treatment of disability, sickness and injury in Irish social welfare, health and related law, including where appropriate, comparisons with principles in use elsewhere in Europe. Such a review should involve an opportunity for people with disabilities to discuss and debate the different principles in use and express an informed view in relation to existing or future legislation.

Any emerging system should provide for a comprehensive disability income scheme based on three principles:

- equity between disabled and non-disabled people
- equity among disabled people, regardless of how or where the disability arose
- equity between disabilities, so that it is the functional impact of the disability that counts, not the disability type

and should consist of two parts:

- an allowance to meet the extra costs of disability, based on the functional impact of disability and paid to all qualifying people with disabilities, regardless of employment status, income level, age or gender
- a basic unemployment payment for all people with disabilities along the lines recommended by the Report of the Commission on Social Welfare (£65 at 1986 prices), paid to all qualifying disabled people regardless of the cause of their unemployment or the level or absence of previous social insurance contributions, paid in part to people with disabilities in part-time work and involving disabled people in the same relationship to the labour market as non-disabled long-term unemployed people.

The administrative system needed to access these payments should be:

- simple and transparent, with clear information and a straightforward appeals system with an independent element, and clear guidelines concerning advocacy and representation
- delivered through the Department of Social Welfare in mainstream settings by staff well-trained in disability equality issues.

The allowance for the extra costs of disability should be flexible. It should take account of both the actual range of activities that the person can undertake and the degree of difficulty, pain, mental stress and cost that they experience in so doing. Concentrating solely on the activities that an individual does undertake would be inadequate since many disabled people make Herculean efforts to maintain their personal independence. This in itself may involve extra costs, e.g. doing their own shopping but from the nearest rather than the cheapest shops. As the environment, transport etc become more accessible, the extra costs of disability may change.

# Income Support, Benefits and Entitlements

## N:3

At least one third of people with disabilities in Ireland rely for their income on disability-specific state benefits. These are low - DPMA, for example, is at present paid at the level of the general poverty line, *before* taking into account the extra costs of disability. In addition, claimants of disability-related benefits are generally excluded from any relationship with the labour market, since most payments are predicated on inability to work. This in itself gives rise to anomalies, since many people with disabilities in receipt of benefit can and do work and/or pursue vocational training courses with a view to finding employment.

The benefits system as it impacts on the lives of people with disabilities is complex. Based on the 1830s Poor Law concept of deserving and undeserving poor and definitive classes of people with disabilities, the system has grown in an ad hoc manner. A recent report on one small aspect of the system, Social Welfare sickness benefit claims and appeals (*Fit for Work: Who Decides?*, Coolock Community Law Centre, 1994) described bureaucracy characterised by poor information flows and the repeated disempowerment of the claimant.

The net result of medicalising what is essentially a social welfare issue effectively discourages people with disabilities who struggle for personal autonomy and economic independence.

The flexibility which has begun to enter the mainstream social welfare system (e.g. in the Return To Work Scheme, which allows participants to retain certain benefits) has not generally been extended to people with disabilities. Instead, payments are used in a way which excludes people with disabilities from access to the labour market, reinforcing the concept of disability as a medical issue and, most significantly from the point of view of people with disabilities, reinforcing the notion of dependency at every level.

The *Costs of Disability Survey* (NRB, 1993) identified a number of core issues in the area of benefits and allowances:

- **level of allowances:** allowances are too low and, importantly, do not reflect disability related costs, which differ according to type and severity of disability
- **accessibility of schemes:** the different disability-related schemes have different criteria of eligibility
- **means-testing of schemes:** some disability-related costs are incurred, whether or not people with disabilities are earning an income. Means-testing as a basis for allocating allowances overlooks this and acts as a disincentive to people with disabilities who wish to take up employment

- people with disabilities whose jobs do not for whatever reason work out should be able to return to the appropriate disability-related benefit without loss of eligibility
- alternative forms of employment, such as systems of transitional and supportive employment common in the US, should be researched and piloted, monitored and evaluated in contrasting locations
- the Government's pledge in the Programme for Competitiveness and Work to consider using, in consultation with the social partners, the processes of public funding and the award of contracts to promote equal opportunities, should explicitly include equal opportunities for people with disabilities and should be implemented without delay, drawing on US experience in this area. A system should be considered through which opportunities could be identified to ensure that all projects where the State is the prime client, above a certain mandatory size, should involve minimum levels of expenditure being placed with organisations employing significant levels of disabled people
- employment opportunities for women with disabilities should be improved and the equality of opportunity debates taking place in relation to the employment of non-disabled women should be addressed to the employment of women with disabilities.

## Strategies to equalise status in sheltered work/employment



NRB recommends that:

- the status of people with disabilities currently in sheltered work settings be reviewed, including such issues as wage structure, the legal status of workplaces and workers, funding, standards and conditions
- people working in sheltered situations should have the equivalent employment rights as other workers under existing employment legislation
- a Rehabilitation Training and Employment levy should be introduced to meet the training and employment needs of people with disabilities who need or choose some form of supported/sheltered employment
- consideration should be given to allocating government responsibility for employment, both open and sheltered, to one Government Department

- all employers should be required to produce evidence of the implementation of equal opportunities policies and practices benefiting people with disabilities, and to achieve set equality targets within enforced deadlines
- tax concessions should be used, along with specifically designated and monitored supplementary grants, to provide assistance with employers' necessary expenditure on increasing access to employment for people with disabilities
- eligibility for funding from Area Partnerships, County Enterprise Boards, LEADER programmes etc should depend in part on evidence of equal opportunities policy and practice benefiting people with disabilities (see page 22)
- existing support schemes, such as NRB's Employment Support Scheme, should be further promoted and extended
- NRB Workplace Adaptation Grants should be extended, renamed and repositioned to include eligibility for the provision of human support resources such as readers, sign interpreters, personal assistants, job coaches etc as well as new and assistive technology
- a Fares to Work scheme, in which people with disabilities receive grants to assist in travelling to work, should be investigated and evaluated in contrasting locations
- people with disabilities in low-paid employment should, in the absence of a specific allowance to meet the extra costs of disability (see page 48), be entitled to retain their secondary benefits
- a funding mechanism in the form of a Rehabilitation Training and Employment Levy, possibly as a designated part of an existing employment levy, should be introduced to meet the training and employment needs of those for whom sheltered provision in some form is the required option
- the proposed National Voluntary Scheme of Work-Sharing, promised in the Programme for Competitiveness and Work, should be made available to people with disabilities
- teleworking and other home-based work options should be developed but not as a substitute for making work environments accessible. Such work should be included in the ambit of employment protection legislation

## Employment

### N:8

The rate of unemployment among people with disabilities is estimated at 70%. Even for disabled people with excellent education and training qualifications, getting a job is fraught with difficulty. A recent study, conducted in the UK for NESF, found that people with disabilities came last in a list of six sources of potential recruits identified by companies (NESF Report 4, 1994). Once in employment, accessing further training, job mobility and promotion presents new and tough obstacles.

In the absence of flexible work arrangements, job supports, personal assistance, political will and creativity generally, many people with disabilities are considered unemployable in the wider economy. To provide work for a large proportion of this group, an ad hoc system of sheltered workshops and settings has been developed. These workshops are currently outside the ambit of employment protection legislation and frequently wages as such are not paid, with participants receiving DPMA and an "attendance allowance". In the system as it presently operates goods and services produced are sold but arrangements lead many disabled people to feel that their labour is somehow not worthy of inclusion in the wider economy. This is reinforced by the fact that most disabled job-seekers are in receipt of benefits which do not entitle them to inclusion on the live register (see income support section, page 48). This in turn limits the access of people with disabilities to employment support programmes and employment schemes aimed at the long-term unemployed, so that NRB has frequently had to negotiate for access after the schemes are in operation.

Work is a crucial ingredient of an individual's economic and social well-being. Without gainful employment, many people with disabilities find themselves losing their skills and becoming demotivated. Referring to people who are long-term unemployed, a 1988 OECD report concluded that "if the situation is allowed to drift, with insufficient assistance provided for those out of work for a long time, it would be tantamount to consigning large numbers of the long-term unemployed to near-permanent social oblivion" (quoted in NESF Report 4). Yet this is the position in which many people with disabilities find themselves, along with the ignominy of not being included in the counting of the long-term unemployed and having to seek special permission and exemption to take part in schemes aimed at assisting that group.

Current levels of prejudice, discrimination and exclusion mean that people with disabilities feel compelled to hide or make light of their disabilities and requirements when job-seeking or in employment, placing themselves under considerable stress and lowering self-esteem. The lack of statutory employment protection in certain "sheltered" settings can make working

- the potential for the accreditation of prior learning as a certification option should be examined
- consideration should be given to allocating responsibility for the vocational training of all people, including people with disabilities, to one Government Department to ensure that vocational policy is fully inclusive and to assure equality of opportunity
- only training centres providing training to people with disabilities which are accredited in accordance with the NRB Standard for Vocational Training should be eligible for public funding for training purposes
- training aimed specifically at people with disabilities should include modules on social and political education, self-advocacy skills, education for leisure, personal development and other lifeskills
- labour market research should be conducted on an on-going basis to identify new and potential employment opportunities for which training should be provided
- trainees should be offered a range of relevant, high-quality training choices, with the guarantee of their delivery by organisations in a way which is cost-effective and which optimises trainee employment potential
- all training agencies receiving public funding should be required to publish annual accounts so that the State can monitor its investment
- trainees should be paid a standardised training allowance, replacing the current situation in which some training agencies pay RMA as an incentive, some pay a supplement to trainees' DPMA and others add nothing at all
- like non-disabled trainees, people with disabilities should be able to return to their previous benefit with no loss of eligibility if they do not get a job at the end of their course
- in recognition of the extra costs of disability and in the current absence of a specific allowance to meet these costs (see income support section, page 48), disabled trainees should retain their secondary benefits while in training
- the eligibility of trainees and potential trainees with disabilities to both training and allowances should be standardised, made transparent and communicated effectively, as under present arrangements a significant number of trainees in special training receive no allowance or other beneficiary payment, thus excluding some from taking up training opportunities



## Training

### N:3

Training and education are the two primary routes available to people with disabilities towards realising their full occupational potential. It is vitally important that people with disabilities have access to the widest possible range of training provision, in particular mainstream training. However, while mainstream training is open in theory to people with disabilities, accessing it can, in practice, be difficult.

Training in specialised settings, while generally segregating disabled trainees from their non-disabled peers, is geared specifically to people with disabilities and offers a degree of flexibility in duration, supports etc at present not generally available in mainstream training. Currently, vocational training in Ireland is heavily reliant on EU funding support which is available only for training programmes leading to the open labour market, thus limiting the kind of training available in specialised settings. Some programmes tend to be traditional in approach and are in many cases insufficiently attuned to emerging labour market trends and opportunities. The EU Green Paper on Social Policy (1994) noted in relation to training in general that it too frequently offers little real chance of finding new jobs and is often palliative, rather than functioning as a real instrument of labour market re-entry. That translates for people with disabilities, facing the difficulties of a prejudiced and discriminatory job market (see employment section page 42), as the overwhelming likelihood of long-term unemployment, without even the dignity of being included on the live register (see page 42).

## Strategies to equalise status in mainstream training



NRB recommends that:

- people with disabilities should have the right of access to the same training opportunities as non-disabled people. Forthcoming anti-discrimination legislation should ensure that people with disabilities will be admitted to training programmes for which they are suited and will not be excluded solely on grounds of disability or by e.g. failing to provide access, personal supports, adapted equipment etc.
- affirmative action programmes, aimed at including minimum targets of disabled trainees within enforceable timescales, should be put in place by all mainstream training providers and agencies

### **Third-Level Education**

This is at present the focus of much attention.



NRB recommends

- the appointment by all third-level institutions of an Equality Officer whose remit includes the equal participation of disabled students in every area of college life, from examinations to accommodation to social activities
- that technical and personal supports, including equipment, personal assistance, note-taking, transcription, reading and other services should become mandatory in third-level institutions
- flexibility in entrance requirements should be practised by all third-level colleges in relation to prospective students with disabilities
- that disability studies should become an option in the curricula of third-level institutions.

### **Adult, Continuing and Second-Chance Education**

The provision of these frequently informal methods of education is a key factor in promoting life-long learning and an inclusive social life for people with disabilities. For many whose education was interrupted by hospitalisation and people with relapsing disabilities etc. it can represent a particularly accessible way of gaining further education.



NRB recommends that:

- all adult, continuing and second-chance education be funded, priced and promoted in such a way as to ensure the active and full participation of the maximum number of people with disabilities
- disability studies, as part of a programme of equality studies, should become available in adult and continuing education and second-chance education projects.

- disability studies in an equal opportunities context should be included in all primary and post-primary curricula
- in order to facilitate people who become deaf, well-resourced lip-reading classes should become freely available throughout the country, instructed by teachers who have completed appropriate certificated training which should be set up as soon as possible.

## Specific strategies to equalise status in education

The general strategies listed above should be taken as read in approaching the strategies detailed below which refer to specific sectors within the field of education.

### **Pre-school education**

For children born with disabilities, early, comprehensive, appropriate intervention will lessen the impact of disability and difference on their lives and developmental processes. Secondary and tertiary disabilities can also be avoided. For the parent/s of disabled children, early intervention helps them feel reassured, less isolated and better able to handle presenting difficulties.

Pre-school education, with its emphasis on communal activity, play, games, music and social interaction and its opportunity for incidental learning and social and interactional experience, is potentially one of the key areas for inclusive, integrated development. Positive pre-school experiences can set the tone and the standards for future inclusive education. It is important that parents' first experiences of their disabled children in education stress acceptance and equal participation.



NRB recommends that:

- consideration should be given to providing free, inclusive pre-school education for all children with disabilities
- specific training on disability issues and working with children with disabilities be given to all pre-school teachers, crèche workers and others who work with young children
- standardisation in the delivery of support services, such as therapies and educational assessments, to children in pre-school education should be developed.

- 
- the right of all people with disabilities to access and participate in the same educational opportunities in the same settings at all levels as their non-disabled peers (inclusive education) AND to access and participate in specialist education
  - the right of parents to have their constitutional rights respected and to be involved in all stages (e.g. diagnosis, assessment, placement and programme planning) of education provision for their children of school-going age
  - the forthcoming Education Act should specify that statutory responsibility for removing barriers and supporting each disabled student with the necessary resources to participate fully in their educational setting is vested in the Department of Education, which should then fund, provide or arrange for the provision of the required information, access, transport, personal supports and resources at all levels
  - the proposed Regional Education Councils should build in disability proofing as part of an overall strategy of equality proofing at all levels and in all services in their remit and jurisdiction
  - statutory responsibility should be established for ensuring the equal participation in pre-school, third-level, adult, continuing and second-chance education of people with disabilities, including funding and/or providing required supports
  - the statutory right of all people with disabilities in education to receive appropriate support predicated on their personal needs and requirements, rather than on the vagaries of any particular educational setting or system, should be enshrined in the legislation and systems developed, including personal assistance and service brokerage, to ensure its practical application and adequate resourcing
  - teachers currently working in segregated education should be given the opportunity to become resource teachers, either centre-based or visiting, at all levels of education
  - special class teachers should be retained in the event of reduction of numbers due to falling rolls
  - training in teaching students with disabilities should form an essential and integral part of the training, both initial and in-service, of all teachers and tutors at all levels of education
  - under the terms of anti-discrimination legislation, it should become an offence to exclude a disabled person from any level of education on the grounds of disability or by e.g. failing to provide access, classroom support etc
-

## Education

### N:8

This submission has already shown that the Constitution's guarantee of every citizen's right to education may not be sufficient to ensure its access to all people with disabilities (see page 24). Yet education is a particularly powerful tool in creating equality for people with disabilities in society. Early experiences of inclusion or exclusion are crucial in shaping the future participation of people with disabilities. As the Minister for Education said in a speech earlier this year, "it is simply not acceptable that pupils, whether because of mental or physical disability or because of socio-economic factors, should be inhibited from full participation in education" (opening address, *The SERC Report and After* conference, Dublin).

Opportunities or barriers experienced by people with disabilities at any level of education - pre-school, first, second or third level or in adult, continuing or second-chance education - impact critically on the choices they can make in the future and the extent to which they can achieve their full potential. The forthcoming Education Act offers a timely opportunity to ensure that barriers are removed and opportunities for people with disabilities maximised.

Before suggesting strategies to achieve the required results, it is important to consider the impact of the current situation on young people with disabilities in Ireland.

### Current Situation of Young People with Disabilities

Young people often receive negative messages which affect their self-esteem and sense of self-worth. For instance, there are the societal messages about incompetence (e.g. "you can't - you're not old enough") and the superior knowledge of others (i.e. adults). Young people with disabilities receive more of these messages than non-disabled young people, because society sees them as needing particular protection. This protection requires special provision to be made for them, which in turn separates them and makes them different from other young people, perpetuating the cycle of exclusion. Those who begin in protected segregated settings continue in the main to be segregated and "special" throughout their lives. This perpetuates the myth that disabled people are inadequate and in so doing legitimates discrimination in all other areas of social life, particularly in employment.

Often children with disabilities are sent to special schools that are segregated from their home community, sometimes by great distance. The resulting

- 
- disability equality training should always include the perspectives of women and older people with disabilities, as well as acknowledging other important minorities
  - funding to train disabled people as disability equality trainers should be made available and suitable training courses should be designed and implemented throughout the country
  - general disability awareness campaigns, both national and local should be designed and implemented, using media and community resources (see also culture section, page 87)
  - all disability awareness/equality training and campaigns should advocate clearly the use of accurate, non-discriminatory language to describe people with disabilities and disability issues, including the use of symbolic and metaphoric language (e.g. “the crippled economy”) (see also media section, page 87).



NRB recommends that the above features be incorporated into specific anti-discrimination legislation.

## Implementation

Legislation, however good, is only a tool and the extent to which it is well used will determine the measure of its success. In view of this, there are certain key elements which must be put in place if legislation is to achieve its purpose.



NRB recommends that:

- there should be clear and unambiguous statements of what is acceptable/ unacceptable under the law and clear definitions of who is covered by it
- there should be clearly stated and enforceable sanctions attached to breaches of the law
- there should be a clear assignation of authority to take an action under the law. This should empower an individual or person acting on behalf of the aggrieved individual to take such an action
- there should be a monitoring body responsible under the law for monitoring the implementation of the legislation. This body should also be empowered to take action on behalf of an individual person with a disability or on behalf of a group or category of people with disabilities
- persons wishing to take an action under the law should have ready access to an adequate legal aid scheme so that a breach of the law may not go unchallenged through the inability of the offended party to fund such an action. Rights made dependent on ability to pay are rights denied.

The current reality in Ireland is that there is a significant legislative vacuum in relation to the rights of people with disabilities. To the extent that there is no legislation there are no effective, enforceable rights and non-enforceable rights are not rights at all.

## The current legislative position

Such legal provision as exists is, at best, ambiguous. Article 40:1 of the Constitution provides a basis for discrimination by the State in favour of a person with a disability but equally provides a basis for discrimination against such a person. Article 40:1 states "All citizens shall, as human persons, be held equal before the law. This shall not be held to mean that the State shall not in its enactments have due regard to differences of capacity, physical and moral and of social function". It is precisely in this treatment of differences that society can artificially create "disabilities" which unjustifiably set people apart.

Furthermore, Article 40:1 deals only with the duty and obligation of the State and cannot be invoked against private organisations, groups or individuals - arguably the potentially greater source of discrimination against people with disabilities. For example, the right to work and earn a living, guaranteed by Article 43 of the Constitution is effectively circumscribed by the provisions of Article 40:1.

While Article 42 of the Constitution establishes the right to education and appears to confer on parents the right to decide how that may be best provided for their child, a recent (and as yet unresolved) court case has demonstrated the degree of uncertainty and fragility of rights even in this seemingly clear-cut area.

Section 68 of the Health Act (1970) obliges Health Boards to discharge certain duties in respect of the training and employment of people with disabilities but makes no provision for establishing standards or for determining or monitoring the extent to which those services are provided or their quality. Only the complete failure of a Health Board to provide any services whatsoever could provide the basis for a legislatively-based challenge - a long way from the conferral of rights on people with disabilities. Other sections of the Act merely enable the Health Boards to provide services (e.g. home help) but do not make such essential services mandatory.

Similar weaknesses can be detected in legislation relating to other key areas e.g. the lack of timescale for the enforcement of the Housing Act (1988). Legislation affecting people with disabilities may be compulsory, but inadequately enforced, e.g. the Building Regulations (1991) (see page 12), or optional and dependent on discretionary factors (see above). Furthermore,



## Equal opportunities policy and practice as key criteria for funding

### N:8

It has long been recognised that what gets resourced, gets done. Equally, it is necessary to target resources very specifically and monitor outcomes carefully to ensure that designated resources produce the intended results. A combination of financial sticks and carrots will focus attention on practical ways to equalise the status of people with disabilities.



NRB recommends that:

- in order to be eligible for public funding, all organisations be required to produce evidence, via equality statements and proven practice, that they are actively promoting the equality and equal opportunities of people with disabilities as employees, participants and customers through, among other strategies, disability proofing, total access and affirmative action measures
- all public financial and funding decisions, at both local and national level, be examined to ensure that proposed and actual services, contracts and grant aid do not ignore or impact negatively on the participation in Irish life of people with disabilities and do not promote or maintain their exclusion. Inclusive policy and practice is to be encouraged at all times and in all fora
- a system of tax concessions and other financial incentives be developed to encourage and reward organisations public, private and voluntary, which adhere to these principles
- a comprehensive monitoring system be developed to ensure that these actions result in measurable outcomes.

- where the development of self-advocacy skills may be curtailed by ability (as in the case of people with significant learning disabilities, mental illness or dementia) or by specific circumstances (dependency on an institution such as a psychiatric hospital) self-advocacy work should be supplemented by the supported, well-resourced development of an independent citizens' advocacy movement, using best national and international practice
- broad consultation procedures, such as that modelled by the Commission on the Status of People with Disabilities in its listening meetings, should be evaluated and a clear model developed for use by other State, public service and large-scale private organisations and companies
- affirmative action programmes should be developed at all levels and in all structures of Irish society to ensure the maximum access to participation and representation of people with disabilities. Such actions and strategies should be carefully equality proofed. Many examples of affirmative action programmes are detailed throughout this submission
- access to the political process should be made easier for people with disabilities through a variety of means including:
  - nominating only fully-accessible buildings as polling stations
  - replacing the current Special Voters' List system with a postal vote
  - improving the access of blind and other non-print-literate people to the voting system
  - introducing social and political education as a mandatory element of curricula in all education and training delivered to people with disabilities
- the process of participation, whether by means of trade unions or other representative structures, should be extended to people with disabilities in long-term training, day care, sheltered work and sheltered employment
- the statutory role and legislative brief of the Inspector of Mental Hospitals should be modified to include consultation with service recipients
- the Consumer Association of Ireland should consider ways of extending its ambit to cover health and social services, possibly using legislation based broadly on the principles of the Sale of Goods and Supply of Services Act (1980).

## Equal participation and representation

### N:8

Equality proofing relies for its success on the direct involvement of the marginalised people it is intended to benefit. Participation and representation in this context depend on the fostering of both advocacy and self-advocacy skills among people with disabilities and the development of consultative structures at every level of Irish society, including fostering them in services aimed specifically at disabled people. The professionalisation of disability services within the framework of a medical model of delivery, without provision for consumer consultation and/or advocacy, ignores the primacy of the experience of disability, and contributes inevitably to the disempowerment of individuals, families and communities, creating a dependency culture for its members for whom the goal of social, political and economic integration becomes a virtual impossibility.

Consultation and advocacy demand the long-term commitment and investment of both consumers and service providers in both specialised and mainstream settings, at macro and micro levels. The recent growth of the disability rights movement in Ireland and the self-advocacy movement of people with learning disabilities has challenged the current status quo. Demands for “a seat at the table” and equal participation and representation require recognition of the rights to autonomy, risk and responsibility of disabled people.

Measures to foster equal participation and representation will begin to dismantle the current passive dependency culture attributed to people with disabilities and will restore them to the mainstream of social, economic, cultural and political life at every level. The exclusion of disabled women and older people with disabilities will require particular attention to ensure their full involvement.

Similarly, measures to assist people with learning disabilities and people with mental health difficulties must tackle the specific exclusions and prejudices that debar them from participation. Since people with disabilities generally have been socialised to expect exclusion, their active participation must be promoted and actively encouraged.



NRB recommends that:

- people with disabilities be actively involved in decision-making at every level which affects them (see section on equality proofing, page 8) and that this become a key criterion in the allocation of funding (see next section). It is incumbent on all organisations public, private and

- in line with best customer-focussed business practice, every effort be made to simplify procedures (e.g. in banks, social welfare offices, hospitals) so that people with learning disabilities and others confused by such procedures are enabled to take maximum personal control of their own affairs
- procedures, assessment criteria etc, particularly in services aimed specifically at people with disabilities, should become more transparent, with a far clearer application of service accountability to the consumer than is apparent at present. This will involve, among other strategies, clear information, contracts and straightforward customer-focussed responses.

## Access services

Among the factors concerning access services which currently exclude people with disabilities are the insufficiency of sign interpretation services for deaf people, guide/companions for deaf/blind people, advocates or others to guide people with learning disabilities through confusing and complicated procedures (e.g. in banks, hospitals, garda stations) and general lack of consideration of the needs of people with hidden disabilities (e.g. renal failure, epilepsy, diabetes) and mental health difficulties in the provision of services, facilities and responses generally.



NRB recommends that:

- guide/companions be provided to deaf/blind people as part of a comprehensive personal assistant scheme (see page 73)
- deaf people be assisted to employ sign interpreters as part of a comprehensive personal assistant scheme (see page 73)
- blind people be assisted to employ readers as part of a comprehensive personal assistant scheme (see page 73)
- funding be made available to ensure the provision of appropriately-trained sign interpreters on call in such settings as clinics, garda stations, banks, libraries
- deaf people should have the right to a sign interpreter of the same gender where appropriate (eg. in gynaecological clinics)
- all public buildings should install loop systems, starting with places of assembly and essential services

Since accurate, up-to-date and relevant information is vital to enable people to make decisions, from the trivial to the crucial, it is imperative that it become universally available to people with disabilities. Walsall Information Federation (UK) recently defined some of the barriers to information of people with disabilities as follows:

- people who are unaware of the existence of a particular service do not know that they need information and so are unable to ask for it
- information is often available in the wrong form, e.g. print when people need voice recordings or braille
- many disabled people have low expectations and so are unlikely to try to seek out information or ask for help
- mobility barriers inhibit disabled people from chasing after information
- many people lack time and/or money to go chasing after information. In addition, many professionals appear reluctant to give access to information freely, appearing to defend institutions rather than prioritise customer satisfaction
- information is sometimes presented in a way that makes it difficult to understand
- those people who are not familiar with using information can find it particularly complicated and may not see its relevance
- some people feel reluctant about approaching strangers or official organisations for help or may take great pride in being independent.



NRB recommends that:

- information relevant to people with disabilities, i.e. all information made available to the public at large by all organisations public, private and voluntary, should be made available in a variety of formats, including print, large print, braille, tape, computer disk and video
- the availability of information should be widely and appropriately advertised and promoted. People with disabilities should be made aware that information to help them is available and should be shown where and how to obtain it. Information providers should develop better public profiles so that they become familiar and approachable
- information providers should provide service guarantees and publicise clear complaints procedures to ensure that standards are maintained
- information aimed specifically at people with disabilities should be made available through appropriate mainstream as well as specialised settings, e.g. information for disabled tourists through Bord Failte etc

# Access to the physical environment and to information

## Nº3

Lack of access to both the physical environment and information constitutes one of the most serious barriers to participation at every level of Irish society of people with disabilities. This issue is considered here under the headings of:

- physical environment
- access to information
- access services.

Housing and transport are considered as specific sectors later in this submission. Taken together, access rights must be fully implemented if people with disabilities are to achieve the level of self-actualisation enjoyed by the population as a whole.

## Physical Environment

Among the factors in the physical environment which currently exclude people with disabilities are features of buildings (steps, narrow doors, inaccessible toilets, lack of ramps and handrails, lack of colour contrast and tactile information etc) and the external environment (lack of clear information on signposts, inappropriately-placed street furniture, high kerbs, lack of accessible, adjacent parking provision etc). Existing legislation is inadequate to support the rights of people with disabilities. Even where the legislation is adequate, implementation and control are often lacking. This is most apparent in the case of the Building Regulations and Road Traffic Acts, impacting negatively on the rights of people with disabilities.



NRB recommends that:

- the Department of the Environment ensure, by funding the provision of Building Control Officers with responsibility for access in each area, that local authorities implement the Building Regulations and Road Traffic Acts fully and immediately
- existing State-owned buildings be made accessible as a matter of priority
- State financial support be made available to provide access to all other existing buildings open to the public



NRB recommends that, as well as gender-proofing its own report and recommendations, the Commission on the Status of People with Disabilities should advocate a programme of positive action to ensure that the obstacles which only women with disabilities face are dismantled and that women with disabilities can participate in Irish society on an equal basis. Some particular solutions to the exclusion and marginalisation of women with disabilities are included in the examination of specific sectors of Irish life later in this submission.

## Disability and ageing

While Ireland continues to be a young country in comparison with many others in the developed world, it is not immune to the general trend of population ageing. There has been a shift in emphasis in recent years from old age being seen as a problem, involving inevitable frailty and dependency, to more positive images of retirement as a time for personal fulfilment. With 100m. people in the EU aged over 50 (44 m. over 65), and with numbers growing in absolute and relative terms, it is not only in their interest but in the interest of society as a whole that older people be fully included and not treated as a class apart.

The longer people live, the more likely they are to acquire a disability, so an ageing population is an increasingly disabled one. At the same time, people with long-term disabilities are increasingly surviving into old age, frequently acquiring new disabilities on the way. At the present time, however, consideration of the requirements of disabled people appears to concentrate on the concerns of younger people, on models of involvement in the labour market and modes of economic and social discrimination as experienced by particular categories of disabled people, as noted in the section on women with disabilities.

This limited vision means that the particular requirements of older people with disabilities are frequently ignored. Particularly insidious is the notion that quality of life automatically and inevitably diminishes in later years. Older people are frequently thought to be incapable of advocating for themselves, running their own lives and so on. However, new generations of both elderly and disabled people will have different and generally higher expectations of what life should offer them. It is, therefore, not enough to plan for the future simply on the basis of those services and facilities which are thought to be acceptable at the present time.

## Disability proofing as an element of comprehensive equality proofing

### N:B

The concept of equality proofing was first developed in Ireland in relation to the work and recommendations of the Second Commission on the Status of Women. As a strategy it is aimed at ensuring that marginalised people and their requirements are included from the start in the development of all structures, policies and practices and as such is the basic tool of inclusion as a concept, goal and strategy. Effective equality proofing ensures that the needs, views and experience of marginalised people are integrated at every stage of policy and decision-making, in the implementation and evaluation of all policy and practice, at every level from macro to micro, Government policy to local initiative. By building in such considerations from the start, the present, painfully slow development of equal rights for disabled people can be replaced by the efficient, best-practice approach which is the hallmark of real inclusive practice.

At its most basic level, equality proofing involves bearing certain key questions in mind when formulating policy or practice or developing structures. Extrapolating from the model developed by the Council for the Status of Women in its submission to the Second Commission on the Status of Women, to ensure the consideration of the impact of any policy or practice on disabled people these key questions might be:

- are people with disabilities directly involved in the development of this policy or practice?
- what are the needs and experiences of people with disabilities?
- how can we meet those needs?
- does the policy or practice we have decided upon meet those needs?
- have we built the experience and perspective of people with disabilities into the evaluation of this policy or practice?

These questions are aimed at ensuring that the situation and requirements of people with disabilities are considered and included in all directives, policies, initiatives and actions aimed at the population as a whole. Any set of questions also needs to be backed up in practice by the development of performance indicators and statistical and qualitative studies of outcome and supported by the development of facilitative guidelines and codes of practice. At present the National Economic and Social Forum (NESF) is working to identify ways of developing equality proofing mechanisms in the Irish context.





NRB's submission is based on the principle of independent living, a central objective of which maintains that disabled people have the right to organise for themselves a quality lifestyle of their choice, not a lifestyle that is imposed on them or one they are obliged to accept through lack of choice. The solutions detailed in this submission, then, aspire to afford people with disabilities the opportunity to maximise their personal independence, especially in decision-making about the pattern of their own lives. NRB's submission contends that people with disabilities are competent to run their own lives unless proven otherwise and that education, training and other interventions which impact on the lives of disabled people must be organised in such a way as to ensure that this is so. This assertion has implications for the universal right of access to institutions and structures, the physical environment and information, which constitute the basic gateways to full participation.

The current exclusion and attendant low status of people with disabilities has led to the negative stereotyping of disabled people and the prevalence of discriminatory attitudes towards them. The issue of exclusion by attitude is the most difficult and all-pervasive barrier that people with disabilities encounter. This submission offers direct solutions to this issue and also recognises that the implementation of its recommendations across the board will, by facilitating the active involvement of people with disabilities in every area of Irish life, of itself tackle attitudinal barriers. The emergence of representative bodies and groupings of people with disabilities will, by the development of lobbying and advocacy strategies, also provide a significant challenge to prevailing negative attitudes.

NRB recognises that at present there are many very good, effective, customer-focussed services available to people with disabilities in Ireland, provided by governmental and non-governmental organisations alike. In this submission, however, NRB has taken the view that, rather than describe the current level of achievement, it is more useful and effective to put forward suggestions and strategies for improvement.

This submission is based on NRB's long history of addressing the multiplicity of disability issues, drawing on its consultation with disabled people, the work of expert committees, research surveys, projects and reports, the operation of schemes and programmes and NRB's extensive information resources. The discussion and recommendations in this submission refer to all people with disabilities, whether those disabilities are congenital or acquired, arise from physical, intellectual, sensory or hidden impairments, at all levels of disability from mild to profound.

The submission will approach its task as follows:

- by proposing general strategies to equalise the status of people with disabilities across every sector of Irish society
- by examining key sectors of Irish society individually and proposing

operation of the Disabled Drivers Board of Appeal etc. NRB operates through a regionalised structure and a national network of 17 centres. Its services and strategic approaches are detailed in NRB's Strategic Plan 1992-1994.

NRB is governed by a Board of twenty members appointed by the Minister for Health. The organisation works largely through the process of consultation, both on an individual basis (as indicated in NRB's Mission Statement) and with other organisations, both statutory and non-governmental. Formal dimensions to this process include mechanisms such as the National Advisory Committee on Training and Employment, the National Advisory Committee on Access and the National Advisory Committee on Medical Rehabilitation.

NRB attempts in all its work to consider rehabilitation in the round and to see it in its broadest context. This can be observed in the organisation's development over the years. This broad context also informs NRB's submission to the Commission on the Status of People with Disabilities.

## NRB's Mission

### N:3

**NRB's mission is, on behalf of the State and in consultation with people with disabilities, to enable and empower people with disabilities to live the life of their choice to their fullest potential.**

In order to achieve this, NRB will

- ◆  
identify and advise on the needs of people with disabilities and the policies and services required to meet them
- ◆  
develop, provide and co-ordinate services
- ◆  
set, monitor and enforce national standards
- ◆  
promote recognition of rights and equality of opportunity

- Third-level education	36
- Adult, continuing and second-chance education	36
- Support to parents of children with disabilities	37
• Training	38
- Strategies to equalise status in mainstream training	38
- Strategies to equalise status in specialised training	39
• Employment	42
- General strategies to equalise status in employment	43
- Strategies to equalise status in sheltered work/employment	46
• Income support, benefits and entitlements	48
- General strategies to equalise status in income support	49
- Interim strategies to equalise status in income support	52
- Strategies to equalise status in other entitlements	54
• Financial services	56
• Transport	58
• Housing	60
- New housing	60
- Existing housing	61
- Rented accommodation	62
- Voluntary housing associations	62
• Residential and institutional care	64
• Health and personal support services	68
- General strategies to equalise status in health and personal support services	69
- Specific strategies to equalise status in health and personal support services	72
- Home help service and home care assistance schemes	72
- Personal assistants	73
- Counselling support services	74
- Technical aids and equipment	75
- Day activity centres	77
• Leisure	78
• Arts, culture and the media	81
- Defining parameters	82
- Portrayal	82
- Participation	82
- Expression	83

