

A Strategy for Equality

Summary of the Report of the
Commission on the Status of People
with Disabilities

The Commission on the Status of People with Disabilities

The Government set up the Commission on the Status of People with Disabilities in November 1993.

The job of the Commission was to find out what life is like for people with disabilities in Ireland today, and to propose ways of making things better. The Commission took the unusual step of going out to meet people with disabilities, their families and carers throughout the country, to ask them to talk about their experience of living in Ireland, and to hear directly from them about the changes that would make a difference in their lives.

Public 'listening meetings' took place at thirty venues around Ireland. Special meetings took place with groups of people with disabilities who might meet extra problems, women with disabilities, travellers, young people with disabilities, people with head injuries, mental health difficulties and those with spinal injuries. Meetings also took place with people with learning difficulties and those in residential care.

The Commission arranged for reports to be prepared on all of the important aspects of Irish life. Some of these are being made available publicly because they helped to shape the Commission's recommendations. These reports do not necessarily reflect the views of Commission. Please look at the main text of the Commission's Report to find out about the Commission's recommendations on any particular matter.

People with disabilities and their families have contributed much to the work of the Commission at all stages; our deepest gratitude must go to all those who sent

submissions, attended listening meetings, took part in Working Groups. They have showed, through their involvement that this work was worth doing. We trust that their efforts will show good fruit and will make a difference in their lives and in the lives of all people with disabilities and their families in Ireland.

PART ONE – OVERVIEW

People with disabilities are the neglected citizens of Ireland. On the eve of the 21st century, many of them suffer intolerable conditions because of outdated social and economic policies and unthinking public attitudes. Changes have begun to come about, influenced by international recognition that disability is a social rather than a medical issue, but many of those changes have piecemeal. Public attitudes towards disability are still based on charity rather than on rights and the odds are stacked against people with disabilities at almost every turn. Whether their status is looked at in terms of economics, information, education, mobility or housing, they are seen to be treated as second-class citizens.

People with disabilities are angry and their justifiable anger was evident in submissions to the Commission and at listening to meetings which the Commission held throughout the country over the past two years. The picture that emerged was one of a society which excludes people with disabilities from almost every aspect of economic, social, political and cultural life. People with disabilities and their families made it clear that they want equality; they want to move from a reliance on charity towards establishing basic rights. They want, and are entitled to, equality and full participation as citizens.

One of the most striking features of the submission was the sense of absolute frustration which emerged from them. The frustration did not centre, as some might expect, on personal experiences of physical pain, discomfort or impaired function. Nor did it centre on the incurable nature of many disabling conditions nor on the question on “why me”, which

is often discussed in relation to the distributor of disability. On the contrary, the frustration revolved around people's sense that they were being put in a position of having to deal with a myriad of oppressive social barriers in addition to their disabling conditions.

Another theme to emerge clearly from the submissions and the meetings was that of marginalisation. This word took on a stark reality and force from the hundreds of pages of submissions sent in to the Commission from people with disabilities and their families. Many people with disabilities felt that they were being either kept at or pushed to the margins of society. They were not being allowed to realise their potential or to participate as fully as they are entitled to in every day life.

Disability can have major implications, not only for the individuals who are directly affected, but also for those who find themselves in the role of informal carers. While it is almost always close family members; parents, spouses or children, who fill this role, friends or neighbours may also be involved in a major way. The Commission received 100 submissions from the family members of people with disabilities. This material was also full of strong feelings and emotion and underlined the point that caring for people with disabilities can be an ongoing physical, mental and emotional strain accompanied by a sense of terrible isolation.

In practical terms, one of the single largest areas of concern raised in the submission and at the listening meetings was the question of access and transport. Clearly, the built environment and most forms of transport are very inaccessible for people with disabilities. Many of the submissions from individuals referred to the inability to get out and about, the need to plan every trip and the sense of being “a prisoner in one’s own home”. They criticised the inaccessibility of public transport: as one person put it graphically, “public transport means that when you are disabled, you are no longer a member of the public”. These problems are not just mechanical ones but ones that have several important consequences. They mean that people are denied full access to education, to employment and training, to cultural and leisure events. They mean that the overall cost of living for people with disabilities is higher than for other people.

Another of the major failings identified at the listening meetings was the lack of information available to people with disabilities and their carers. And not just the absence of information but the way in which people were treated when they went looking for it. The difficulty of obtaining access to entitlements and services, both public and private, was of major concern. Many submissions emphasised the lack of coordination between service providers, the fragmentation of services and the difficulty in getting entitlements. There is no one source of information for people with disabilities and they frequently have to go from organisation to organisation in an attempt to identify their options. The absence of easily accessible information is clearly a major factor in the isolation and marginalisation experienced by very many citizens.

There was serious concern too about education: a failure to provide comprehensive education for people with disabilities results in their being denied access to employment and training opportunities comparable to those available to people without disabilities. Other areas which attracted a large number of comments in the submissions included employment and training, income support, health and personal support. In addition, many complaints were received from people about the length of waiting lists for services.

All that said, people with disabilities are not without hope. This hope does not centre on finding a “cure” for disabling conditions, but on the possibility of improving their quality of life through changes in existing attitudes and improvements in services which will together allow them to develop their own potential. As one submission put it, “it is our earnest wish that people with disabilities will be given their rightful place in society, the opportunity to participate and to contribute fully in all areas of Irish life”

The Commission on the Status of People with Disabilities wants to see that hope become a reality and has wide-ranging, even radical, proposals to make it happen. For example, it recommends that a Disability Support Service will be established with resource centres all over Ireland, providing information, advice, advocacy and practical support to people with disabilities and their families from the minute they need it, either from the ante-natal stage or whenever the need arises later in life. It proposes the establishment of a National Disability Authority, charged with overseeing the implementation of new laws aimed at improving the lives of people with disabilities, and co-ordination of everyone’s efforts to do this. It proposes that new ways of thinking about people with disabilities,

underpinned by laws and supported by practical measures, will spell an end to the discrimination and exclusion that is their experience now.

Perhaps one of the most telling indications of the neglect of people with disabilities is the silence of relevant official statistics. Unlike most European Union countries, there are no comprehensive statistics available for Ireland. The opportunity to determine accurate figures was missed again in the 1996 census of population: it should not be lost in future censuses. In addition, the Commission repeatedly came up against an absence of information about people with disabilities in relation to a wide range of issues.

The Commission itself was not in a position to conduct or commission a major survey of the population because of the complexity of the task, the resources and time it would require and because of its own deadlines. However, it asked the Economic and Social Research Institute to assist it by collating existing quantitative data on disability to help it arrive at some overall estimates.

On the basis of that and reports from other EU countries, the Commission concluded that some 360,000 Irish people or 10% of the population have a disability. This number is a conservative estimate and compares, for instance, to 12.5% of the population across most EU countries.

Disability is not present in equal proportions among all age groups, tending for obvious reasons to be more common among older people. Recent surveys in Northern Ireland estimated, for instance that 17.4% of the adult population there have disabilities compared to 3.5% of the child population. Our own estimates suggests that half of all people with disabilities are included – and the Commission

specifically included families of people with disabilities in its considerations, a large and significant proportion of the population is clearly affected by disability. There are few families who have not been, are not, or will not be, affected by disability to some extent or other at some time in their lives.

Pending the next census of population, the Central Statistics Office should carry out a survey of the extent of disabilities in Ireland and establish a system to ensure that relevant data is regularly updated. This survey should be undertaken in the early part of 1997 and updated bi-annually thereafter. All agencies responsible for the monitoring of quality control of services should also ensure that adequate management statistics are collected as a matter of course.

In drawing up a strategic Irish policy on disability for the first time, it is important to look at the context of change. Attitudes towards disability have changed considerably over the past 15 years, led by a stronger and more vocal movement of people with disabilities throughout the world. The United Nations International of Disabled People with disabilities in 1981 marked a watershed in thinking and led to the UN in 1982. In essence, this international movement has changed the approach towards disability. Rather than being seen as a “personal” or “medical” problem which was the result of an individual’s physiological, anatomical or psychological impairment and caused by disease, accidents or other “personal tragedies”, it is now seen as a “social” problem whereby disability is caused by society’s failure to adapt itself to the different ways in which those with disabilities accomplish activities.

Three key principles have informed recent international legislation and practice:

- The recognition that disability is a social rather than a medical issue
- The adoption of a civil rights perspective, and
- The recognition of equality as a key principle of the human rights approach.

These principles have come together in the United Nations’ Standard Rules on the Equalisation of Opportunities for Persons with Disabilities which were adopted in 1993 in consultation with organisations representing people with disabilities. The Rules, while not legally binding on UN member states, do not reflect current thinking about disability policy and are intended to provide the basic international legal standard for programmes, laws and policy on disability in the coming years. They are aimed at ensuring that all people with disabilities can exercise the same rights and

obligations as other people. To do so, they set out a list or preconditions for equal participation, including access to the physical environment, access to information and communications, public transport, education, employment, income maintenance, family life, culture, recreation and sports and religion. They also set out specific implementation measures and monitoring mechanisms.

The Commission see the UN Standard Rules as being a key document in the future development of disability policy and many of the recommendations in the report are aims at implementing them. It welcomes the change of emphasis away from a medical approach to disability, towards a more social approach, especially when a medical or diagnostic approach ignored the imperfections and deficiencies of surrounding society. A given level of impairment or degree of restriction does not necessarily lead to disadvantage: it is the societal response (in terms of attitudes and expectations as well as the services and facilities made available) which has an important impact on the extent to which impairment or disability lead to disadvantage. The impairment may be caused by physical, mental, intellectual, emotional or sensory factors. The fact, for example, that many public buildings are inaccessible to people with mobility impairment is not something which is caused by the impairment. It is perfectly possible to construct buildings which are readily accessible to people who use wheelchairs or have other types of mobility impairment. Inaccessible buildings are caused by society's decision, whether informed or uninformed, to build structures in such a way that they will not be accessible to some people.

After various stops and starts over the years, the Irish disability movement restarted again towards the end of the UN Decade of Disabled Persons (1981 – 1990). As the

European movement of disabled people grew, more Irish people with disabilities became aware of organisations controlled (i.e. with over 51% of their membership) by people with disabilities.

The core message of politically active groups such as the Forum of People with Disabilities, the Centre for Independent Living and the Advocacy Ireland Movement was and continues to be heard both by the media and by policy makers.

At the European Non-Governmental Organisation (NGO) level members of various Irish NGO's have contributed at the highest level to the many debates that take place on disability issues. One of the highlights for the Irish disability movement was the impact made by the Irish representatives at the first European Disabled People's Parliament held in Brussels in 1993 and co-chaired by an Irish person. Of the 60 delegates were among the attendance of 500 people with disabilities.

The recommendations in the report must also be seen against the background of overall developments in Ireland, in particular the development of measures which recognise the importance of equality and equity. Included in those are measures to deal with poverty as well as efforts to improve the delivery of services to people who need them.

The Commission welcomes and strongly supports the establishment of a representative Council for the Status of People with Disabilities. It recognised the need to allow the Council to establish itself and to develop its own priorities and ways of working and believes that it will fulfil a central role in lobbying for the implementation of the Commission's recommendations. The Commission recommends that the

Department of Equality and Law Reform should provide ongoing core funding at a level appropriate to the importance of the task facing the Council and which takes account of the additional costs which arise in respect of disability, for example, sign language interpreters, brailing, transport and so on. We wish the Council and all its members every success in their work.

The establishment of the Department of Equality and Law Reform is a significant indicator of the Government's recognition and the importance of equality. This is also recognised in the "Equal Participation" section of the Programme for Government – A Government of Renewal – which states that the Government regards "the work of the Commission for the Status of People with a Disability as being fundamentally important" and commits the Government to taking "specific action to end discrimination and to ensure equal opportunity for participation by all our people in Irish life".

In particular, the Government has committed itself to introduce a Disabilities Act "to set out the rights of persons with a disability, together with the means of redress for those whose rights are denied". The Government will also "put in place mechanisms for full and equal participation by every citizen with a disability in every aspect of our economic and social life".

The importance of equality has also been emphasised in a report from the National Economic and Social Forum on Equality Proofing Issues which found that people with disabilities are discriminated against in terms of rights and opportunities which other people take for granted. The Commission strongly endorses the NESF recommendations on "equality proofing" as it refers to people with disabilities. The Commission believes that there is an urgent need for the Government to adopt a policy of "disability proofing" legislation and any public policy initiatives. It recommends that the Minister for Equality and Law Reform should bring proposals to Government within months aimed at securing agreement to adopting a policy of "disability proofing".

Given the connection between poverty and disability, the Government's commitment to draw up a National Anti-Poverty Strategy to address all aspects of poverty and social exclusion is also relevant. Under the Strategy, all government departments and state agencies will be expected to include the reduction and prevention of poverty as key objectives in the development and implementation of their policies and programmes. They will also be required to consult and involve people affected by poverty in this process. As a person with a disability stated, "if you are poor you are likely to be disabled, and if you are disabled you are likely to be poor". Disability is a cause of poverty and social exclusion and it is important that specific measures to respond to the needs of people with disabilities are included in the Anti-Poverty Strategy.

The Programme for Competitiveness and Work, published in February 1994 contains an important commitment to people with disabilities where it states that: "*The report of the recently established Commission on the Status of People with Disabilities will be considered in consultation with the social partners with a view to effecting a real advance in the position of people with disabilities in all aspects of life*".

One of the most important facts about the Commission itself is that almost two-thirds of its members are people with disabilities or are carers of, or members of families of, people with disabilities. In their meetings and deliberations over the last three years, they have learned a lot about disability, the many forms it can take and the many hardships that can be imposed and those affected. Those members who have been previously in other disability groups readily admit that they too have learned a lot. All these experiences underlie the Commission's approach to its task and its findings.

The Commission decided a number of issues early on and adopted guiding principals for its work. Among the issues decided was to use the term “people with disabilities” rather than terms which have been used in the past such as “the disabled” or “the handicapped”. It does so in order to emphasise the point that people with disabilities are people first and foremost.

For the purpose of its work, the Commission understood the term “people with disabilities” to include children and adults who experience any restriction in their capacity to participate in economic, social or cultural life on account of a physical, sensory, learning, mental health or emotional impairment.

It also decided that it should make recommendations for all people with disabilities rather than attempt to divide them up according to types of disability. In doing so, the Commission fully recognises the specific needs of particular groups but is seeking to address the common sense of exclusion experienced by all people with disabilities. The Commission was also particularly mindful of doubly disadvantaged groups, such as women, children or Travellers with disabilities. It was also conscious of the fact that there is inequality and discrimination between groups of people with disabilities, some of whom for reasons of numbers or history are able to exert greater influence than others. For this reason too, the Commission has adopted the approach of making recommendations as relevant as possible to all people with disabilities.

The three guiding principals adopted by the Commission to inform its work were:

- Equality
- Maximising Participation
- Enabling Independence and Choice

The key principal, the principal which underlies all the recommendations in the report, is the principal of equality. People with disabilities must be recognised and treated as having equal status with all other citizens. The State should provide for programmes of affirmation action and positive discrimination to address the past inequalities experienced by people with disabilities. Equal status can only be achieved if the rights of people with disabilities are upheld.

It is important to explain what we mean by equality. There are many ways in which equality can be understood, ranging from formal legal equality, to equality of opportunities, to equality of status at all levels of Irish life. Formal legal equality would simply ensure that all existing formal discrimination against people with disabilities was removed. This is obviously a precondition for equality but it is only a beginning.

There must also be equality of opportunity so that people with disabilities can participate in education, employment, and all other walks of life on an equal basis. This could involve measures to encourage people with disabilities to participate in education, sport, or cultural activities, or disability and equality training for people working in public services. But equality of opportunity would still not ensure equality of status.

To ensure that people with disabilities have equal status and are widely represented at all levels of Irish life will require affirmative action. Government must take that lead in this but every other sector of Irish life, including local authorities, churches, public bodies, employers, trade union and sectoral organisations, nongovernmental, voluntary and community organisations and individuals must recognise that the existing exclusion of people with disabilities from so many aspects of Irish life impoverishes all of us. Examples of affirmative action, or positive discrimination, could include training policies to develop senior management skills among employees with disabilities, or university access programmes for students with disabilities to enable them to participate on equal terms in the university system.

The second principal – maximising participation – means that people with disabilities have the right to participate in all

areas of Irish life to the fullest extent possible, and that individually and collectively (and where appropriate, their families and friends) they have the right to influence decisions which affect their lives. It also means that in the course of all policy making, the State should have regard to the needs and interests of people with disabilities.

The third principal – enabling independence and choice – means that people with disabilities have the right to be able to achieve their full potential. They have the right to make their own decisions and choices regarding the conditions of life best suited to their circumstances. They also have the right to quality services which meet their needs at all stages of life and they must not be dependent on charity or voluntary effort.

The State must acknowledge its responsibility to ensure equality of status. In particular, it must assume special responsibility for marginal or vulnerable groups of people with disabilities, and support them, their families and friends to the extent that they cannot do so for themselves.

The Commission proposes a wide range of measures to ensure that people with disabilities become full participants in society, independent where possible and, above all, equal. It puts forward a detailed plan for the overall structures required to achieve that aim as well as specific recommendations on all aspects of life. When implemented, these recommendations will transform the lives of very many people.

Recommendations on overall government policy and new structures for state services are outlined in detail, along with costings for all the Commission's proposals. The Commission addressed the economic issues raised by

disability, dealt with, specific areas of social and civil rights for people with disabilities, issues affecting those people with disabilities who are particularly vulnerable and research.

Arising from its work, the Commission concluded that there are a number of issues on which it is necessary to have minimum ethical standards, based on respect for human dignity and a safeguarding of individual rights, particularly in the areas of medicine, biology, biotechnology, law and administration. The Commission did not consider that such matters came properly within its terms of reference. It recommends that the Government should take appropriate steps to have such matters addressed at an early date.

Throughout the report, the Commission's intention is that where people with disabilities are mentioned, this will include parents and families of people with disabilities when appropriate.

This is ambitious report which, when the recommendations are implemented, should change the world for many people with disabilities, including their families and carers. That is no less than people with disabilities deserve and what they, as equal citizens of this state, are entitled to as of right.

PART TWO – RECOMMENDATIONS

Rights

It is the Constitution and the laws that protect the civil rights of all citizens. The Commission therefore recommends the following:

- Amend the Constitution to guarantee the right of equality and prohibit discrimination
- Amend the Constitution to guarantee the right to education
- A Disabilities Act to be introduced, to set down in law the rights of people with disabilities
- The needs and rights of people with disabilities be included when any new laws are being introduced and that current laws be amended
- The European Union ensures within its laws that each member State is actively seeking the equality of all its citizens
- Offensive terms such as ‘imbecile’ or ‘idiot’ are removed from all our legislation.

A Policy for Equality

We need policies to ensure that the rights set down in law are implemented in the daily lives of people with disabilities. At present there are several Government Departments responsible for disability policy and their individual policies do not always ‘gel’ together, resulting in gaps and/or overlaps in services and worst of all confusion and frustration for people with disabilities.

The Commission therefore recommends that:

- The Department of Equality and Law Reform should have overall responsibility for disability policy, with other Departments being responsible for policy within their own area.
- A Disability Equality Unit should be established within the Department of Equality and Law Reform headed by an official at Assistant Secretary Level.
- All Departments having consulted with people with disabilities should prepare and publish a five year plan for the improvement of services for people with disabilities.
- A **National Disability Authority** should be established. Its' tasks will be to monitor policy, standards and the implementation of this Commissions recommendations. It will ensure that there are grievance procedures and appeals system in place, where necessary for decisions taken that affect people with disabilities.
- People with disabilities and their families should make up at least 60% of the Board of the National Disability Authority.
- A new service, the Disability Support Service should be established under the control of the National Disability Authority, this service should have offices throughout the country called **Disability Resource Centres**. These centres would be a 'one stop shop' for information on everything relevant to the person with a disability.
- Each Disability Resource Centre should have adequate staff which would include a **Disability Support Co-ordinator**. This person would be available if required to assist a person with a disability, to find and apply for the appropriate service/device to meet their particular needs.
- Every person with a disability should be entitled to a single **Assessment of Needs**. This assessment should involve the person with a disability and result in a **Statement of Needs**.

- There should be a single **Assessment of Eligibility for Services** and this assessment should take account of the Statement of Needs, and result in a single 'passport' to a range of services.
- **An Independent Advocate** should be available for people with disabilities especially those in residential services.
- There should be a right to information about oneself from all public services and publicly funded services.
- There should be an appeals and complaints procedure for all services and benefits.
- The National Disability Authority through its local Disability Resource Centres should co-ordinate the development of local **Community Action Plans**. These Community Action Plans should draw on all the essential local services, such as those dealing with, transport, education, health, housing and people with disabilities.
- The Department of Equality and Law Reform should provide the funding needed by the Council for the Status of People with Disabilities.

Income and Costs of Disability

Many people with disabilities live close to the poverty line, because they are prevented from working and /or on account of the additional costs associated with disability. There is a bewildering array of schemes, matched by an equally bewildering set of eligibility assessment procedures. The Commission proposes a more simplified system and improvements in the level and coverage of certain benefits.

- At the moment many payments are discretionary – there is no legal right to the payment. There should be a legal right to payment.

- There should be national standards, so that payment does not differ depending on which part of the country you live in. There should be an appeals system for all payments.
- There should be two main payments: A Disability Pension and A Costs of Disability Payment.
- The Disability Pension would compensate for loss of income due to an incapacity for full-time work, or work to full potential.
- The Costs of Disability Payment should be a graduated payment to meet the additional everyday costs associated with disability. This payment would be made irrespective of whether the person is at work or not.
- A 'package' of improved benefits should be available for all carers, including those who work outside the home. Carers of more than one person or of a person in a five day residential setting should be paid on a pro-rata basis.
- The means tests should only count carers means.
- Carers should be credited with social welfare contributions.

Work and Training for Work

People with disabilities face many barriers when they want fair play in the world of work. The Commission proposes new laws and new policies to bring about equality in the workplace. Sheltered workplaces are included in our proposals.

- There should be new legislation, as soon as possible to ban discrimination on the grounds of disability in employment and training.
- The Department of Enterprise should take full responsibility for providing work and training services for people with disabilities. That Department should produce

a plan for the employment and training of people with disabilities.

- People with disabilities should be able to go on any Government scheme for the long term unemployed; all public employment services should be fully accessible; better occupational guidance and job placement services are needed.
- The 3% quota of public service jobs reserved for people with disabilities should be reached within three years.
- Contractors applying for state business contacts should be encouraged to comply with the 3% employment quota.
- Organisations which get state funding for providing services to people with disabilities should reach an 8% employment quota within 4 years.
- If fewer than 3% of private sector jobs are held by people with disabilities within a three year period, a mandatory employment quota should be introduced.
- At least 500 extra jobs on NRB's Employment Support scheme and 500 additional jobs through NRB's Workplace and Equipment Adaptation scheme should be funded over the next three years.
- There is an acute shortage of sheltered work places. 500 extra places should be provided for, in the 1997 budget. The legal status of workers in sheltered workshops should be protected.
- There is an enormous range of training opportunities available now to the general public. People with disabilities should have full access to these. New ways of providing training, for example in employers' premises should be available.

Insurance

Insurance plays a very big part in all our daily lives. Without it, we cannot work, drive, run an event, take part in a sport, and get essential life assurance. Yet people with disabilities regularly meet barriers and discrimination in getting insurance. The Commission proposes that unjustified barriers be removed through legislation.

- There should be a new law to stop insurers from discriminating on the grounds of disability, when they quote for or issue insurance cover to a person or group of people with disabilities.
- The law should prohibit insurers from discriminating against people with disabilities when they are being asked to provide cover for an event in which people with disabilities are taking part.
- Insurers should be prohibited from discriminating against people with disabilities who need motor insurance.

Access

People with disabilities must be able to get into buildings and move freely within those buildings. This is a very basic right. Without it, other rights - to work, to education, to leisure – simply cannot be exercised. Yet needless physical barriers face people with disabilities and cause huge frustration, anger and exclusion. There should be universal rights of access for citizens.

- The Department of the Environment should have laws and regulations to bring about the universal right of access,
- The Department of Environment should ensure that these laws are strongly enforced through its planning laws, by

inspections and controls. The County Councils are the bodies who must carry out this enforcement.

- The new laws should apply to roads, pavements, parkways and signs.
- Owners and landlords of buildings should to get an access certificate, just as they to get a fire certificate at present.
- New anti discrimination laws should give people with disabilities the right of access to goods, facilities and services.
- Legislation should be introduced to enable the District Courts to make the inclusion of proper access for people with disabilities a condition for the granting of a licence to public houses, restaurants, places of assembly and entertainment.
- Access should be required in building projects which are getting funding from the National Lottery.
- Each County Council should employ an Access Officer to plan and promote access in their areas. These officers should give support to local access groups through training, technical support, advice and funding.
- County Councils should introduce Community Action Plans for access. They should consult with local access groups.

Health

People with disabilities have the right to a health service which is fair, accessible (both physically and geographically) and which meets their needs. The Commission's proposals put the user at the centre of the service.

- Each Health Board should review the services it provides right now, to see if they are fair and accessible. They should look at the standards and quality of service. Each

Health Board should then draw up a 5 year plan for services in consultation with service users.

- Some vital community based services are absent or at an unacceptable level in parts of the country. New funding should be provided throughout the next 5 years to get rid of these serious gaps in services.
- A number of Special Units are urgently required to provide continuing care and social support in the community for those who have suffered serious physical injury or brain damage.
- Counselling services should be provided for the families of people who experience emotional or mental health difficulties. Genetic counselling services are also urgently needed throughout the country.
- One of the services which people with disabilities rely on very heavily for their quality of life is the supply of technical aids and mechanical aids such as wheelchairs, walking aids, mobility aids. New laws are required to make sure that there is a right to essential equipment, efficient and speedy assessment, and a reliable supply of technical aids.
- There should be 'key workers' in hospitals and the community to help people with disabilities to plan for the move back from hospital to the community.
- Laws, policy and practice to protect the rights of people with disabilities who are using the health services should be introduced. These measures should guarantee information about consent to treatment, the right to refuse treatment; the right to be informed of a diagnosis in a sensitive manner; the right to attend case conferences and the right to be consulted before participating as the subject of tutorials or teaching practice for students.
- Ways of maximising choice of service should be examined. For example, people with disabilities or their

carers could be given control, either direct or indirect, of part or all of their allocation of resources for the purchase of services, for example in choosing home help services.

Education

If we are to measure the status of people with disabilities by their rate of participation and success in education, equality is still a long way off. The Commission asserts that every student with a disability has the right to education in the least restrictive environment and the right to essential support services.

- The Commission is proposing a **Charter of Rights for Students with disabilities**.
- The new Education Act, which is due to be introduced soon, must make legal provision to allow students with disabilities to be part of the mainstream education system.
- School authorities should have to prove that their school is not the best educational placement, if they propose to refuse an application for admission from a student with a disability.
- Students should be entitled to an independent assessment of their educational needs, and an individual education plan.
- Parents should be full and equal partners throughout the educational process, and be given all the supports and information they need to enable them to participate fully in their child's education.
- The Department of Education should be the Department responsible for all educational matters of concern to people with disabilities.
- The new Regional Education Boards should have the legal duty to ensure that each child with special

educational needs is provided with an appropriate education.

- The Regional Boards should have the duty to provide assessment, support, services, independent appeals procedures and in consultation with parents and children, in service planning and provision of information.
- The Regional Boards should have a duty to draw up Community Action Plans to meet the needs of students with disabilities in their area. They should consult fully with people with disabilities in making these plans.
- At present we have two separate education systems – a special system and a mainstream system. Students should be able to move much more freely between special schools and mainstream schools. To allow this to happen, schools will need to have flexible enrolment, and flexible transport services.
- The best use of the excellence and experience of our existing special schools and how to spread this expertise throughout the system must be examined.
- The National Council for Curriculum and Assessment should make sure that there are flexible programmes available for students with disabilities as well as support for teachers in mainstream schools who need to learn new teaching methods.
- The Commission supports the recommendations of the Report of the Committee on Access and Participation of students with disabilities in Higher Education.
- One percent of the education budget should be allocated every year as additional expenditure to meet the educational needs of students with disabilities.
- Funding should be linked to the students and to his or her support needs and should follow the student as he or she moves to appropriate educational settings.

- A permanent Committee should be set up, to help co-ordinate policy and planning for students with disabilities. This committee would include representatives of people with disabilities.

Housing and Accommodation

Housing provides much more than shelter in modern society; it is the base from which people join in the life of their community. The way we organise housing may restrict choices, make people dependent on family members, or even lead to a person being removed from their local community and being placed in institutional care.

- The Department of Environment should have a policy on housing for people with disabilities. This policy should have as its aim, “the right of people with disabilities to live as independently as possible” if they so chose.
- The Commission strongly recommends a national policy of building **Lifetime Adaptable Housing**. These are designed and built to be easily adaptable as the needs of a family or family member change. By including certain features, (such as downstairs toilet and wider doors) at the construction stage, homes can be adapted easily and cheaply later on.
- Local Authorities should build up a supply of suitable housing for people with disabilities in their areas. There should be a choice of house type, including group housing, in every area. These should be situated close to shops, schools and other amenities.
- Three new schemes should be put in place to improve the prospects of people with disabilities on low incomes of home ownership and to help offset the additional costs of

suitable housing. Each of the proposals builds on an existing scheme.

- A new grant to incorporate the Disabled Person's Grant and the first time purchaser's grant should be introduced where a first home is being purchased by a person with a disability and where additional housing costs are likely to be incurred.
- The Shared Ownership System should be widened to allow house purchasers with a disability on low incomes to receive the new grant for first time purchasers.
- A financing arrangement should be developed to allow approved voluntary and non-profit housing bodies to provide and equity sharing tenure based on a 50% ownership by people with disabilities on limited incomes.
- The Disabled Person's Grant Scheme should cover up to 95% of the costs of a home adaptation. The Grant should be extended to include the occupants of new houses and those renting should be able to claim this grant. It should be much easier to get information about the grant and its appeals procedures.
- There should be a review of residential centre catering for people with disabilities and their waiting lists, in order to plan for the future and ensure that people with disabilities are accommodated in the most suitable accommodation that is possible.
- The rights of people living in residential centres must be protected. They should have a Charter of Rights. They should have their own income. There should be an Ombudsman for residential centres. Standards in residential centres should be checked by the relevant authorities.

Transport and Mobility

Having accessible forms of transport would benefit many citizens. Unfortunately, Ireland has lagged behind other countries in making its transport system more accessible for all, with especially harsh consequences for people with disabilities.

- All new and used rail rolling stock and road vehicles ordered for public transport from 1st January 1997 should be accessible to all users. Every CIE, Bus Eireann and Dublin Bus depot should have at least one accessible bus by June 1st 1997.
- The local Authorities should have Community Action Plans for accessible local transport in their area.
- All school buses should be accessible to all students within 5 years. The Government should examine how school buses could be used for community transport purposes outside the times when they are needed for transporting students.
- At least 80% of all transport and transport services purchased by Health Boards should be wheelchair accessible.
- When issuing taxi licenses, Local Authorities should take account of the needs of people with disabilities.
- The Commission suggested a number of other options for providing transport services for people with disabilities which could be examined. These include:
 - Vantastic: set up in Dublin in 1995, this involves two accessible vans and eight trained drivers and can be booked for regular or one off trips.
 - Service Routes: Bus Services open to everyone but specially adapted for people with mobility impairments. Using smaller than average vehicles,

the routes could go into housing estates and up narrow roads. They could be of particular benefit to rural areas where the basic problem with public transport is its unavailability. Service routes could be set up as joint ventures between private operators and voluntary or statutory groups.

- Post Buses: These collect and deliver mail and carry passengers, using vehicles like estate cars, Land Rovers and mini-buses. They run on a published route and to a timetable and could also provide a valuable service for people in rural areas and people with disabilities if accessible vehicles were used.
- Social Car Schemes: They provide volunteer drivers (who receive a petrol allowance) for people with disabilities, usually for short trips.
- People with disabilities should get more help with the cost of transport. There should be a standard Disabled Persons Travel pass, to cover a companion and give full access to public transport. The mobility allowance should be increased to £40 per week.
- Information on accessible transport and travel should be available in all formats at all terminals and stations.
- A National Mobility Training and Advice Centre should be established.

Technology and Communications

Technology can help people with disabilities to achieve greater independence and to cope well with daily living.

- The Department of Transport, Energy and Communications and the Department of Social Welfare should bring in new legislation to make sure that people

with disabilities have access to technical aids and communications.

- The present way of providing technical aids to people with disabilities is totally inadequate. People do not have a clear entitlement to services. There are unacceptable variations between groups of people with disabilities and between people in different parts of the country.
- One agency should be responsible for all technology and for giving out information about new kinds of equipment. This agency should provide an assessment service in centres throughout the country.
- The Department of Transport, Energy and Communications should ensure that all companies providing telephone services, provide telephones suitable to people with disabilities, at no extra cost.
- People who qualify for the disabled driver's concessions should qualify automatically for free mobile phone rental and a number of free call units, to cover emergencies which might arise when travelling alone.
- At least 50% of all television programme hours should be subtitled by 1998 and this should increase to all programme hours as soon as possible afterwards.

The Law and the Legal System

In a democracy, people must have access to the law and the legal system – the courts, legal aid, and the services of the gardai. There are many barriers standing in the way of full access to the law and the legal system for people with disabilities in Ireland.

- All public documents should be easily readable. Advice should be available for people with disabilities about the courts and court proceedings.

- The Department of Justice should have an action plan to make all Courts accessible within a five year period.
- The Legal Aid Board should make sure that its services are available to all those with disabilities who have need of them.
- People with learning disabilities giving evidence should have alternative choices to the taking of an oath.
- The provisions whereby some people with disabilities are excluded from serving on Juries under the Juries Act 1976 should be repealed.
- There is urgent need of reform of the criminal law system as it relates to people with disabilities, particularly those with mental incapacity.
- The Council for the Status of People with Disabilities should have discussions with the Law Society, the Bar Council and the Kings Inn about legal services to people with disabilities from training as lawyers.
- Research from other countries shows that people with disabilities are more than likely than others to be the victims of crime, including physical and sexual abuse. There is a need for urgent research on this matter in Ireland.
- Many children who get in trouble with the law are described as having learning difficulties. However, they often suffer from other disadvantages. The Juvenile Justice System should be reformed urgently to create a child centred system of juvenile justice.
- People with disabilities in our prisons need suitable educational courses and materials. Remedial support should be provided to prisoners with learning disabilities.

Political Rights

The right to vote is a basic democratic right which is often denied to people with disabilities because of lack of access to polling stations and voting procedures. This discrimination needs to be removed.

- All polling stations and booths should be made accessible to people with disabilities.
- Voting procedures to help disabled voters should be introduced. For example, photographs of candidates could be included on ballot papers. Ballot papers should be printed in suitable formats such as large print or Braille.
- People with disabilities should be entitled to be registered on a postal voting register and thereby entitled to a postal vote.

Including Women with Disabilities

No woman's experience of disability should take away from her the basic rights of all women, the right to be a partner, wife, mother, the right to be a homemaker, community leader, the right to work and the right to economic independence.

- Women with disabilities have tended to be excluded from the women's movement and the general debate about family life and sexuality. Women with disabilities are under-represented in the decision making structures of state and voluntary services.
- Action is needed to combat this double exclusion. The National Women's Council has an important part to play in this.

- Women with disabilities should be consulted about their needs.
- In order to participate fully, women with disabilities need places to meet together to discuss matter of common concern.
- Policy makers and others need to be aware of the issues which arise from women's experiences of disability.
- Disability equality and awareness training for non-disabled women should be provided, so that they can learn, understand and reflect upon their own attitudes to disability.
- All women's groups should include women with disabilities and should consult with local women with disabilities.

Sexuality and Relationships

The right of people with disabilities to the same degree of fulfilment through relationships and sexuality as anyone else is a basic right. People with disabilities are often denied their sexuality on account of the stigma and the fears of parents and service providers.

- The Department of Health should develop policies to protect the sexual rights of people with disabilities.
- These policies should deal with the right to privacy and dignity, the right to bodily integrity, the right to information on all aspects of sexuality and access to counselling.
- Service providers' especially residential providers should respect the rights of the individual; practices which deliberately prevent informed, consenting relationships should be stopped.
- People with disabilities and families need access to counselling in sexual and reproductive health, genetic and

medical counselling and suitable ante natal and post natal care.

- Sexuality and relationship education should be provided in accessible formats in schools, training centre and residential centres.
- The sterilisation of people with disabilities on the grounds of disability alone should be prohibited. Informed and free consent should always be sought. Where informed consent is not possible, strict legal protection must be given to the person with a disability.
- Medical interventions for contraception purposes against the wishes of the person with a disability should be prohibited.
- Sexual abuse involving people with disabilities should be researched and corrective legislation introduced if required. This may include mandatory reporting.

Religious Practice

Religion plays an important part in the lives of many Irish people, including people with disabilities. At present, barriers of attitude, communication and architecture stop many people with disabilities from joining in social activities or their congregations.

- People with disabilities should be made welcome and should be fully involved in every aspect of congregational life.
- Every religious community should set up a small task force, including people with disabilities, to plan how to get rid of the barriers which stop people with disabilities from joining fully in the life of that community.
- Disability awareness should form part of the formation of religious leaders at all levels.

Arts and Culture

The arts are very important for people with disabilities. They can open up possibilities for creativity and self expression and help people to achieve other personal objectives.

- New anti-discrimination laws should give access to all arts venues in the future.
- Arts and cultural organisations should give information on their facilities, services, events or performances in a wide range of formats. The Department of Arts, Culture and the Gaelteacht and the Arts Council should lead by example.
- People with disabilities should be included in the 1995-97 Arts Plan.
- People with disabilities should be encouraged to take part in the arts as performers and audience.
- The Arts Council should provide:
 - Guaranteed funding to increase access and opportunity for people with disabilities.
 - Incentives such as concessionary card systems and priority seating.
 - Bursaries for artists with disabilities in all art forms.
 - Resource packs for art organisations to help them to find ways of involving people with disabilities in their activities.
- The County Arts Officers should produce a community action plan for arts and disability in consultation with people with disabilities.
- Children and adults with disabilities should have the chance to participate in arts activities in school or in adult education activities. Arts awareness courses should be run in disability organisations to increase understanding

about the importance of the arts for people with disabilities.

- Talented artists with disabilities should be identified. The Council for the Status of People with Disabilities should find ways of doing this. They should employ an Arts officer.

Media

People with disabilities and their concerns tend to be invisible in the media. Yet the media can change attitudes to disability.

- RTE and other media should increase the coverage of disability issues and participation by disabled people in general interest programmes.
- Research into the effects of the ways in which people with disabilities are shown in the media should be undertaken.
- The Advertising Standards Association of Ireland should make sure that their standards about people with disabilities in advertising are strictly enforced.
- RTE, the independent Radio and Television Commission and the National Newspapers of Ireland should fund an independent Media and Disability Unit. This Unit would provide training to media organisations to help them to include people with disabilities in media services.
- New information technologies should be used to the full, to assist people with disabilities take their place in all media.
- Complaints procedures to deal with complaints about programmes for or about people with disabilities should be provided.

- People with disabilities should get grants to help them to take journalism and media courses.
- All students on courses in media, journalism and public relations and those already working in these areas should be given disability awareness training.
- Media studies in post-primary schools should include disability equality/awareness training.

Sports, Leisure and Recreation

Sport, leisure and recreation are an important part of the lives of all citizens. These pursuits are important for health and fitness. They provide opportunities for social contact and outlets for talents and skills. If these are barriers which stop people with disabilities from these activities, then their rights are being denied.

- People with disabilities should be able to get into all major sporting venues. The granting of planning permission for new facilities should be subject to the inclusion of proper access for people with disabilities.
- Very few mainstream sport and leisure organisations have a policy of enlisting people with disabilities as members. The National Governing Bodies of these organisations should develop such policies. This should be a condition of funding.
- Many voluntary clubs working with people with disabilities have done excellent work in promoting activities for people with disabilities. These clubs should be fully supported.
- Bord Failte and the regional tourism authorities should ensure that all tourist information includes details of facilities for people with disabilities and that tourist information is produced in accessible formats.

- Centres providing services to people with disabilities should open their facilities and centres in the evenings and at weekends and develop a policy on sport, leisure and recreation.
- Funding should be provided to enable Ireland to host the Special Olympics early in the next century.
- Lottery funding should be provided to the sporting organisations which represent Irish athletes with disabilities so that Irish athletes can compete with those from other countries.

Vulnerable People with Disabilities

The Commission made a special commitment to give a high priority to the concerns of very vulnerable or marginalised people with disabilities. Here the Commission deals with the concerns of four groups who are particularly vulnerable—highly dependent people with severe or profound disabilities, people with rare disabilities, those with spinal injuries and those with head traumas.

- High quality day activity services are really important for people with severe disabilities, including those in residential care. Health Boards should provide this service.
- The well being of people with disabilities living at home is bound up with the well being of their carers. Respite care and home help support services must be provided as well as a decent income for carers.
- People with severe disabilities almost always require special services. They should have a right to an independent assessment and to an appeal, if they are refused a place in a required service.

- Funding should be linked to the person's need and should follow the individual to any service.
- Support services for people with disabilities in a Health Board's budget should not have to compete with other services such as hospital services.
- A special capital fund should be set up urgently to replace run down facilities being used by people with disabilities. This fund should be directed to the replacement of the poorest facilities throughout the country. Because of the large numbers of people in St Ita's Hospital, Portrane, it should be among the first to be replaced under this programme.
- A National Centre for Rare Disabilities should be set up in a modern teaching facility such as the new Tallaght Hospital.
- People with spinal injuries who are discharged from hospital need a plan for their support in the community after leaving hospital. This should be prepared before leaving the hospital.
- There should be a specialist team with expertise in spinal injury care within each Health Board.
- The Department of Health should allocate additional funding for a special housing facility to help those with severe physical trauma moving from hospital back into the community.
- Families and carers of people affected by head traumas or brain damage should receive special support, counselling and a special educational programme.
- There has been very little focus on the plight of young people with disabilities in particular those young people in rural communities and in institutional care. Health Boards should address these needs in consultation with young people with disabilities.

Research

We need much more information on the numbers and needs of people with disabilities. There is very little funding for research into disability issues, and there appears to be little if any co-ordination. The sharing of information on current and completed projects is patchy.

- The proposed National Disability Authority should commission and conduct research on disability issues.
- A Research Co-ordination Group should be established by the NDA to provide a forum where researchers could exchange information and agree priorities.

A full report of the Commission's recommendation is available.