

Disability Legislation Consultation Group

Equal Citizens

Proposals for Core Elements of Disability Legislation

February 2003



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Foreword

The need for comprehensive legislation which addresses the needs of people with disabilities in Ireland has long been recognised by all stakeholders in the disability sector. The last decade has seen a broader recognition of this need, developed and strengthened through active debate. This document *Equal Citizens - Core Elements of Disability Legislation* marks a particularly important and historic stage in this process. It puts forward, for the first time, proposals for the key components that need to be included in legislation, which have been agreed unanimously by the representative bodies of stakeholders in the disability sector.

The Programme for Government (June 2002) contains a commitment to publishing a Disability Bill which includes provision for rights of assessment, appeals, provision and enforcement. The European Year of People with Disabilities, 2003 presents a unique opportunity for Ireland to introduce landmark legislation, which encapsulates all of these.

In March 2002 the Department of Justice Equality and Law Reform wrote to the NDA regarding the establishment of a new consultation process on disability legislation as follows:

"As you know, the Minister has established a high-level consultation team to guide and co-ordinate the consultation process which is headed up by Sylva Langford, Assistant Secretary in the Department. The purpose of the consultations is to provide an opportunity for all interested parties to put forward their views. It is expected that the consultations will focus primarily, although not exclusively, on key issues raised, including among other issues a new power of enforcement to ensure compliance with the provisions of any future legislation and issues relating to assessment of need and the provision of related services.

The Minister would be anxious to draw the experience of the NDA into the consultation process to support the consultation team in its dialogue with the disability sector. In this connection, the Minister is seeking the involvement of the NDA in bringing together a group that is seen to be representative of people with disabilities, their families and carers and service providers in the sector. The identification and delivery of such a representative group would facilitate meaningful dialogue at national level, both with the sector and with the consultation team.

The Minister has asked me to say that she wants to ensure that facilitation of the representative group is accorded full priority within the NDA and she would like to see that the group is directed at the highest possible level within the NDA. She would be pleased if you yourself were in the position to Chair meetings of the representative group".

Over the last eleven months, the DLCG has worked through debate and consultation to clarify, debate and consult on the core elements which need to be addressed in comprehensive disability legislation in Ireland. By September 2002, the DLCG released a draft document for discussion throughout the disability sector. Three regional consultation meetings and four organisation specific consultation meetings were held. In addition, sixty eight written submissions were received following a nationwide advertising campaign.

The views, opinions and range of feelings expressed by those individuals and groups who made submissions both in writing and through the meetings were considered in depth by the DLCG. I am confident that this unique consultative initiative has contributed greatly to the strength of the proposals now being put forward for disability legislation in Ireland.

The *Core Elements of Disability Legislation* presented by the DLCG, details why people with disabilities and their families need this legislation; what should be contained in it; and how the legislation should be implemented, monitored and enforced. The DLCG is clear that comprehensive disability legislation is necessary to remove barriers to participation so that people with disabilities can live with independence, autonomy and dignity within a framework of a social and human rights model of disability. It should combine enforceable rights to accessible services, needs assessment and advocacy and a mainstreaming approach that places duties on public bodies to remove barriers to participation. Disability legislation should build on the existing equality legislation, as well as EU and international obligations, in the development of social policies that place the person with disabilities at the centre of service provision.

I would like to thank the many individuals and organisations who contributed to this consultative process. I look forward to legislation that comprehensively addresses the needs, aspirations and realities of the lives of people with disabilities in Ireland today.

Finally, I would like to pay tribute to the members of the DLCG for their dedication, commitment and hard work in consulting with their members in forging these proposals. My sincere thanks are due to the Director and staff of the NDA for their support and assistance throughout all stages of this initiative.

Angela Kerins,
Chairperson, Disability Legislation Consultation Group,
February 2003.

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The DLCG wishes to acknowledge the considerable commitment in terms of time and effort of the following people who represented their organisations and to thank them for their contribution and consultations with their membership in preparing the Core Elements of Disability Legislation Document.

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The DLCG would finally like to thank all those who sent submissions, those who attended the regional and organisation specific consultation meetings and to all those who contributed in anyway to the DLCG *Proposals for Core Elements of Disability Legislation*. Your views have established the framework for which to achieve lasting rights for people with disabilities through legislation in Ireland.

Introduction

In March 2002, following the withdrawal of the Disability Bill, 2001, the Department of Justice, Equality and Law Reform (DJELR) set up an Expert Consultation Team with the task to consult with all stakeholders and report to government. At the same time the Minister of State invited the Chairperson of the National Disability Authority (NDA) to "facilitate meaningful dialogue at the national level with people with disabilities, their families, carers and service providers". This led to the formation of the Disability Legislation Consultation Group (DLCG), made up of umbrella groups and organisations in the disability sector. The NDA acted in a support capacity as well as secretariat to the group.

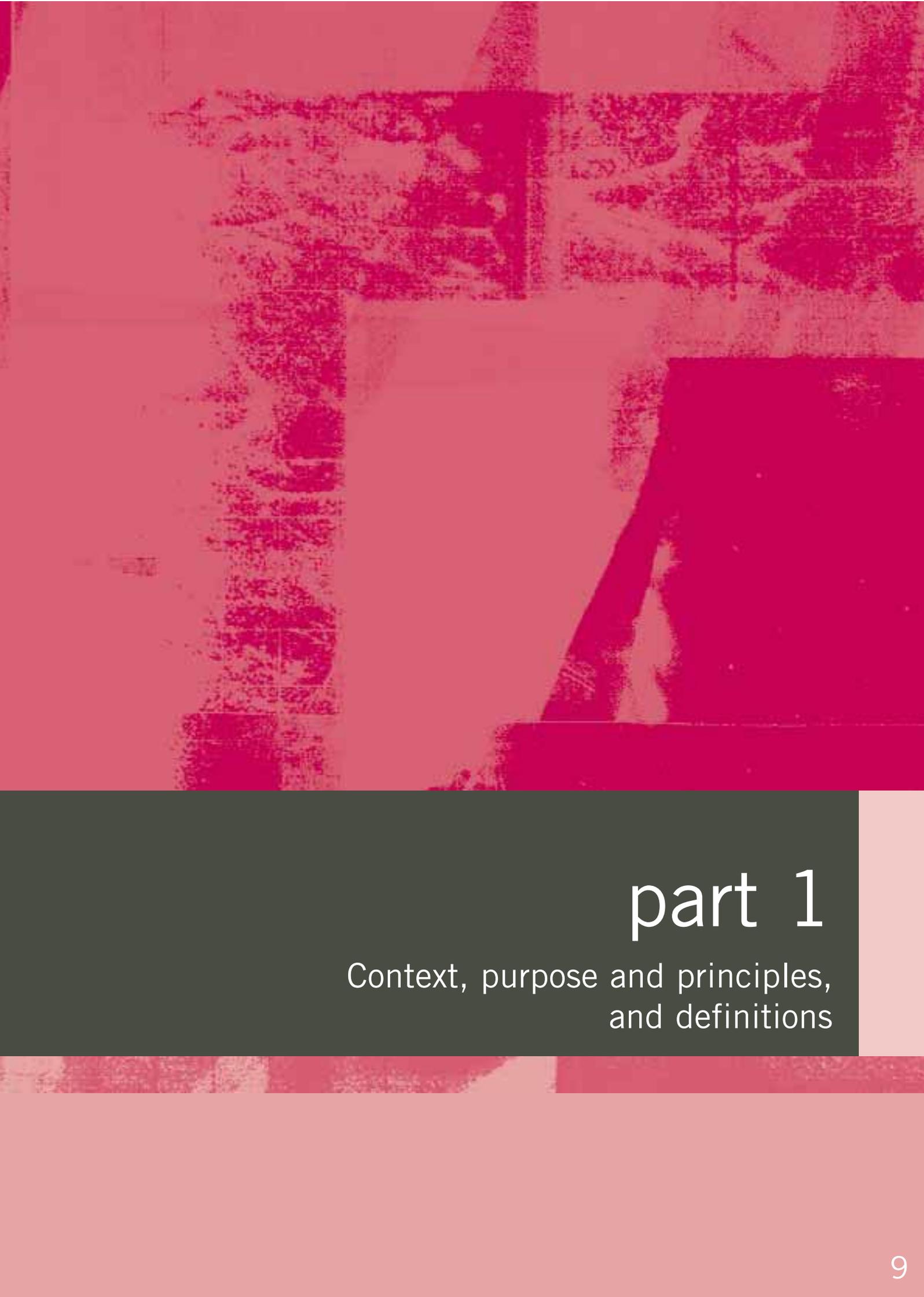
The government made a commitment to an amended Disability Bill in the Programme for Government (June 2002) including provision for rights of assessment, appeals, provision and enforcement. The Bill is due to be published in 2003 and is a legislative priority for the Department of Justice, Equality and Law Reform.

Discussions in the DLCG and a wider process of consultation, including sixty-eight written submissions and meetings in Cork, Galway and Dublin have helped to inform the content, focus and shape of this document and what the DLCG consider to be the core elements of disability legislation. The DLCG is of the view that these core elements include the right to an independent assessment of need that leads to a Statement of Needs and a plan that outlines how the needs identified will be met. This should be in line with the recommendations made in *A Strategy for Equality, the Report of the Commission on the Status of People with Disabilities*. In addition, the legislation should include the right to independent advocacy, physical, information and communications accessibility, and redress. Certain duties are also placed on public bodies to promote the mainstreaming of disability as well as duties on all public and private providers of services regarding accessibility.

This document summarises the consultations, recommendations and discussions undertaken in and by the DLCG on what should be included as core elements and underpinning principles in the new disability legislation¹. This document is the outcome of that process and proposes inclusion of fifteen core elements of disability legislation which are divided into four main parts:

- Part I: Context, purpose and principles, and definitions
- Part II: Rights and provisions contained in the legislation
- Part III: Implementation, monitoring, review, complaints and redress
- Part IV: Areas outside of the legislation

¹ This document also draws on *A Strategy for Equality: the Report of the Commission into the Status of People with Disabilities (1996)*; submissions on disability legislation received by the Department of Justice, Equality and Law Reform, the conclusions of the *Get Your Act Together Conference, 2001*, disability law in other countries and in Ireland, UN Standard Rules on the Equalisation of Opportunities for People with Disabilities, discussions in the DLCG and submissions to the DLCG consultation.



part 1

Context, purpose and principles,
and definitions

This part of the paper explores the:

- Context, vision and rationale for the legislation
- Provisions for the mainstreaming of disability
- Definitions used in the legislation
- The purpose and principles underpinning the legislation

1. Context, vision and rationale for the legislation

New legislation on disability in Ireland is part of a broader process of change internationally and nationally that is shaping a new social model in Ireland. This is based on changing values, rights and principles, with equality, participation, quality and inclusion being increasingly regarded as key values and principles underpinning Irish social policy. Ireland has also contributed to and benefited from the development of the European model of social rights rooted in social cohesion and social inclusion. This includes measures to improve the lives and rights of people who are disadvantaged, excluded and vulnerable². The greater focus on a social model of disability and rights also results from the changing and greater complexity of needs, including those related to achieving full participation in society. Meeting these needs in turn can help to build the values of trust, community and solidarity. The costs of not providing these rights will impact negatively on individuals, families and communities, as well as Irish society overall. The opportunities of embracing the legislation will have far-reaching economic and social benefits, including the more rational and effective use of resources, the enhancement of government-citizen connections, improved quality of life for people with disabilities, and the creation of modern, high quality, person-centred services.

For these reasons the DLCG believe that the disability legislation represents an important shift in thinking about how services can be provided more effectively and efficiently in order to realise the expectations and rights of people with disabilities³. A key issue is that a rights-based approach positions the individual person with disabilities at the centre of service provision, and through needs assessment and service coordination resources are attached to the person him/herself.

There is also substantial evidence to show that services for people with disabilities are not always provided and managed in the most effective ways. This can lead to costly services that are inappropriately delivered. This has resulted in experiences of neglect, poor services or gaps in services for some people with disabilities. Organising and delivering services differently will impact positively on cost-effectiveness as well as on the full and equal participation of people with disabilities in society.

² This European model of social rights includes norms and legal instruments resulting from the European Social Charter (Council of Europe); the Social and Employment Chapters of the Treaty on European Union and the Charter of Fundamental Rights of the European Union. The latter was introduced in 2000 and sets out six fundamental rights and values that should be promoted by the EU: dignity, freedom, equality, solidarity, citizens' rights and justice. The Nice Treaty also signalled significant new developments in the area of poverty and social exclusion, including National Action Plans against Poverty and Social Exclusion which include objectives regarding facilitating people's participation in employment and access to resources, rights, goods and services necessary for participation; and guarantees that resources are available to enable people to live "in accordance with human dignity".

³ Throughout this document the term people with disabilities covers both adults and children with disabilities.

Disability legislation is necessary for creating a society where all people with disabilities can participate fully as equal and active citizens. By exercising rights that assist in removing barriers to full participation people with disabilities can live with maximum autonomy, independence and dignity. The DLCG considers disability legislation to be one element of a genuinely inclusive society that is open to all by promoting and supporting equality, participation and social inclusion of people with disabilities. This legislation should implement the commitments made in *A Strategy for Equality*. It will complement national, European and international obligations, and set an ambitious agenda for the future rooted in a social and human rights model of disability.

The human rights model sees people with disabilities as people with the same enforceable rights as everyone else. Instead of the disabled person being seen as a 'problem' to be cured or cared for, this approach reflects the need for the State to remove discrimination and enable people with disabilities to participate fully in society. This is reflected in the Barcelona and Madrid Declarations, in United Nations, Council of Europe and EU policy, reflecting a vision where disabled people are holders of rights to autonomy and independence.

In this context it would be appropriate for the disability legislation to build on, and not undermine, existing national anti-discrimination legislation. Furthermore, the expressed reluctance of the courts to engage in socio-economic rights⁴ does not prevent the introduction of legislation for new rights for people with disabilities that can be enforced in the courts.

Effective legislation for people with disabilities needs to combine two approaches:

- Positive rights that can be enforceable by individuals.
- Duties and requirements placed on public and private bodies that are providing services to the public, aimed at removing barriers to full participation of people with disabilities in Irish society.

A major emphasis given to the new disability legislation by the DLCG concerns the development of positive and enforceable rights for people with disabilities that go beyond anti-discrimination. A shift to a rights-based approach was first signalled in *A Strategy for Equality, the Report of the Commission on the Status of People with Disabilities*. In the area of anti-discrimination, disability is also one of the nine grounds covered in the Employment Equality Act (1998) and the Equal Status Act (2000).

The DLCG believe that rights of people with disabilities need to be further elaborated beyond those found in the anti-discrimination legislation to ensure that appropriate economic and social supports are available to enable people with disabilities to exercise those rights in practice. This requires a focus on social policies that can help to meet the different and diverse needs of individuals and to enhance their autonomy and participation so that the person with disabilities is at the centre of service provision. In this context the legislation should also lay out clear duties on public bodies to promote equality and to remove barriers to full participation.

⁴ In *Sinnott v the Minister for Education and TD v the Minister for Education*

The principles of this Bill should be carried through to other relevant areas of legislation, including the forthcoming Education Disabilities Bill and the equality legislation.

2. Purpose and principles

This section outlines the main purpose of and principles underpinning the legislation. The purpose of the legislation should be to provide enforceable rights, duties on public bodies to promote equality and the active participation of people with disabilities. The principles underpinning the legislation include advancing the dignity, freedom and quality of life for people with disabilities, maximum independence, autonomy, privacy, bodily integrity and dignity, and for realising her/his potential to the full.

The DLCG believes that the legislation should be based on individual rights and duties on public bodies, with mechanisms for it to be cross-cutting and implemented by all Government departments. It should be based on the following underpinning principles:

- To advance the dignity and freedom of people with disabilities.
- To enhance the quality of life for people with disabilities within a framework of equality and social justice, and economic and social rights.
- To enable people with disabilities to live with maximum independence and autonomy, with privacy, bodily integrity and dignity and realising his/her potential to the full.
- To ensure that people with disabilities have full and effective participation in all areas of society, including recognition of multiple discrimination.

The purpose of the legislation is:

- To establish a set of enforceable rights to enable people with disabilities to achieve equal access, participation and outcomes in all areas of service provision and employment and to exercise the same rights and obligations as others to fully participate in Irish society, including independent needs assessment, services, advocacy and redress.
- To require all public bodies to remove barriers to full participation by people with disabilities. This requires that the legislation establish the statutory basis for mainstreaming equality for people with disabilities in order to remove barriers to the full participation of people with disabilities.
- To ensure conformity with, to build on and to extend the existing equality legislation. The legislation should go beyond anti-discrimination, establish the statutory basis for the mainstreaming of disability in all areas of public policy and public service, and establish best practice.

- To require the active participation of people with disabilities, through advocacy where necessary, in policy development and service planning. This means that all Ministerial regulations, guidance and Codes of Practice that result from provisions contained in the legislation should be subject to consultation with all stakeholders including people with disabilities, their families, carers and support groups.
- To be drawn up with reference to Ireland's obligations to implement and/or observe EU and international instruments⁵. These commitments should be advanced in a positive way.
- To require that all services provided to the public (public or private) should be covered by the legislation, as recommended in *A Strategy for Equality*. Whilst this is the approach taken in the Equal Status Act, 2000, under 'reasonable accommodation', the DLCG would like to see the proposed legislation contain stronger provisions and positive action for both public and private services.
- To meet the needs of people with disabilities through mainstreaming, whilst allowing for individualised services and positive action.

3. Definitions

In this section definitions are provided for disability, mainstreaming, access and accessibility, equalisation of opportunities, positive action, reasonable accommodation and service.

Disability

The DLCG proposes that the definition of disability in disability legislation be based on that found in Section 2(1) of the Equal Status Act and Section 2(1) of the Employment Equality Act⁶. The legislation should include an obligation to develop and broaden the definition of disability in the light of new EU and international obligations and a review of national legislation. This should adopt a social and human rights model of disability that recognises how social organisation creates disabling conditions that result in social, economic, political and cultural exclusion. This should be in keeping with the definition of disability found in *A Strategy for Equality* which includes "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". Account should be taken of different definitions in the EU, the Council of Europe and the World Health Organisation's International

⁵ These commitments include the EU Framework Directive 2000/78/EC, the UN Standard Rules on the Equalisation of Opportunities for People with Disabilities, UN observations of the Committee on Economic, Social and Cultural Rights under articles 16 and 17 of the Covenant that recommended a human rights approach to the Disability Bill.

⁶ Disability means: "(a) the total or partial absence of a person's bodily or mental functions, including the absence of a part of a person's body, (b) the presence in the body of organisms causing, or likely to cause, chronic disease or illness, (c) the malfunction, malformation, disfigurement of a part of a person's body, (d) a condition or malfunction which results in a person learning differently from a person without a condition or malfunction, or (e) a condition, illness or disease which affects a person's thought processes, perceptions of reality, emotions or judgement or which results in disturbed behaviour, and shall be taken to include a disability which exists at present, or which previously existed but no longer exists, or which may exist in the future or which is imputed to a person." This definition covers all disabilities including physical and sensory disability, intellectual disability and mental health, as well as multiple forms of disability.

Classification of Functioning, Disability and Health (ICF). Ultimately there must be common definitions of these concepts in the Disability Bill and in the equality legislation.

Mainstreaming

The DLCG is of the view that this Bill should address all services provided to the public whether these be provided by statutory or non-statutory entities.

The mainstreaming provisions outlined in this document should be applied to public bodies. Public and private bodies are required to implement provisions on disability access and training. The definition of service should be in line with that found in the Equal Status Act, 2000. It should be extended to include the functions of the public sector in exercising their powers and duties. The statutory exemption applying to section 14 of the Equal Status Act should be deleted.

Mainstreaming requires that:

- (a) People with disabilities should be able to equally participate in mainstream service provision and receive adequate supports to enable them to do so. Any separate or targeted services should be limited to meeting specific needs of particular groups that are not met by mainstream service provision and to taking positive action to enhance outcomes for people with disabilities from mainstream provision. Mainstream services should in no way disadvantage or marginalise people with disabilities.
- (b) A statutory duty on public sector organisations to promote equality for people with disabilities. This requires all public bodies to establish clear equality objectives within their remit for people with disabilities and produce a strategy for the achievement of these objectives. This also requires them to disability proof or disability impact assess and monitor their policies, plans and programmes, in consultation with people with disabilities.

Access and Accessibility

Access should be covered in the legislation in the widest sense to include physical, information, and communications accessibility, and to cover all public and private services provided to the public. This should include the built environment, transport, and information and communication technology, as well as all facilities and services used by people with disabilities. Accessibility includes all measures necessary to ensure people with disabilities can equally participate in society, as well as enter and make use of a place, a good, or a service.

Equalisation of Opportunities

Equalisation of Opportunities is the process through which the various systems of society and the environment, such as services, activities, information and documentation, are made available to all.

Positive action

Measures intended to reduce or eliminate the effects of discrimination against a person. Disability legislation should include a clause to the effect that nothing shall prevent the taking of such measures that will enable people with disabilities from fully participating in all aspects of life.

Reasonable accommodation

Reasonable accommodation is defined in Section 4 (1) and (2) of the Equal Status Act 2000. A key issue for the DLCG is that 'reasonable accommodation' should not be limited by the concept of 'nominal cost' when applied to public bodies. Private and public bodies should be incentivised and adequately resourced to provide for reasonable accommodation (financial or fiscal measures, or best practice schemes and awards). The European Council Directive establishing a general framework for equal treatment in employment and occupation for people with disabilities (2000/78/EC) will, in any case, replace the 'nominal cost' test with a 'disproportionate burden' test. Although this only applies to the Employment Equality Act, it is recommended that the same approach be adopted for the Equal Status Act when the Directive is transposed.



part 2

Rights and provisions to be
contained in the legislation

This part of the document outlines the rights and provisions that the DLCG believes should be contained in the legislation. The DLCG proposes that disability legislation should embody specific values and rights that are enforceable. These rights are necessary to enable people with disabilities to participate fully in society as equal citizens and to exercise the same rights and obligations as others by providing for the following:

- Independent Needs Assessment leading to a Statement of Need and coordination of resources, including individual funding where required and services to meet those needs
- Advocacy
- Mainstreaming and disability proofing
- Accessibility of public services: including information, communications and physical accessibility
- Disability equality awareness training
- Public service employment

4. Independent needs assessment and service coordination

The Programme for Government (June 2002) has a commitment to ‘include provision for rights of assessment, provision, appeals and enforcement’. The DLCG is of the view that there should be a statutory right to an independent assessment of need leading to a Statement of Need, as outlined in *A Strategy for Equality*:

The prioritisation of needs should reflect the relative importance of each need in enabling the person to exercise his/her rights to participate to the fullest extent of his/her potential in the cultural, social, civil and economic activities of society. Any identified needs that prevent the person from doing this must be met and where necessary budgetary provision should be made for them by the appropriate government departments (Para 4.38, page 105).

The DLCG consider that the right to independent needs assessment should result in services that are made available as a right for people with disabilities. These services should be identified to meet the needs set out in the Statement of Need. In the event of services not being available, a programme of measures should be put in place in order to realise these services within an established timeframe.

Needs assessment must take place in a coordinated and multidisciplinary way so that it results in the coordination of services. Mechanisms for service coordination will need to be strengthened. Independent needs assessment must be made available to all people with disabilities.

This means that:

- Resources should be allocated to a person with a disability on the basis of the Statement of Need.
- Funding should be attached on the basis of the Statement of Need and the prioritisation of needs under the direction of the disabled person, his or her family/ advocate where appropriate, including possibilities for people with disabilities to be responsible for organising their own provision.
- Needs assessment should be person-centred, with information available and accessible to all people with disabilities. Where appropriate the capacity of families, carers and informal support services should be taken into account.
- Needs assessment should provide for a professional service and accurate identification of needs that are not influenced by existing service levels or cost / economic considerations.
- Needs assessment should be available at the onset of a disability, at times of transition and when circumstances change. There should be regular reviews. Needs assessment will need to take place more frequently for young children and older people.
- Assessments cover all areas of need, including accommodation, independent living, income, education, training, employment, advocacy, health, and social and leisure activities.
- Access to services to meet the needs should be based on a transparent system of resource allocation.
- The person with a disability should be at the centre of needs assessment and with their active involvement and self-assessment, with advocacy services where required and involvement of family and carers where appropriate.
- The Statement of Needs results in coordinated services with coordination mechanisms to put this in place. If these are not available in the public sector the State should be prepared to purchase services in order to meet needs. This also means that where there is more than one service a disabled person should be given the right to choose a service.
- Services should promote the autonomy and independence of people with disabilities, including people living in any institutions.
- Provision should be made for legal redress, complaints and appeals.
- Services should be of a high quality and able to stand up to rigorous quality standards.
- The outcomes of individual assessments should be aggregated (without identifying individuals) for the purposes of service planning.

Detailed guidelines on effective systems, structures and processes for independent needs assessment should be made through Ministerial regulations which are supported by NDA Standards and Codes of Practice and which are carried out within a reasonable timeframe. All stakeholders, including people with disabilities, their families, carers and support groups should be consulted in the drawing up of these systems and processes. Specific systems and processes should be developed to cater for the needs of all people with disabilities.

A Disability Support Service, as recommended in *A Strategy for Equality*, should be established on a statutory basis. The Department of Social, Community and Family Affairs should be the parent department for the Disability Support Service, which should also be responsible for needs assessment and the coordination of services in the care / living plan. Funding for services needs to be attached to the disabled person.

5. Advocacy

The legislation should provide for the right to the full range and types of advocacy for all people with disabilities and in all settings. This should be provided through an independent advocacy agency that is located under the Disability Support Service, proposed above, who will be responsible for providing advocacy, advocacy training, support and monitoring of the service. Detailed guidelines should be drawn up through Ministerial regulations within an acceptable timeframe. All stakeholders, including people with disabilities, their families and carers should be consulted in the development of the advocacy services and in the drawing up of appropriate systems and processes.

The legislation should provide people with disabilities with the right to an advocacy service as laid out in the document *Advocacy – A Rights Issue* (Forum of People with Disabilities, 2001). The advocacy service should:

- Include the full range and types of advocacy for individuals and organisations, including self-advocacy, peer advocacy, carer advocacy, citizen advocates and specialist advocacy for people with disabilities who may require extra support for their voices to be heard.
- Assist people to access public services, to take a complaint to a service provider and advocacy to enable people to take a case through the courts.
- Be available to people with disabilities in community, residential, hospital and prison settings and covering the full range of disabilities, including mental health and intellectual disability.
- Provided by people who are independent of the organisations providing services.
- Inclusive of specific initiatives for parents and families, including the advocacy services they need and provide support to them where it is appropriate they advocate for family members.
- Advocacy services should provide training for people with disabilities in advocacy.

The creation of the Disability Support Service, as recommended in *A Strategy for Equality* (specified above and located in the Department of Social, Community and Family Affairs) should also be responsible for advocacy services. The successful implementation of advocacy services will have implications for the work of all public bodies and relevant government departments.

The Disability Support Service should also be responsible for providing training and support for advocacy, monitoring of advocacy and providing advocacy service coordinators. People with disabilities should be trained as advocates with negotiating skills.

Detailed guidelines for an effective advocacy service, including the appropriate systems, structures and processes should be made through Ministerial regulations or and supported by NDA Standards and Codes of Practice. This should be carried out within an appropriate timeframe. All stakeholders, including people with disabilities, their families and caregivers should be consulted in the development of an advocacy service and in drawing up appropriate systems and processes.

6. Mainstreaming

Mainstreaming is an important mechanism for enabling people with disabilities to participate equally in society. In *A Strategy for Equality* the Commission recommended that the needs of people with disabilities should be met through mainstreaming.

Meeting the needs of people with disability through mainstreaming requires that a statutory basis be given to mainstreaming in the legislation to ensure that public bodies promote equality of participation in society and the active involvement of people with disabilities in mainstream activities. Mechanisms for achieving mainstreaming include establishing equality objectives, preparing disability strategies to meet these objectives, conducting impact assessments, and ensuring participation and monitoring outcomes for people with disabilities.

In some cases mainstream services may be either inadequate or it may be inappropriate to provide services to people with disabilities through mainstream services. Mainstreaming should, therefore, take account of diversity within the range of people with disabilities. Mainstreaming should also operate as part of a dual approach to disability equality through positive action and allowing for the provision of individualised services.

The legislation needs to recognise that by designing services for the majority of the population the effect is to inadvertently discriminate against certain groups by neglecting to recognise, respond to and plan for their particular needs and circumstances.

In order to provide a framework for mainstreaming the DLCG recommends that the legislation provide:

- A statutory basis to mainstreaming in the legislation.
- A statutory duty placed on public bodies to promote equality for people with disabilities.
- The active involvement of people with disabilities in mainstreaming activities, including the formation and implementation of laws, policies, regulations, administrative provisions and in the provision of services.

There exists much international best practice on different aspects of equality mainstreaming, including Section 75 of the Northern Ireland Act 1988, and there is substantial experience in the Department of Justice, Equality and Law Reform in the field of gender mainstreaming.

The disability legislation should be implemented both through mainstreaming mechanisms and a statutory duty on public bodies to disability proof and promote equality for people with disabilities. This should cover all policies, plans and programmes of public bodies and would also include:

- Government Department and Statutory Agency Strategy Statements, Business Plans and Customer Action Plans required under the Public Service Management Act 1987. This should include monitoring and reporting requirements.
- Annual Reports of the Controller and Auditor-General
- Health Board Service Plans and Annual Reports
- Local government and City and County Development Board Strategies and Annual Reports
- Public procurement procedures and tendering, service agreements and contracts between public bodies and other providers, including Annual Reports of providers.

In addition, each public body should, as part of their overall strategy statement, develop a disability strategy for complying with the legislation and produce an annual progress report on progress in implementing the disability strategy. It is recommended that these annual progress reports will be submitted to the Equality Authority who will have the power to require public bodies to take action to comply with their obligations under disability legislation.

National Action Plans on Social Inclusion, which the Government has to submit to the EU every three years, should include a national strategy for complying with the disability legislation and a progress report on the status of implementation of the disability legislation.

In order to promote good practice a system of disability monitoring and disability awards for services provided by public and private bodies, voluntary and non-statutory agencies should also be introduced. This should be undertaken by the NDA as provided for in the National Disability Authority Act, 2000.

It is important that the legislation also specifies that positive action or individualised provision is still possible and may be necessary in order to equalise opportunities and participation.

7. Accessibility

The accessibility of public and private services provided to the public need to be guaranteed in the legislation within the broadest possible definition so that it includes the right to physical, information and communications accessibility and to genuine reasonable accommodation. This must be given the highest priority and be set within acceptable timeframes. All bodies, public or private, that come into contact with the public should be covered.

The *Programme for Prosperity and Fairness* states that "Each government department will ensure that reasonable steps are taken to make its services and those of agencies under its remit accessible to people with disabilities" (page 100). The DLCG considers the emphasis on 'reasonable steps' to be inadequate and that accessibility and the concept of universal design for all at early stages should be provided as a right. The disability legislation should build on this commitment by specifying provisions for accessibility to public buildings, public services, transport, information and communications. Detailed guidance on accessibility should be developed through Ministerial regulations. This can be complemented and supported by guidance issued by the NDA or the Equality Authority. There should be full participation of people with disabilities, their families and carers in the drawing up of this guidance.

These measures to make public services accessible to people with disabilities need to be set within acceptable timeframes. The DLCG recommends that priority be given to implementation and within the earliest possible timeframes. Implementation should be coordinated and integrated so that the outcomes are convenient to people with disabilities.

Previous proposals were not acceptable to the DLCG who are of the view that the legislation needs to contain a commitment to a right to accessibility and to genuine reasonable accommodation within a minimum reasonable time frame. Public bodies must be responsible for implementing access provisions and for drawing up plans and reporting on progress in realising these plans.

Information accessibility

The legislation should include:

- The provision of all information, for example, paper based, web based, telephone based, e-Govt products and services available to the public in accessible formats and language that is appropriate and readily understood by disabled users, including mainstream and specific services, therapeutic interventions, rehabilitation, impairment, advocacy, needs assessment etc. This should include information in a variety of different formats including, ISL and Braille.
- Information on conditions, treatments, prognosis and available services.
- Reference to and build upon the provisions for disability access laid out in the Communications Regulations Act, 2001, and World Wide Web Consortium's Web Access Initiative Guidelines.
- A provision that publishers should make information accessible to individuals for their personal use without infringing copyright laws. Sanctions should be specified where access is not granted and for abusing information made accessible in this way.

Public procurement and tendering

All public bodies should be required to purchase only accessible goods, services and information technology products and services⁷. This should include accessible venues for meetings and conferences and a refusal to award contracts to bodies that

⁷ This should be in line with the forthcoming revision of the EU's public procurement rules which states that the inclusion of tenderers' equal treatment policy be included among the criteria governing the choice of the most economically advantageous offer.

discriminate against people with disabilities. There should also be an obligation to re-tender in the absence of a tender being received from an accessible body, with an emphasis placed on awarding contracts to the body most willing to become accessible or by requiring the implementation of accessibility.

Physical accessibility

Public and private bodies providing services to the public, including the following, should be required to be fully accessible, within specified timeframes:

- Access to transport (air, sea, road and rail)
- Access to public buildings and public services
- Access to private services provided to the public
- Access to the built and external environment

Consideration should be given to accessibility requirements in licensing criteria regarding transport, public houses and hotels and to incentives (financial or fiscal) that can be provided to support accessibility.

Voting

The legislation should include access to civic and political structures and mechanisms, including electoral systems so that all people with disabilities, including people in institutional settings, can be supported to vote.

Communications accessibility

The legislation should include specific language and communications provisions and supports for people with disabilities, including people with learning disabilities, people who are deaf or hard of hearing, people who are deaf-blind, and people who are blind or visually impaired etc.

There should be recognition of the unique linguistic and cultural identity of deaf people. This means recognising Irish Sign Language (ISL) as the first language of deaf people and the rights of deaf people to receive services through ISL, and via lip speakers, note takers and speed text operators. This includes consideration to the recognition of ISL as an official language of the State so that it gains parity of recognition and treatment to spoken Irish (this could be achieved through a proposal in the legislation for a Constitutional amendment)⁸.

⁸ The European Parliament Resolution A2-302/87, adopted on 16 June 1988, officially recognises sign languages as official languages and urges national governments to do the same.

8. Disability awareness/equality training

Disability awareness training needs to take place within a framework of equality in order to raise awareness in society of the rights, needs and contribution of people with disabilities. All public and private bodies providing services to the public should be required to provide training to their staff within an acceptable time frame.

It will be important for the legislation to take action to raise awareness in society about the rights, needs, potential and contribution of people with disabilities. This should be provided within an equality framework. All public bodies and private services and amenities open to the public should be required to provide disability awareness training to all their staff over an appropriate time frame with provisions to ensure that disability equality training takes place as an ongoing obligation. This should include all public bodies and services provided to the public, including education and transport providers, employers, training agencies, community groups, the media, the entertainment industry etc.

The training should be in accordance with and supported by any Codes of Practice and Guidelines for such training developed by the NDA and the Equality Authority. The training should be embedded in standards and accredited; it should be led by people with disabilities and coordinated and funded through Comhairle.

9. Public service employment

More robust mechanisms and remedies need to be put in place to strengthen the enforcement of the 3% employment quota for recruiting people with disabilities into the civil and public services. The responsibility for monitoring and enforcing the provisions should remain with DJELR.

The DLCG believe that the 3% employment quota for recruitment of people with disabilities in the public services should be strengthened with effective enforcement mechanisms and remedies. There should be a gradual increase in the quota in order to increase the number of people with disabilities recruited. This could be achieved through positive action measures, within the meaning of the Employment Equality Act, and a requirement in relation to public sector employment, and other measures such as flexible working hours for people with disabilities. Reporting requirements on how the 3% target is being met should be required and the monitoring and enforcement of these provisions should remain with the DJELR.



part 3

Implementation, monitoring, review,
complaints and enforcement

This part of the document covers the following mechanisms that should be included in the legislation:

- Implementing and monitoring
- Review
- Complaints, redress and enforcement

10. Implementation and monitoring

The DLCG believes that there should be a Minister for Disabilities with cross-departmental responsibilities.

The task of monitoring the legislation should rest with the Equality Authority. Sufficient resources and powers should be conferred on the Equality Authority in carrying out the implementation and monitoring of the legislation.

The DLCG understands that the EU Framework Directive on equal treatment (2000/78/EC) will be fully transposed in 2003. In the light of the requirement to transpose the Directive by the end of 2003, the government should bring this into effect alongside the disability legislation. This would be in keeping with the spirit of European Year of Persons with Disabilities and gives an ideal opportunity to align the provisions of the Directive with the legislation. The Directive will require that the 'nominal cost' exemption be changed to 'disproportionate burden' in relation to the Employment Equality Act. The same approach should be adopted under the Equal Status Act when the directive is transposed.

11. Review procedures

In the light of European and international commitments the legislation should be reviewed within two years of operation or within three years of its enactment, whichever is the soonest.

The review of the legislation should also include a review of the definition of disability used in the proposed legislation and other relevant legislation. There should be scope to widen the definition and/or the inclusion of additional rights, particularly in the context of the implementation of the Framework Directive for equal treatment in employment and occupation for people with disabilities (2000/78/EC).

12. Complaints mechanisms

Effective and accessible complaints systems should cover all service provision, buildings and services, transport, and information and communications technology. An independent complaints system should be established under the Office of the Ombudsman, with powers and resources also covering the private sector.

Redress and complaints mechanisms are necessary for individuals seeking to resolve problems with public bodies or services. These must be accessible for people with disabilities, must comply with the Ombudsman's Guide to Internal Complaints Systems and identify appeals procedures. Redress should be available through robust complaints mechanisms in the following:

- Service provision: service providers' own internal systems for handling complaints and complaints mechanisms of public bodies that fund services.
- Buildings and services: Office of Public Works, the Department of the Environment building inspectorate (Building Code Part M) and the Fire Safety Officer concerning fire regulations adapted for people with disabilities.
- Transport: transport providers and authorities own complaints mechanisms and the Department of Transport complaints procedures.
- ICT: expanded powers of the Commission for Communications Regulation, established under the Communications Regulations Act, 2002, regarding access to communications technology.

An independent complaints process should also be put in place. It is suggested that the Ombudsman's Office could take these complaints (with powers extended into the private sector). This should not include officials from the assessment departments or service providers involved in the assessment of need.

13. Enforcement and remedies

Rights based legislation requires effective means of enforcement and remedies and for this reason the legislation should provide for enforcement of the provisions outlined, ensure that the rights are justiciable and contain no provision that precludes the right of people with disabilities to take legal action. A failure to comply with the provisions of the legislation should be construed as 'discrimination' under the Equal Status Act and therefore under the remit of the Equality Authority and the Office of the Director of Equality Investigations.

The DLCG are of the view that this rights-based legislation requires that remedies exist in order to claim the rights. The legislation should:

- Provide for people to have access to redress through the Courts to enforce their rights granted on the legislation. This means that the rights are expressly stated in the legislation and are justiciable.

- Contain no provision, direct or indirect, that precludes the rights of people to take legal action.
- Provide for enforcement of both the rights of individuals and the rights, duties and responsibilities of public bodies and service providers.
- Specify that failure to comply with the provisions of the disability legislation should be construed as 'discrimination' under the Equal Status Act and therefore the remit of the Equality Authority and the Office of the Director of Equality Investigations. Their roles should be extended to investigate and provide redress under the disability legislation.

The functions and powers of the Office of the Director of Equality Investigations and the Equality Authority should be extended to support and provide redress under the disability legislation. The levels of redress that can be awarded by the Office of the Director of Equality Investigations should be raised to ensure that they are effective, dissuasive and proportionate.

Proposed next steps

The DLCG document should be widely circulated. The DLCG request that the government publish the Bill and institute a consultation process on this, including a summary of the key points. The explanatory memorandum should be published and released at the same time. This consultation should be for at least a two-month period to enable all stakeholders to express their views before the Bill is published by the Oireachtas and enters the Parliamentary process.



part 4

Some key matters outside the remit
of this proposed legislation

The following are issues of urgency that fall out of the scope of the legislation that have been identified by the DLCG that need to be addressed as a matter of priority. This is not an exhaustive list.

(a) Determining the Competence of Vulnerable Adults.

There is considerable concern about the minimal legal provision for supported decision-making, informed consent and rights. Separate legislation is needed to identify the competence of vulnerable adults and particularly adults unable to make decisions on their own behalf, to provide protection for those who lack competence. The Department of Justice, Equality and Law Reform should make this legislation an urgent priority and specify within the Disability Bill that this should be enacted within 24 months.

(B) Genetics

The issue of genetics requires separate legislation. The government should treat this as a matter of urgency. It will be important for additional legislation on genetics to put protections in place to ensure that genetic testing does not discriminate against people with genetic disorders. The legislation should ban the use of genetic testing for commercial purposes and ensure that the full and informed consent of the individual is given.

(c) Proposal for Constitutional Change

Article 8 of Constitution should be amended to include Irish Sign Language as an official language in line with the European Parliament Resolution, 1988.

The DLCG draws the attention of government to the Concluding Observations of the UN Committee on Economic, Social and Cultural Rights with regard to Constitutional change (E/C.12/1/Add.77, paragraph 23).