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Speaker's Notes on
Inclusion Ireland

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The invitation to Inclusion Ireland to speak at FLAC's seminar is very welcome. Inclusion Ireland is now over 40 years old, founded in 1961. Its first President was Former High Court Judge, Declan Costello, whose "Just Society" document in the late 1960s painted a vision for a modern Ireland based on social justice and equality. I believe Inclusion Ireland continues to fight for such a society which is inclusive of all its citizens.

History of Disability Movement

The concept of human and social rights for people with disabilities has developed over the past five decades. This movement has sought to counter deep layers of prejudice and cultural influences which normalised the institutional isolation and segregation of disabled people and, in many cases, legitimised the handing of their care over to people, who had a lesser view of their humanity.

Professor Gerard Quinn, Professor of Law and Dean of the Faculty of Law at NUI Galway, who has published extensively on disability law, has pointed out that the application of the human rights approach in the field of disability is relatively new. He states that the human rights revolution in the context of disability has to do[1] with making the human being visible and making the benefits of human rights and democracy available to all.

In the last two decades there have been a number of international conventions, covenants and treaties drawn up to protect people from abuse and discrimination, including people with disabilities. Many of these international instruments are legally binding in the states that ratified them and they are obliged to observe them. For example, the following have all been ratified by the Irish Government:

- The International Covenant on Economic, Social and Cultural Rights (1966)
- International Covenant on Civil and Political Rights (1966)

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[1] Quinn,G. with Bruce,A (2003) " Towards free and inclusive societies for people with disabilities" in Quin, S. and Redmond, B. (eds) *Disability and Social Policy in Ireland.* University College Dublin Press. P182

- The Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment(1984)
- The Convention on the Rights of the Child (1989)

In addition, many countries have introduced into their national law anti discrimination legislation to protect the rights of marginalised groups. In Ireland, the broad equality legislation of the late nineties made an impact on people with disabilities in their right not to be discriminated against on the grounds of their disability in their access to employment and goods and services.

Human rights should not just be about protection against power but about restoring power to the person. To quote Professor Quinn again when describing the importance of using rights to restore power to people, *"economic, social and cultural right have an enabling function: they provide a bridge whereby persons with disabilities can take their place as valued and often highly productive citizens."* [2]

The core principles at the heart of the rights based perspective is that the real problem in relation to disabled people lies not with the person but in the way society treats the difference of disability. This is not to deny that differences exist, but while all people are different they are, as our Constitution acknowledges, equal in the eyes of the law.

This poses many challenges for us and creating a society that recognises and values differences is not easy. The medical model of disability is still a dominant force in our society. This model defines people in terms of their physical deficiencies against a bench mark of some ideal type of norm of the able bodied.

It has led to the creation of services dominated by the "expert" or "professional" whose job is to provide care and cure or the "culture of care" as long time disability campaigner Donal Toolan calls it. Disabled people and their families were expected to participate in this process and if they did not do so wholeheartedly enough or questioned what was being put in place for them were, either dismissed as not having come to terms with the reality of their condition, or as has happened, and continues to happen, more frequently than we might care to believe, were told if they did not like what was on offer they

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[2] Toolan D. (2003) "An emerging rights perspective for disabled people in Ireland: an activist view" in Quin, S. and Redmond, B. (eds) *Disability and Social Policy in Ireland*, University College Dublin Press p.183

could look elsewhere - a realistic option in a society where choices are few and rights nonexistent.

Historically services in Ireland have been provided under the medical model. Religious and charitable organisations dedicated to single type of disability "the mentally handicapped," "the deaf" "the blind" provided care and services in the absence of any state provision. Their pioneering role in this area must be recognised and applauded. However, at the same time the traditional charitable model can be rightly viewed as a reactionary force in the development of a modern policy in relation to disability;[3]for example, charities' preoccupation with private fundraising is due to the lack of adequate state support and their perceived role as interpreters of what disabled people need.

The first major landmark in the breaking with this model in Ireland was the publication of the report of the Commission on the Status of People with disabilities in 1996[4]. Chaired by Justice Flood the Commission set out a radical programme for change on how services for people with disability are delivered including a call for disability legislation which would establish rights for people with disabilities. This was indeed a major shift in philosophy when it is recalled that a little over ten years previously a Green Paper on services for people with disability, discussing the need for legislation, stated "the most important thing which any disadvantaged minority needs is good will and understanding" and continued with, "the Government are convinced that the promotion of the rights of the disabled people can best be achieved by general agreement rather than by measures of compulsion.[5]"

Disability Act

Today we have a Disability Act which was passed last year amidst much controversy after the government was forced to withdraw a previous Bill in 2002 by the strength and sheer anger of the disability community at its contents and its attempt to prevent people having redress to the Court

This is an Act which is considered by my members and many disabled people to fall far short of the vision imagined by the Commission. The Irish Human Rights

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[3] Quin.S. and Redmond, B (2003) "Disability Policy in Ireland" in Quin, S. and Redmond B. (eds) *Disability and Social Policy in Ireland*, University College Dublin Press. Pp.1-9

[4] Commission on the Stauts of People with Disaiblities (1996) *A atrategy for Equality.* Dublin Stationary Office.

[5] Department of Health and Social Welfare (1984) *Towards a Full Life: A Green Paper on Services for Disabled People* . Dublin : Stationary Office. P.112.

Commission in their observations on the Bill before it became an ACT listed 17 areas in which it could be improved upon

Campaigns / Issues

The recent scandals about the illegal charging of elderly people for long stay care, which I also may add was happening to people with disabilities, and the appalling scandal of Leas Cross Nursing home are examples of what happens when people are left to the vagaries of a system that had no legislative backbone. The practice of moving vulnerable disabled people to private nursing homes is still alive and well – I can assure you. These scandals have led to a call for an independent Social Services Inspectorate for elderly people. What most people do not know is that children and adults with disabilities in residential care have no protection from any type of inspectorate. Research shows that they are amongst the most vulnerable groups in our society and experience higher levels of abuse than others, such as children and the elderly. The delay in introducing standards for and inspections of disability services is one of many indicators to measure progress in developing a more inclusive society. Others include the well documented high unemployment rates of disabled people and the number living below the poverty line.

Another issue of great concern to Inclusion Ireland is the lack of any law in relation to guardianship or assisted decisions making for vulnerable adults. The Law Reform Commission has also drawn attention to this problem in it recent publication on capacity and vulnerable adults. The topic is very timely today given the recent Supreme Court decision on statutory rape. Our book *Who Decides and How* explains our concerns in greater detail.

If we and the Government are serious about promoting change in this sector significant changes as to how services are provided for and financed must be made. This will require extra resources, but surely there has never been a better time in our history to do so. But above all these changes must be underpinned by legislation which is clear and unambiguous and which has at its centre the rights of people with disabilities.

People with disabilities, their families and representative groups have fought long and hard to get this issue on the political agenda and what has been heartening in the last few years has been the reaction of the general public. It is such positive public support that will ultimately ensure the political will to give rights meaning for disabled people not only in this country but throughout the world as they fight for a new UN Convention on the rights of Disabled People.