

# Get Your Act Together

## Conference Report and Campaign Toolkit

**January 2002**

This report was compiled by Jacqui Browne on behalf of the Get Your Act Together Conference Organisers.

These guidelines are available in alternative formats including diskette, large print and braille on request by contacting the **Disability Federation of Ireland**, at (01) 2959344 or Email: [info@disability-federation.ie](mailto:info@disability-federation.ie)

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# Introduction

The enactment of rights based legislation is essential to enable real and equal participation by people with disabilities in Ireland.

However, the delivery of a broad and comprehensive rights based Disability Act requires a clear understanding of the breadth and depth of the issues involved. It is essential to recognise the cross-cutting and complex nature of drafting appropriate legislation to ensure that it is fit for the purpose intended. It was in this context that the *Get Your Act Together* Campaign organisers decided that there was a need for a national event to take place.

On December 3<sup>rd</sup> 2001 a major conference called *Get Your Act Together* was held in Dublin. The purpose of the conference was to inform the context and content of a Disability Act in Ireland. This report presents the key issues and concerns raised by the various speakers and participants at the event. Over 400 people, individuals with disabilities, families of people with disabilities and organisations of and for people with disabilities attended the conference. Both the numbers in attendance and the atmosphere at the Conference demonstrated loudly and clearly the level of interest in securing effective rights based legislation.

The purpose of the *Get Your Act Together* Conference was to provide an opportunity for individuals and organisations nationwide to become better informed, while hearing each others views and insights.

The Conference was also to serve as a focal point. It ended up being a platform from which the *Get Your Act Together* Campaign was launched as a vehicle to move the Disability Bill forward.

This pack is an outcome of the campaign. It does two main things:

1. Acts as a roadmap to campaigning and
2. Reports the outcomes of the conference which will be fed back to both the Department and the Minister for Justice, Equality & Law Reform.

Four organisations came together to provide the Campaign with leadership and focus, namely - the Forum of People with Disabilities, NAMHI, People with Disabilities in Ireland (PwDI) and Disability Federation of Ireland (DFI). The Get Your Act Together Campaign has also received the endorsement and support of a broad range of individuals and other organisations statutory and voluntary particularly the National Disability Authority(NDA), Comhairle, the Irish Council of Civil Liberties (ICCL), the National Association for the Deaf (NAD), and Vantastic.

# **Report of Speakers input and Workshop Feedback presented to the Conference**

The Conference was opened by John Dolan of DFI on Behalf of the Get Your Act Together Campaign. John Dolan welcomed the hundreds of participants, many of whom had travelled long distances, to what perhaps was one of the most significant events to take place on the European Day of Disabled People in Ireland.

The Conference format was a plenary session in the morning with a number of key inputs by the various speakers listed below. The afternoon of Conference was the time and opportunity for the four hundred plus participants to name and discuss their views and priorities for rights based legislation in a number of workshops.

The morning of the Conference was chaired by Inez McCormack, Regional Secretary of UNISON, the Public Service Union, and Past President of the Irish Congress of Trade Unions.

Speakers:            Prof. Gerard Quinn NUI Galway  
                         Kathryn Sinnott Parent and Advocate  
                         Mary Wallace T.D., Minister of State, Justice Equality & Law  
                         Reform, with Special Responsibility for Disability & Equality  
                         Dr Pauline Conroy Social Researcher  
                         Seamus O’Cinneide NUI Maynooth

## **Toward an Emancipation Act for People with Disabilities in Ireland**

Gerard Quinn in the opening speech talked about the reasons why so many people were at the event. He stated that the delegates were there in their hundreds for one reason – our passion for justice. He stated: “We have failed to make any significant breakthrough in relation to disability rights. When I look around this hall I see many

different people, many different groups, and I sense many shared and unshared experiences – experiences of hardship, of neglect and of discrimination.”

Quinn went on to outline the three significant factors that have inhibited the pace of reform and the development of rights for people with disabilities in Ireland. They are he said: the problem of our understanding the very nature of rights, the fact that we have no champion for rights as a principle across all Government Departments and thirdly our relative closure as a country to value of and lessons to be gained from international law. Quinn illustrated how each of these inhibiting factors have precluded the development of civil rights reform for people with disabilities in Ireland.

### **First Inhibiting Factor – The Logic of Rights**

Our failure to introduce civil rights reform for people with disabilities in Ireland, Quinn suggested could have to do with the very nature of rights themselves. Have we got a common understanding of what we mean by rights? We value rights because they centre the person and unsettle accepted ways of doing things. Old habits die very hard and are often challenged by the fear of change, especially when power and authority are competing with the delivery of rights to individuals.

### **Second Inhibiting Factor - No Champion for Principle across all Government Departments**

Securing a Disabilities Bill that has integrity and that is shot through with the golden thread of rights is difficult to achieve given the way Departmental responsibilities are – well – Departmentalised. We have no Ministry of Civil Rights – no one sits at the top table in Cabinet to advance such principles. We have no one Minister or agency whose role it is to pro-actively advance and promote rights and who has the capacity to propose substantive legislation.

### **Third Inhibiting Factor – The Relative Closure to International Law**

The third inhibiting factor has to do with the relatively closed mentality of the State toward international law and policy. Our political and legal systems continue to respond negatively towards allowing international law to have any sort of meaningful influence over domestic policy debates. This attitude of negativity is most plain in the minimalist way in which the European Convention is being incorporated into Irish

law at the moment. This closure to the cosmopolitan legal order cuts off potentially fresh streams of thought and this wilful diversion of knowledge adversely affects policy debates over people with disabilities. Opening up a window onto international law could meaningfully advance the disability law reform process in this country.

These three inhibiting factors - the fact that rights are unsettling and that power just does not like being unsettled, the fact that there is no champion for principle at the top table of Government, and the fact that our system seems hostile to the fresh winds of international law – are key to understanding the context within which any debate on a Disability Bill takes place. They are not insurmountable obstacles along the road to reform, but they are side constraints of which it is best to be aware of.

Quinn warned that we must not be railroaded into believing that because of the shortcomings of the Irish Constitution legislative reform is not possible. In fact, he argued that while we do need constitutional reform, effective and advanced legislative action can still be enacted if the political and public will exists.

In relation to the development of a Disabilities Act, Quinn stated that the process of constructing such an Act should be informed by some fundamental basics that are person centered.

In relation to the process of constructing a Disabilities Act, Quinn stated: 'Let us all agree now that disability is a human rights issue. As such it straddles all policy areas of Government. Do not fall into the trap of leaving out particular areas since they might more appropriately be dealt with under separate legislation. Instead treat the Disabilities Bill as if it were an *Act of Emancipation for Irish People with Disabilities* and err on the side of including matter.'

Quinn also urged that we need to bring people with various different kinds of impairments under the same tent. Each person or group might have different needs but everyone shares a common citizenship and everyone deserves the same rights.

We also need to push for real changes in the Irish law dealing with incompetence on the grounds of disability according to Quinn. This, he stated, is an equality issue since it goes to the equal protection of the rule of law for all citizens and especially for people who are vulnerable.

Quinn argued, that we need to open the window to international and comparative law. Keeping this window shut only postpones the inevitable. There is a wealth of international law on disability. Much of this international law has been ratified by Ireland so it is perfectly legitimate to use it as a departure point in relation to the content of the Bill.

In relation to the process of informing a Disabilities Act, Quinn called upon individuals and organisations to combine their strengths. “All of you can learn from each other. Individually your resources don’t amount to much. Collectively, you do have the capacity to capture high ground and to set the agenda. Make sure your blueprint is backed up with irrefutable research.”

### **Substance of the Act**

In relation to the substance of the Act itself Quinn nominated six key themes for inclusion in the Disabilities Act.

#### **1. The need to be comprehensive**

The Act needs to be comprehensive but in a way that tracks the life cycle of the person. Start with the basics – namely with the right to participate in and benefit from all preparatory processes for participation. They chiefly include education, vocational training and guidance, etc.

#### **2. Tackle the various obstacles in the life world of disabled people**

The Act should tackle the various obstacles in the life world of disabled people, including transport, architecture, and communications. These life areas Quinn argued should not be seen as separate but as connected. After all, what is the point of having an accessible airport if there is no accessible transport to the airport.

### **3. Be forward-looking and innovative**

Quinn urged that the Act should be forward-looking and innovative. Look also to new opportunities, he argued. Seek to find ways in the Bill to positively harness new technology and especially the Information Age. Demand your rightful place in eGovernment and in the eDemocracy of the future. Seek to harness the purchase power of the State to get it to buy accessible telecommunications and other equipment. Demand that the private contractors to the Government have to meet stringent equality standards. Investigate the possibility of enshrining in law some sort of Office of Contract Compliance and ensure that contractors who are in persistent violation lose public contracts. Don't be put off by those who insist that such a move would be contrary to EU law. Do your own research and satisfy yourself on this point.

### **4. Look to new threats such as genetic testing**

In relation to new threats such as genetic testing, Quinn advised that we should make sure new advances in biomedicine are harnessed positively and not negatively. This is the wave of the future and it is up to you to insist that scientific discoveries do not set you further back but are used to liberate you. Don't let the new science entrap you further. Look to the EU Convention on bio-ethics.

### **5. Embrace the broad equality agenda**

Quinn urged that we should seek an early implementation of the EU Directive and the consequent removal of the cap of nominal costs in the Employment Equality Act. Be innovative he said. Equality is broader than non-discrimination. Legislate ways to enable people with disabilities to start their own businesses or to come together to start their own businesses. Be smart – amend the tax code to enable employers to hire people with disabilities. The sad thing about Title I of the Americans with Disabilities Act, which forbids employment discrimination against persons with disabilities, is that it has not led to more people with disabilities in the workplace. Realise the limits of non-discrimination. Insist that equality and equal treatment require more than just outlawing discrimination.

## **6. Think creatively about services including State services**

Finally, Quinn encouraged us to think creatively about services including State services. Make sure that the welfare code does not get in the way of emancipation, Quinn warned. Demand the right to shop around for services. Seek ways of placing the purchasing power in the hands of the consumer. Demand advocacy now and put it on a statutory footing. Level the playing field among parents. Enable all parents to extract maximum advantage from the educational and related systems for children with disabilities through the creation of parent resource centres (something that is funded by the US Department of Justice).

In his concluding remarks, Quinn urged people not to be afraid to assert that seeking justice for people with disabilities is a productive factor in our market economy. Engage with economists, he said, as allies of the disability movement and as people with skills to enable you to get your arguments across. And do not be afraid to insist that seeking justice for people with disabilities is also a civilising factor in any Republic worthy of the name.

## **Needs & Rights**

Kathryn Sinnott, a parent and advocate in her speech identified three things that she believes are essential in the Disabilities Act to establish the rights of people with disabilities.

### **Policy Led Provision versus Rights Based Provision**

The first issue is that there is a need to move from policy led provision to rights based provisions. Sinnott citing the example of the Paul O'Donoghue case argued strongly that policies, which are made by the chosen few, create situations which are manageable and cheap. Policy funds and supports institutions and service providers not individuals. For example, the State pays for heavy drugs and medication but not behaviour analysis or modification programmes.

Warning that we need to be very careful about being ‘content’ with shifts in policy, Sinnott concluded that policy is based on power – not on rights. She also called for constitutional and legal rights – based on fundamental, natural and human rights. As a result of the ruling of the Supreme Court in the Jamie Sinnott case a call was made for a referendum to articulate the right to a free primary education – irrespective of age. Sinnott also identified advocacy as a rights based issue, stating that it is essential that advocacy groups are recognised.

Sinnott cautioned that we need to ensure that we are consistent in our language of rights. For example, ‘entitlements’ should be just that – based on rights and they should be named in the Disabilities Act.

### **Assessment of Need**

The second core issue that Sinnott identified as being essential was that the Disabilities Act must include the right to an ‘Assessment of Need’. She went on to argue how we first of all need to establish it as a right and then that there is a need to have clear procedures for accessing and undertaking the process of having an ‘Assessment of Need’. The Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA) in the US were cited as existing examples where such a right is already established.

### **Do not be rushed**

The third essential issue cited by Sinnott as of fundamental importance in the journey towards a Disabilities Act was that she cautioned: ‘Do not be rushed... to accept inadequate legislation.’

## **Mary Wallace T.D., Minister of State with Special Responsibility for Disability & Equality, Justice, Equality & Law Reform.**

In her opening remarks Minister Wallace stated that the “Government’s approach to disability policy and legislation since coming into office has been that of equality for people with disabilities”. The “final piece in the equality jigsaw” according to Minister

Wallace will be a Disabilities Bill. This Bill will, the Minister said, support the removal of barriers through a range of 'positive action measures' that place a duty on the state in relation to access issues. Minister Wallace spoke about the Government's plans to establish a range of statute based 'positive action measures' in relation to access, access to communications, transport, health and social services and the right to an assessment of need by the health boards.

The Disabilities Bill, the Minister promised will also consider appropriate complaints mechanisms, genetic testing issues in relation to insurance, e-government and universal design – design for all.

The Minister concluded saying that her colleague the Minister for Education is also developing proposals for a separate Disabilities Education Bill which would "provide for early educational intervention and the provision of education in adulthood where the circumstances warrant it". The Education (Disability) Bill will also, the Minister stated, provide for the establishment of a register of children with special education needs, a statutory right to an assessment of needs and individual education plans.

## **Towards a Disabilities Act**

Dr Pauline Conroy in her opening remarks stated that the Disabilities Bill is being prepared in the context of intensive judicial action by parents of people with disabilities and individuals with disabilities themselves. This is because as Conroy puts it: "services are not delivered, delivered too late, too little, or the wrong service is delivered." The problem with this situation is that we are now relying on the courts to make orders requiring the state to deliver services on an individual or case by case basis.

Ireland's legislative framework in relation to the rights of people with disabilities is very problematic, because we have to date used a piecemeal framework, which at the moment encompasses at least six existing pieces of legislation and two more Bills pending rather than one comprehensive Act. The result of this piecemeal approach is that existing legislation is not comprehensive enough, not enforced, or not delivered.

According to Conroy three essential conditions are necessary to successfully mainstream disability issues into public policy. These are the need:

1. for a comprehensive legislative framework,
2. a cultural climate favourable to change and
3. independent review mechanisms for the entire process.

The Disabilities Act, should according to Conroy be coherent, comprehensive in embracing all grounds of disability and enforceable with sanctions and remedies so that it can deliver to people with disabilities today and in the future. The Act should, she argued, include the right to:

- \* an updated, consultative, annual individualised assessment of need
- \* an advocate, for example in Sweden 300 advocates are currently being employed to advocate on behalf of people with disabilities
- \* a costs of disability payment
- \* direct participation by people with disabilities and their advocates in their dealings with public, social, health and other services
- \* a rehabilitation programme at an approved quality standard for people who acquire disabilities

The legislation should also look to amend and extend the existing functions of the Ombudsman to investigate complaints against persons or bodies who provide health care or disability services. A Disability Advocacy Service such as that called for in the Health and Disability Commissioners Bill, published by the National Parents & Siblings Alliance in April 2001, could be implemented by an existing agency such as Comhairle.

Conroy also identified a range of other measures which should be given serious consideration in the development of the Disabilities Bill. These include:

- \* developing and implementing policies where the money follows the individual, not the service. Similar policies exist in Canada and British Columbia where

- children and adults, following an assessment of need, are purchasers or consumers who have contracts with the public authorities to deliver services
- \* the allocation of sufficient staff and resources to enable the real participation of people with disabilities
  - \* the need for a change in the tax code to provide for a variable grade of tax credits to off-set the additional and essential costs of economic activity
  - \* the inclusion of accessibility as a key criteria in public procurement tender specifications
  - \* for those who are economically inactive, a variable non-means tested costs of disability top-up payment to existing welfare payments
  - \* an extension of the medical card / health insurance to a proportion of those at work with recurring costs
  - \* an extension of labour law to cover those who work in sheltered workshops
  - \* a Department of Finance funded study of the prevalence of disability in the entire population.

Conroy concluded by stating that: ...”in the past there have been wrongs, in the future, let us hope there will be rights... and when it comes to the fine print of a Disabilities Act, we should never forget the old saying ‘the devil is in the detail’.”

## **Citizenship**

Seamus O’Cinneide, spoke about the need to open out the concept and reality of citizenship to truly include people with disabilities. He identified the three core elements that should be captured in the Disabilities Act as follows:

1. a positive shift in public attitudes,
2. rights based legislation and
3. a range of quality services including the appropriate structures and personnel.

O’Cinneide argued that the administrative machinery of the state needs to change and become more flexible by demonstrating openness and transparency. He

concurred with the view of Kathryn Sinnott that the time has come for ‘no more deals to be done behind closed doors’.

O’Cinneide proposed that as people with disabilities ourselves we need to develop a consciousness of our own rights. He also posed the question should we be talking about the rights of people with disabilities ‘to’ ... rather than the rights ‘of’ people with disabilities arguing that due care needs to be taken with regard to separating out people with disabilities from the rest of the population.

The fundamental rights that must be enunciated in the Disabilities Act according to O’Cinneide include: the right to achieve our full potential, whether that is in relation to income, transport, education, the arts, etc. and the right to self-determination – the act of making decisions for one-self.

## **Conclusion of the Plenary Session of the Conference**

In concluding the plenary, Chairperson Inez McCormack, reminded the audience that “Rights are never conferred – they have to be fought for”. She reminded us to make use of both the Human Rights Commission and the NI Good Friday Agreement - which requires an examination of the impact of public policies on people’s lives.

Alliances of people in a common cause seeking justice are a formidable force to be reckoned with by government. It is the foundation we need for a republic that is based on a dynamic between the citizen and the government.

McCormack’s closing remarks brought together many of the common themes identified by the different speakers. She acknowledged that while there is diversity in the range of needs among people with disabilities, one effective piece of rights based legislation can go a long way towards meeting their disparate needs.

# **Workshop feedback**

## **Presented to the Conference**

The Feedback from the each of Workshops was presented to the Conference, followed by a response from Donal Toolan, Get Your Act Together Campaign. This session of the Conference was chaired by Fintan O'Toole, journalist, broadcaster and author.

Workshop 1

### **Making It Work – Successful Implementation and Enactment**

Chair: Christine Whyte, Head Policy & Public Affairs, NDA

Inputs: Judy Walsh, College Lecturer, UCD Equality Studies Centre  
Micheal Shevlin, Special Needs Education, Trinity College Dublin  
Cearbhall O'Meadhra- Institute of Design and Disability  
Selina Bonnie, Center for Independent Living

Rapporteur: Mary Keogh, Disability Options

This workshop discussed the critical elements which need to be included to ensure that the Act is successfully enacted and implemented.

#### **Constitutional Context**

There needs to be constitutional recognition that the concept of equality enshrined in the Constitution at present needs to be altered. *The constitutional context, participants agreed, must be clarified and dealt with finally and conclusively.* Radical change it was argued can only be secured through a constitutional amendment.

## **Law Reform**

The speakers and participants agreed that policies change but rights don't. A number of strategies considered essential in the area of law reform were proposed:

### *Short-term strategies should include:*

- \* Shifting policy making from 'discretion' to 'duty' – in other words shift the current situation from one where disabled people can access services and participate in society on 'our terms' to one of 'rights';
- \* Requiring the mainstream to take on responsibility in relation to the rights of people with disabilities;
- \* Maximise the potential of existing civil rights concepts and have them introduced into a legislative packet;
- \* Continue to lobby strongly for the establishment of a Disability Rights Commission to oversee the successful enactment of any rights legislation ;
- \* Utilise existing bodies such as the Human Rights Commission by giving it the power to conduct enquiries;
- \* Lobbying the Human Rights Commission to take test cases.

### *Medium term strategies should include:*

- \* Collective or Class Actions - Moving from individual complaints to 'group' complaints, removing the onus of proof on the individual to a wider group or organisation, therefore making complaints more accessible. Class actions ease the burden of proof for individuals.

## **Coherence**

Coordination and coherence between existing legislation is necessary. For example, the Disability Act must look at how it can re-enforce what is already in existence, such as the Education Act. This is essential to ensure that legal reform does not take a piecemeal approach. There needs to be a coordinated strategy so that rights are not given in isolation and that gaps will not appear.

## **Enforcement Mechanisms**

Citing the failure that already exists with implementing Part M of the Building Regulations participants agreed that enforcement is crucial and with that so too is the need for resources.

*Once enacted the legislation MUST be monitored and enforced* - If the commitment and resources are not invested in the monitoring and enforcement of the Disabilities Act, it will be ineffective. It is in this context that serious consideration should be given to extending the role of either the Office of Ombudsman or the National Disability Authority to include responsibility for enforcing the Disabilities Act.

## **Reporting**

Everyone needs to be vigilant and take on responsibility for reporting any contraventions of the Disability Act when it is enacted.

Workshop 2

## **What's to be Included...**

Chair: Michael Ringrose People with Disabilities in Ireland

Inputs: Anne Doyle Department of Justice Equality and Law Reform  
Shivaun Quinlavan, Law Lecturer, NUI Galway  
Kevin Stanley National Association for the Deaf  
Seamus Greene National Parents and Siblings Alliance  
Sinead Murtagh ADM

Rapporteur: Donncha O'Connell, Irish Council for Civil Liberties

This workshop discussed the key issues which need to be included in the Disabilities Act. It was agreed that a rights based approach is crucial, that is where rights are bestowed on the individual, allowing the funding to follow the right rather than 'making' the individual fit into a system.

**Anne Doyle** opened the session by contextualising the new disabilities legislation as follows: mainstreaming – which was launched eighteen months ago – underpins the policy approach to disability and while an equal opportunities approach is now enshrined in law there are practical and constitutional difficulties regarding “nominal costs”.

Some of the focus of the new bill would be on standards and positive action and also on the National Disability Authority (NDA) and its powers. The areas to be included would be personal health services, access to the built environment, support for e-accessibility and transport. The Supreme Court judgment in the Article 26 reference of the Employment Equality Bill would not pose insuperable obstacles to effective legislation which, hopefully, would further underpin attitudinal change towards disability.

**Shivaun Quinlivan** spoke of the importance of individualised assessment of needs – that the money should follow the individual who should have a right to participate in that assessment and in the provision of the relevant service. The Education Act and the Equal Status Act were not adequate and new legislation should be much more explicit, provide support for mainstreaming, be rights-based with proper complaints mechanisms.

She stressed the importance of equality-proofing in public procurement. On the question of the determination of capacity she posed the question of whether it should be context or purpose-specific. Shivaun asserted that the Building Regulations were not being complied with and called for training in the building industry with a stronger system of enforcement and fines. She felt that the recent Supreme Court decision in the Article 26 reference of the social housing legislation might give cause for hope on the possibility of stronger legislative support for lifetime adaptable housing and accessible transport.

In the area of mental health Quinlivan argued that much more work needed to be done notwithstanding the advances for the minority of involuntary psychiatric patients

in the new Mental Health Act. In conclusion she raised the complex issues of medical testing, genetic screening and insurance as issues which required urgent attention in legislation.

**Kevin Stanley** opened by stressing the importance of empowerment for people with disabilities. He argued that there was an imbalance in power / control in the design and delivery of services with too great a focus on medical issues. There is greater prevalence of paternalism in Ireland than in other countries. Public attitudes towards disability needed to change through long-term education focusing on respect as a value in democratic society.

Equality legislation, he said, had too many loopholes and there should be a continuous focus on the Constitution as an instrument of fundamental law. Citing the example of 25 other countries worldwide who have done it, Stanley argued that Irish Sign Language should be recognised as the third official language under Article 8 of the Constitution.

Stanley in his concluding comments stated, that there is insufficient support for parents of people with disabilities and the medical profession is unaware of their needs, wants and desires. Leadership in policy and legislation must come from people with disabilities and must be facilitated by inclusion.

**Seamus Greene** questioned the need for two bases of assessment, one based on health needs and the other on educational needs. If health needs were to be assessed this should lead automatically to an assessment of education needs. He complained about the “vale of tears syndrome” whereby Governments appeared to do God’s work of maximising suffering. There was a need for a Disabilities Commissioner whose powers would include a right to take legal proceedings. It was not enough for the NDA to have moral authority – it needed real teeth and real independence. Everyone taking part in the conference needed to form a cohesive alliance with one clear voice between now and the time of promulgation of the Disabilities Bill.

**Sinead Murtagh** opened by stating that barriers to participation in every part of life experienced by people with disabilities were considered normal by everyone else. The experience of mainstreaming had not been good. Similarly, the experience under the Constitution and before the courts had been bad. The Bill should include provisions for income and cost of disability, independent living, transport as well as genuine strategies to tackle unemployment and not more schemes. Enforcement mechanisms must be effective and whatever systems are put in place must be open to development by way of periodic review.

*The discussion was then opened to the floor and there were many contributions from the participants present.* The key points arising from the participants were as follows:

While the Article 26 reference of the original equality legislation was very disappointing for people with disabilities the more recent decision of the Supreme Court on the social housing legislation gave some cause for hope. European law will provide supplementary legal protection to fill some of the gaps in the level of protection afforded by the Irish Constitution – 2003 is the Year of Disabled People in Europe and this should be of some use to campaigners:

- \* Public procurement rules should be very strict as a means of preventing disability discrimination in public services
- \* Analysis of needs should be done on the basis of a life analysis of needs
- \* The Building Regulations (Part M) should apply to old as well as new buildings
- \* There should be a mechanism for dealing with complaints about mainstreaming
- \* The needs of disabled women are different
- \* The right to a personal assistant should be guaranteed and this is very important in the context of advocacy
- \* We must not let welfare codes get in the way of rights.
- \* A periodic review of new legislation is vitally important

- \* Every impairment should be represented on a Disability Commission, on the same basis as the elections among the Networks of People with Disabilities in Ireland, as opposed to ministerial appointments
- \* The next election should be used to maximise pressure for reform including constitutional reform. If necessary an alliance of independent candidates should contest the election in constituencies in which the Government is vulnerable. If the political will is absent it should be generated by mobilisation of the disability movement
- \* All legislation – and not just a Disabilities Bill – should take account of the needs of people with disabilities
- \* There is a need for representation on state boards by people with disabilities
- \* The exclusion from jury service of people with disabilities is an offensive exclusion from the legal process
- \* There is too much focus on the cost of participation by people with disabilities and not enough on the benefits of such participation
- \* A date should be fixed for the closure of certain “institutions”
- \* There is a need for anti-discrimination protection in the context of insurance and genetic testing. It was recommended that the DPI Resolution on Bioethics, February 2000 should be included in the Act.
- \* Tax credits should be introduced for disabled workers and the disabled drivers’ concessions should be improved
- \* If there was greater integration of people with disabilities into the broader communities there would be a much higher public awareness of disability
- \* Enforcement mechanisms must provide for monetary sanctions and exemplary damages should be available in cases of non-compliance by public services
- \* Should be greater co-operation between statutory and non-statutory bodies
- \* Carers’ allowance should be increased and there should be more respite for parents of people with disabilities
- \* Access issues arise for people using guide dogs which are indicative of very low levels of awareness among service providers of the needs of people with visual impairments

- \* Legislation should reflect values of self-determination and self-realisation as well as providing for accountability by service providers
- \* Support should be provided for seeking alternative therapies abroad
- \* All people with disabilities (regardless of age or other considerations) should be entitled to a medical card for their lifetime

The issues below, in relation to what should be included in the legislation, it is worth noting arose in other workshops during the Conference.

The key issues in relation to Independent Living for inclusion in the Disabilities Act are the need to address the right of individuals to *Personal Assistance as a Legal Right*, and *Direct Payments as a Legal Right* - where the disabled person is allocated funding which they use to buy in the services they need. These services could be personal assistance, physiotherapy, transport, enabling aids or assistive technology. The disabled person has choice and control over what services they receive and who provides them. In the UK the Direct Payments Act has been enacted since 1996 and in Sweden direct payments have been in existence for longer.

In relation to the accessibility of buildings, it was agreed that the Act should impose a requirement for Accessibility Certificates, especially for government buildings and licensed premises, like the current requirement for Fire Certificates.

Participants urged that a social model of disability be used in the definition of disability in the Disability Act. They also agreed that the Act should extend to and include people living in institutions, hospitals and other closed spaces.

## Workshop 3

### **Advocacy - Ensuring My Rights are Real**

Chair: Niall Crowley, Equality Authority

Inputs: Michael Gogarty, ITUT  
Annie Ryan, NAMHI  
Tom Cooney, UCD, Law Faculty  
Deborah Birmingham, FORUM  
Martha McClelland, Mind Yourself & Foyle Advocates.

Rapporteur: Peter Kearns, Workhouse

The participants in this workshop explored what needs to be in the Act to ensure that people with disabilities can exercise their rights under the Act?

“Traditional medicine takes the view that disabled people shouldn’t have a voice.” - Tom Cooney

Advocacy is a human rights issue. Advocacy is the right to – speech, expression, movement and assembly. Advocacy the participants agreed must be recognised as a necessary support that enables equality of participation.

The fundamentals for advocacy services were identified as follows:

#### **Who Needs Advocacy Supports**

1. People who are not in an institutional environment need advocacy just as much as those in closed environments.
2. People with disabilities who are not aware of their rights or how to exercise their rights.
3. Parents who haven’t been given informed choices and need access to advocacy.

4. Relatives and carers need skilled advocates as well.

### **Independence**

1. Advocacy services must be independent.

### **Training**

2. Need for competent advocates, including disabled people themselves.
3. Need for training of disabled people as advocates.
4. Advocates need training on how to communicate, relying on family members is not enough as disabled people and their families are, at times, quite happy with services when they are asked in institutional settings.

### **Essential Elements & Resources**

1. The Act should have positive rights and negative rights, that is, where negative rights include the right to say no, for example, giving the right to an individual to right to say no to certain procedures or medication.
2. The Act must allow for a clear workable appeals system – with confidentiality.
3. There is a need for training for the judiciary in rights based work.
4. Advocacy must be properly resourced – e.g. professional advocates with different backgrounds – such as race, gender, employment, culture etc.
5. As there is a direct correlation between disability and poverty, advocacy services should be free to those in need.
6. Ultimately, advocacy must be based on equal citizenship.

### **Statement of Needs**

In relation to the 'statement of needs' model as proposed by the Minister in her speech concerns were expressed that it would neither be independent nor would it address the full life world needs of people with disabilities. The model proposed, many participants believed, represents a medical view that ignores advocacy and ensures that the 'power' and 'allocation of resources' resides in the hands of service providers. Needs are not identifiable on the basis of service providers *think* what is needed nor on the basis of what *can* be provided. The promised Statement of Needs in the Act, should be based on independent and should fully involve people with

disabilities or their advocates where required. Equally, the need for an accredited independent assessment team of 'needs assessors' was highlighted.

Needs, all of the participants agreed, have to be met - lack of funds is not always an issue; it is often the case that the existing resources are often poorly targeted.

## **Conclusion of the Workshops & Feedback Session of the Conference**

Donal Toolan in his response to the both the morning and afternoon sessions of the Conference, noted the resounding consensus amongst the Conference participants that the Disability Bill must be rights based and person centred. In relation to the right to an assessment of need, Toolan re-iterated why the creation of individualised service delivery is essential for the real inclusion of people with disabilities in the mainstream of everyday life.

In order to realise such a shift in our approach to service delivery we must, he stated, legislate for the right to an individual, independent and mandatory assessment of needs. The right of access to an individual assessment of needs should be available from the cradle to the grave. The assessment must also be holistic in approach.

In relation to the current problems associated with giving effect in law to the concept of 'reasonable accommodation' as it currently exists in other countries, most notably the United States of America, Toolan highlighted the options that are open to government. One way is to move is by supporting and reflecting Article 13 of the European Treaty. Other approaches include the holding of a constitutional referendum to enshrine the rights of people with disabilities in Ireland.

Fintan O'Toole, Chairperson of the Feedback Session of the Conference proposed that there are four key issues arising out of the Get Your Act Together Conference which require a sharp focus:

1. The need to be clear about what we want. What are the specific demands that people want? Such as, for example, tax breaks or are we looking for legislation that sets down some basic principles to be applied across the board? Such legislation O'Toole suggested should be dynamic, broad and flexible.
2. We must be clear about the critical issue of what or which mechanisms do we want in terms of implementing and policing the legislation.
3. We need to consider the dilemma and relationship between a specific piece of disability legislation and other citizens. How can we get legislation that connects into existing mainstream legislation?
4. How are we going to take power – Decide what happens next! O'Toole urged the Get Your Act Together Campaign to organise and develop strategies about what kind of actions it might support or use to get the system – political and bureaucratic – to deliver what people with disabilities in Ireland want.

The Conference as an event in its own right concluded. However, the atmosphere at the end of the day clearly indicated, that in fact, many people had just begun a journey, very clear that they were just about to embark on a campaign. The Get Your Act Together Campaign objective, it was clear, is to promote and secure the rights of people with disabilities to participate in the mainstream of everyday life.

# Conclusion

The outcome of the Get Your Act Together Conference was that a number of the key issues of concern to people with disabilities and their families were highlighted as areas for inclusion in the Disabilities Act. It could be argued that the following issues were considered to be the ten fundamentals which must be included in the Disability Bill to reflect real disability rights legislation:

## **The Act must:**

1. Be comprehensive and mandatory, clearly establishing the rights of people with disabilities to participate in the mainstream of society clarifying how those rights are to be given effect.
2. Focus on the rights of individuals to disability support services, including a range of advocacy services and assessments of needs.
3. Provide for an *independent*, comprehensive and holistic assessment of need.
4. Provide for a mandatory obligation to meet the needs identified in accordance with an individual's Assessment of Need.
5. Provide for an independent and effective appeals/mediation process.
6. Demand that inclusion and accessibility be a key criteria in public procurement tender specifications.
7. Provide for disability proofing systems to copper fasten mainstreaming and to establish in clear terms how an accessible inclusive environment will be defined.

8. The Disability Bill should complement and enhance existing legislation by making provision for effective implementation and enforcement of all relevant existing legislation, such as, the Building Regulations, the Education Act, the Employment Equality Act and the Equal Status Act.
9. Provide for effective sanctions and penalties for non-compliance.
10. Make provision for effective implementation and enforcement of the legislation, including reviews of the legislation.

The conference participants were quite clear that it is now time to move beyond the anti-discrimination agenda citing the reality that while we have both the Employment Equality Act and the Equal Status Act, they alone do not enable people with disabilities to take part in all of what life has to offer.

People with disabilities must be enabled, through rights based legislation, to take full advantage of the web of social and economic areas of everyday life.

The conference and on-going campaign for the enactment and enforcement of rights for people with disabilities in Ireland is the careful result of a coalition of organisations of and for people with disabilities working together.

It is now over five years since the publication of *A Strategy for Equality* - the Report of the Commission on the Status of People with Disabilities in which many of the organisers and participants in the Get Your Act Together campaign played a key part. This coalition of diverse views will continue its efforts to inform, involve and promote the rights of people with disabilities in Ireland.

# CAMPAIGN TOOLKIT

The purpose of this toolkit is to provide a road map for organisations and individuals to be used in campaigning in the run up to the general election. It gives examples of the types of action and useful tips that can be used in furthering an understanding or influencing the shape and implementation of the proposed Disability Act.

## Things you can do...

1. First of all know what you want. Do not just complain, propose a solution.  
Demand the 10 fundamentals
2. Get together with others and create alliances.
3. Remind politicians of the commitments given to implement A Strategy for Equality – the report of the Commission on the Status of People with Disabilities.
4. Involve the media to highlight your case. You can build a body of momentum by working the media both on the local and national angles.

## Dealing with T.D.s & Senators

Politicians have hectic schedules - every day they deal with constituents and make representations on their behalf, attend a range of meetings, answer letters, calls and questions, and then they have to read volumes of dense documentation before speaking to the Dáil or voting on an issue.

Typically politicians are hugely under-resourced and very hard pressed for time. They do not have a team of researchers and policy advisors behind them. This often means they do not have all the in-depth details needed to draft the finer points of legislation. For this reason politicians welcome information and analysis of issues. This is where you play an important part. But if you are going to cut through their busy schedule and work successfully with politicians to influence the Bill then you need to bear in mind:

- They are highly pressurized
- Their style is often reactive, not reflective
- They have little time for reading – so give it to them on one page only!
- They respond better to specifics - what explicitly do you want them to do?
- Find out their known areas of interest: or develop one for them!
- Give credit where credit is due
- Remember they are poorly resourced, they have no middle-level advisors, so help them out and advise them
- Not hearing from you creates a presumption that the issue is not important or it has gone away
- Meetings must be businesslike: choose your representatives carefully
- Most will expect you to deal with their rivals
- If you disagree with something they say/do/propose, ask for a meeting
- Deputies have a right to meet Ministers
- Most will give you good advice on who you should influence and how (door-opening function). Ask deputies for advice.
- Support does not always follow predicted patterns. Some will surprise, others will disappoint
- There is no substitute for serious systematic lobbying of individual deputies.

### **Members of the Oireachtas Can...**

- Ask a question - priority, oral, written (Dáil only)
- Raise a matter on the adjournment of the House
- Speak on a motion
- Introduce a Bill
- Put down amendments to a Government Bill
- Get a meeting with a Minister
- Make representations to a Minister
- Write to a state agency on your behalf
- Introduce a Constitutional amendment (Dáil only)

- Speak on a Bill

### **Lobbying the Oireachtas requires...**

- Persistence, persistence and persistence
- Patience, patience and patience
- Thoroughness
- Attention to detail, accuracy
- Humour and proportion
- Flexibility about time
- Being reachable when needed
- Personable manner by phone, in person and on paper
- An understanding of the pressure on politicians

### **Don't do it if...**

- You don't like politics or politicians
- You're a fanatic
- Going on a delegation?

### **Dáil & Seanad Dates...**

Jan 25 - March 25

April 18 - July 18

Oct 25 - Dec 18

### **Dáil Times**

Never on a Monday

Tues 1430 - 2120

Wed 1030 -1750

Thurs 1030 - 1750

Fri 1030 1530 (no questions)

## **Seanad Times**

Never on a Monday

1430 on first day

1030 on following days

## **Tips for Making an Oral Presentation**

- Make sure it is relevant to the occasion and the audience.
- Keep it short – no long speeches
- Structure it logically under key headings
- Try to get four or five main points across
- Show conviction but don't be emotive
- Be good mannered and good humoured

## **Qualities of a Spokesperson**

- Understands the members of the groups and their needs
- Appreciates difference of opinion in the group
- Has detailed knowledge of the group's case and objectives
- Is easy to contact at all times

## **Going on a delegation?**

- 2 / 3 is best size
- One person is sufficient if she/he is known
- Meetings can be postponed, delayed. Be patient. Allocate time.
- Phones will ring incessantly. There will be interruptions.
- Get down to business swiftly.
- Choose an articulate, not a representative delegation.
- Know exactly what you want the deputy/senator to do: write to a Minister? Ask questions? (generally delighted to) put down a motion? Arrange a meeting with a Minister? Amend a Bill - or what?
- Making a deputy 'aware' of something is no reason for a delegation.
- Admit there is another side to the story. Keep your case in perspective.

- Leave a page behind - more for further reference.
- What do you want your, and his, parting words to be?
- Arrange a commitment to continue the relationship.
- Write a thank you letter afterwards noting areas of agreement and agreed areas of action.

### **The 5W's & 6C's of Communication**

Whatever communication task you are undertaking, always remind yourself of the 5W's & 6C's *before* you start. This will give your communication a better chance of success *and* make the task easier:

\* **Always Know** Why? Who? Where? When? What? How?

\* **Always Be** Concise, Concrete, Courteous, Constructive, Correct, and Complete.

### **Media Work**

It is difficult to influence the political agenda and decision-makers unless they are persuaded that there is some underlying public concern 'out there' and the level of media interest in a topic is often the yardstick by which this is judged. More positively, the media can focus and intensify interest in and concern about an issue, to the extent that decision and policy-makers feel obliged to respond.

### **How to Write a Press Release**

The information contained in a press release should be presented in descending order of importance, with the most important facts first, followed by supporting facts and information presented in decreasing order of importance. The first paragraph of a release should contain all of the most important information:

**Who** - who is announcing, reacting? Who will it affect?

**What** - What is happening or being said?

**When** - When is something happening – day, time, date?

**Where** - Where is something taking place?

**Why** - Why is it happening? Why is it newsworthy? or unique?

**How** - How will it be done? How will it affect people?

The next (second) paragraph should contain more elaboration or background information.

The third paragraph may contain further information and may also contain a 'quote' from someone in your organisation (commonly your Chairperson) about the news you are announcing or the reaction you are giving to an issue or a topical news story. Again you are saving the journalist time if you give them a quote they can use without having to call you. Don't forget to mention the title and the organisation of the person giving the quote. The best press releases are the ones which could be used 'verbatim' (word for word) by the media so when writing a release make sure it is clear, concise, direct and presented with all of the main facts and information in the first and second paragraphs.

Fourth, fifth and sixth paragraphs may be needed to present further background material but your release should not contain any unnecessary or irrelevant information. In terms of length, a release should be as short and concise as possible while still containing all relevant facts and information. It is permissible to include a brief paragraph about your organisation (membership / evolution / significant achievements) but this should be a final paragraph to your news / press release. A press release should not be more than two pages long.

## **Style Tips for Press Releases**

- Be factual and direct.
- Have short sentences and relatively short paragraphs.
- Avoid repetition.
- Include contact names and phone/fax/e-mail details, (including an after office hours contact number if the news story is very important), at the end.
- Be one page if possible, two at the most. Include words 'more follows' at bottom of page one if it runs to two pages. Have word 'ends' at bottom of second page.
- Identify the sender (headed notepaper with name, address and phone/fax is ok).
- Have the date prominently displayed (on both pages if sending two).
- Have good size margins.
- Use double spacing.
- Be neatly typed with no factual or spelling errors (proof read carefully, have more than one proof-reader).
- Stick to facts and avoid comment except in a quote.
- Be typed on one side of A4 paper only – never use both sides of the paper if you overrun one page.
- Spell out numbers one to ten (use the words), for numbers above ten use numerals.
- When using dates in text do not use 'th' and 'nd', e.g. 22nd June 1999. Instead use this format: June 22 1999.

- Avoid improper use of capital letters.
- Have a 'headline' (capitalised, top of both pages) which encapsulates content of news story, for example, 'WATERFORD NETWORK OF PEOPLE WITH DISABILITIES SECURE EU FUNDING FOR LOCAL PROJECT'.
- Have numbered pages.

### **Checklist for a P.R. & Media Strategy**

- What is the problem, the difficulty, the issue?
- Why is it a problem?
- Why are its effects so serious?
- What costs does it impose?
- What do we want done about it?
- Who do we want to do what?
- Is this a problem of policy, allocation of resources, procedures or what?
- Who benefits if this problem is solved?
- Show how changes benefit everybody.

### **Issue your own press release...**

Use the 10 fundamentals outlined in this pack to prepare your own press release. Issue it locally. Give it your own slant. Make the headlines by illustrating your news with human interest.

### **Ways of Working with the Media**

- Press conferences
- Press releases
- Photo events and opportunities
- Offering comments
- Proposing articles, features
- Seminars
- Launches of reports
- Letters to the editor

## **Key Media Skills**

- Keeping contacts and mailing lists up to date
- Writing a Press Release
- Knowing how to make a story newsworthy
- Organising a press conference
- Handling relationships with journalists
- Participating in radio and television interviews

## **Resources & Further Reading**

Much of the material used in this pack has been taken from...

- **A Guide to Influencing Policy in Ireland**, By Brian Harvey, Combat Poverty Agency, 1998.
- **Houses of the Oireachtas Pack**, Public Relations Office Leinster House, 1997.
- **Telling It As It Is – PR & Media Handbook**, By Jacqui Browne, Sharon Browne & Helen Fitzgerald, People With Disabilities in Ireland Ltd., 2000.
- **IPA Administration Yearbook & Diary 2002**, 36th Edition, Institute of Public Administration.