Advocacy

A Rights Issue

A Reflection Document • 2001

FORUM OF PEOPLE WITH DISABILITIES
IDENTITY • RIGHTS • CHOICE

The Forum of People with Disabilities

ADVOCACY: A RIGHTS ISSUE

A Reflection Document

December 2001
Deborah Birmingham

This document is produced as part of the ongoing campaign for disability rights legislation in Ireland.

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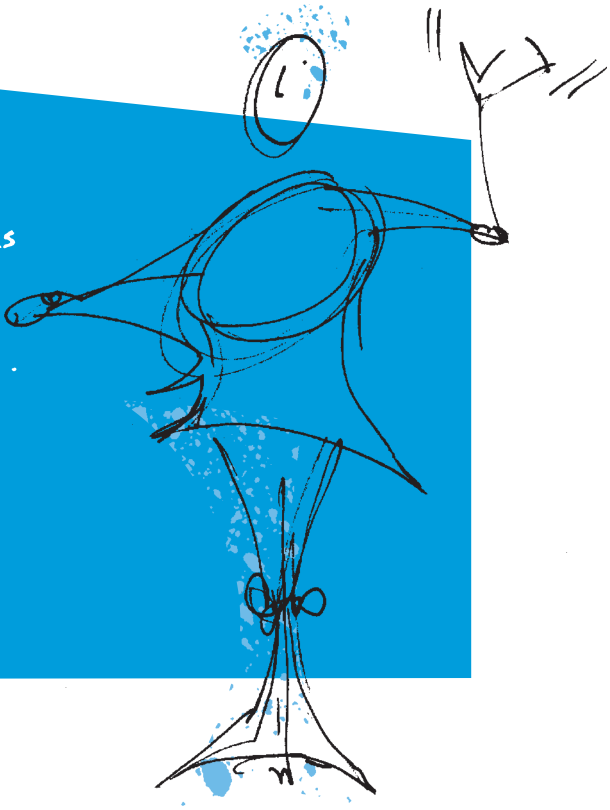
Concept Design for ‘Lorette’: Sean Hamill.

Hello, My name is Lorette and
i am your guide throughout this
reflection document.
I can be whoever I want to be...
Welcome to Advocacy:
A Rights Issue...
Lorette



Other recent Publications of The Forum of People with Disabilities include:

A reflection document on a Cost of Disability Payment (2001)
Ralaheen Ltd and The Forum' of People with Disabilities

Information Leaflets:

Information Leaflet on Advocacy: A Rights Issue (2001)
Advocacy: 'Nothing About Us Without Us': Easy To Read Leaflet (2001)
Advocacy Now Poster (2001)
Your Rights As A Disabled Person Under the Law:
The Equal Status Act, 2000 (2000) Theresa McAteer and
the Forum of People with Disabilities
Your Rights As a Disabled Person Under the Law:
The Employment Equality Act, 1998 (2000) Theresa McAteer
and the Forum of People with Disabilities

Future Publications:

Information leaflet on the Built environment (Jan 2002)
Copies may be obtained from The Forum of People with Disabilities
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Comments:

"The Realisation of Rights can only be achieved if those rights are readily acknowledged and mechanisms and processes exist to give them efffect. Currently, Disabled People's rights enjoy neither acknowledgment or effect, which will ensure that people can enjoy real citizenship and equality. This is particularly the case for Disabled People and others whose lives are largely experienced within closed spaces. To move to where Disabled People and others are to have full citizenship and equality through the enactment of

effective laws and policies, Advocacy must be recognised as a pivotal aspect in those rights being realised. This document 'Advocacy: A Rights Issue' seeks to contribute to such a reality."
Donal Toolan Co-ordinator, Forum of People with Disabilities

"Advocacy in my opinion is the Politics of Empowerment. Choices and Rights often remain aspirational rather than actual in disabled people's lives. Advocacy and the role of advocates are central to collective and cultural change. It's not just about role-modelling its about actual words that articulate an experience of vulnerability and oppression. Advocacy, for me, is knowing that other people are going to pull me through a tough time. Discrimination is not just a one-off incident, it's a schematic process, which annihilates your self-esteem and ultimately breaks or shapes your identity. Advocacy is about not colluding with the system or the status quo. As a disabled woman, my advocates come from two different communities: the Traveller community and the Disability Community. Advocates actually explain what sexism or racism is and then leave you with the tools to tackle the specific issues in your life."
Rosaleen McDonagh National Traveller Women's Forum;
Chairperson, Centre of Independent Living

"Access to competent communication empowers people with disabilities to full participation in Irish Society. It is absolutely essential for people with disabilities to lead the legislative changes necessary to enhance their civil and human rights."
Kevin Stanley Chairperson, Irish Deaf Society

"The NDA welcomes the Forum's initiative in preparing a reflection document on Advocacy and views it as a significant contribution to an informed debate on how best to progress the development of effective independent mechanisms for people with disabilities in Ireland."
National Disability Authority

Advocacy in its various forms is key to the effective implementation of rights. The Equality Authority is promoting a model of community advocacy to reinforce rights established in equality legislation. The work of the Forum of People with Disabilities in this area makes an important contribution to a rights based approach to disability issues.
Niall Crowley Chief Executive, Equality Authority

"How can children with disabilities and children living in closed environments ensure that their human rights be respected? What structural reforms are required to enable vulnerable children to prevent their rights from being routinely and systemically violated? Advocacy: A Rights Issue offers important answers to these urgent questions as well as recommendations for actions that need to be taken without further delay if we are to honour our

obligations to promote and safeguard the basic rights of all children, particularly those most at risk."
Raymond Dooley Chief Executive, Children's Rights Alliance

"The Irish Human Rights Commission warmly endorses the general concept of advocacy in the context of securing the human rights and interests of persons with disabilities. It views advocacy as a necessary measure to give voice to the voiceless and to ensure that people with disabilities can have a direct say in all matters that affect their own personal destiny. As such, the Irish Human Rights Commission views advocacy as a key factor in advancing the autonomy and independence of persons with disabilities. These goals are not merely desirable in themselves. They flow from the basic rights that we all share in common as human beings."
Donal Barrington President, Human Rights Commission

"Human Rights advocacy is especially important to those whose voices are not heard by virtue of their existence in closed environments. It is not about platitudinous invocation of the abstract rights of hypothetical persons. Human Rights Advocacy is only worthwhile if it facilitates positive change in the life chances of those on whose behalf it is used. Disabled People must become agents of their own change and Human Rights Advocacy is an essential tool in that life affirming process. The Forum' of People with Disabilities are to be warmly congratulated for playing such a vital leadership role in this regard."
Donncha O'Connell Director, Irish Council of Civil Liberties

"The Forum of People with Disabilities are to be congratulated for this brave and long overdue initiative. Offenders, frequently victims of serious abuse themselves as children, live in a space which by definition is closed and secret. Although rightly deprived of their liberty, they are also as a consequence, frequently deprived of many other basic human rights also. Those who are mentally ill are too often subjected to solitary confinement as 'treatment' for their disability. 'Advocacy: A Rights Issue' is an important document in that it can help give a voice, however, indirectly, to those most silent of all: the mentally disabled in our prisons."
Valerie Bresnihan Chairperson, Irish Penal Reform Trust

"*It is one of Comhairle's guiding principles and values that information, advice and advocacy services empower people to access their rights and entitlements, and that information, advice and advocacy should be of a high quality, customer-focused and developed in consulation with customers. We particularly recognise the greater needs of people who are disadvantaged, particularly those with disabilities who may need advocacy services."*
Comhairle, 2001

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Preface

The time is ripe for a contribution to the debate on advocacy in relation to disability issues. The case for a formal system of advocacy has a special urgency. Disabled people have been deprived of their basic civil rights for too long. To be meaningful in practice, rights must be enforceable. Advocacy has a pivotal role to play in making rights enforceable.

The intention of this ‘Reflection Document’ is to raise awareness of the importance of advocacy in the struggle by disabled people for basic civil and human rights. It is part of a package of resources designed to include an information document, leaflets, easy- to-read leaflets, an advocacy poster, compact discs and an illustrative drama sketch.

In preparing this document the Forum of People with Disabilities relied on a wide group of people, who responded to drafts of the work-in-progress on the basis of their own knowledge and experience. In particular, I acknowledge gratefully the support of the staff and council members of the Forum. I would also like to thank all those listed in the acknowledgments, who afforded me advice, insights and support.

Deborah Birminghan
December, 2001

Terms of Reference:

This is not a legal or academic document. It sets out a normative political argument. Its core aim is to provoke debate and discussion about advocacy as a civil rights issue. It takes account of the various domains –public, private and political – in which disabled people have to struggle to assert their right to respect as equals. It is animated by a concern about the political failure to turn the recommendations of the Commission's Report *'A Strategy For Equality'* into reality.

This reflection document on advocacy has particular concern for disabled people, within closed environments i.e. residential care, workshops, prisons, hospitals, nursing homes, workshops, children's homes, and total institutions. It also recognises that disabled people can be equally vulnerable at times within families and those that are homeless.

Definitions:

For the purpose of this work, the terms impairment and disablement are defined as follows:

"Impairment is the loss or limitation of physical, mental or sensory function on a [temporary] *long-term or permanent basis"*

"Disablement is the loss or limitation of opportunities to take part in the ordinary life of the community on an equal level with others due to physical and social barriers"
(Disabled People's International 1981)

This document seeks to:

A. Show that advocacy is a matter of civil rights;

B. Make the case for an independent statutory system of advocacy;

C. Draw upon the available research literature in the area of advocacy;

D. Provide a comparative examination of advocacy in the international context (with particular attention to models of advocacy in Canada and Australia;

E. Add to the knowledge base relating to advocacy; and,

F. Propose practical reforms

1 Introduction

The fortresses of confinement functioned as a great, long silent memory
(Foucault, (eds.) 1997:209)

1.0 There is, and has been historically in Ireland, a widespread exclusion of disabled people from advocacy mechanisms, to represent their interests and facilitate decision making processes. This is especially true for those living within residential care and total institutions.

It is unacceptable that a section of our population, some of whom are very vulnerable, live in largely unaccountable private spheres with no form of independent, accountable representation. This is due in part, to the unique asymmetrical situations of power which disabled people have been forced into throughout history in relation to doctors and other professionals, their own families and wider communities. Advocacy is a tool, which can redress power dynamics because it gives people a mechanism to place their own concerns, views and contributions into the wider arena. It can reframe an individual / group or community's position within the various domains of the public, the private and the political.

1.1 Advocacy can be a difficult concept to grasp; there are many interpretations on what advocacy is and what it is not. Some people have never heard of the word, others only equate it with legal and trade union representation. Some believe it is simply about speaking up and out, on behalf of oneself and others. Advocacy is all of these things but it is more. It is about a process; how one speaks or represents another, whether the principle person is involved, how people are involved, and the accountability we have to those we represent.

1.2 Advocacy is difficult when there is no formal structure or legislative framework in which to work from. People and services in Ireland tend to address advocacy on an ad-hoc basis. There is no shared vision or knowledge. Everyone seems to have an opinion on it, but no-one quite knows what is happening. People are doing their own thing within their own services, organisations and lives. It appears fragmented and territorial. At times, it can be difficult to think outside of ones own space or direct experience. Advocacy can itself become misrepresented.

Chapter 2 explores the concept of advocacy, and proposes that advocacy requires a broader understanding than traditional formal models allows us. Different models of advocacy are outlined in chapter 3, illustrating that advocacy systems are like shoes; one size does not fit all. Not everyone will be able or willing to self-advocate; families and service-professionals will have conflicts of interest. Different advocacy models are appropriate to different situations and should acknowledge and reflect the multiple identities which people have.

1.3 Current policy and thinking on advocacy is explored in chapter 4, drawing on statutory reports; in particular the report of the Commission on the Status of People with Disabilities (*A Strategy for Equality,* 1996), and the progress report (*Towards Equal Citizenship*, 1999). These reports provide a barometer as to what recommendations and progress have been implemented. It is also suggested in this chapter that Non Governmental Organisations should utilise and lobby other established offices to recommend and help effect change on advocacy provision. However it is clear in this chapter that advocacy is at an embryonic, critical stage in terms of policy and provision. There have been many changes at statutory level; Comhairle and the National Disability Authority are newly established. Both of these state agencies have advocacy as part of their remit, one in terms of provision and the latter for the development of policy. It is fundamentally important that systemic advocacy is placed firmly on the table as a civil rights issue, and that disabled people to whom it is directed are strategically placed at the centre to inform planning and policy. Some illustrative examples of advocacy in action in Ireland are explored in chapter 5, outlining different models.

1.4 Chapter 6 argues that advocacy should be a claim right in line with the social model of disability. There has been a paradigm change in moving from the medical to the social model of disability, in other jurisdictions, which disability academics have documented on the subject.[1] This change has reclassified disability firmly, as a human rights issue. With the evolution of civil rights legislation for disabled people such as the Americans with Disabilities Act (ADA), the legal paradigm has shifted from welfare law to civil rights law (Degener, Quinn 2000). Ireland however has not moved at a similar pace.

1.5 The 1990s in particular was a banner decade for disability law; more than forty nations[2] enacted disability discrimination laws during this period and new equality laws have emerged at the national, supernational and international level (ibid). This seismic change is evidenced in Ireland in two significant pieces of legislation – the Equal Status Act, 2000, and the Employment Equality Act, 1998 – where disability is named as one of the nine grounds under which people can claim to have been discriminated against. However, advocacy and the representation of interests have not been addressed with the same urgency as structural and employment discrimination law. This is perhaps due to the emphasis being placed in the realm of economic, social and cultural rights. Advocacy as being within the arena of civil and political rights has been neglected in social policy.

1.6 The fundamental rights of advocacy are freedom of speech, expression, assembly, representation and in a more formal sense, the franchise. All these rights are mirrored both in domestic and international instruments. According to Quinn (2001:21-July), existing UN instruments have considerable untapped potential and Ireland has international legal obligations with which it has to comply. Although geographically separate from Europe, we are clearly linked with the international community. In defining and framing advocacy, we must identify and utilise Ireland's international legal obligations. Clear links must therefore be drawn between Irish constitutional rights and international human rights in relation to advocacy. These links are drawn together in chapter 6, exploring rights, rights language and international treaties, to promote advocacy as a claim right.

1.7 It is clear that an alternate, inclusive model of advocacy is required. However, to borrow an analogy there is no need to reinvent the wheel. There are recommendations from the report *A Strategy for Equality*, and positive examples of legislated, funded advocacy systems in other jurisdictions. Chapter 7 examines two international systems, and suggests that we operate with those in mind. However, it is difficult to compare and analyse advocacy systems, as there is a lack of comparative research. To this end, alternate advocacy systems in Australia and Canada are both explored and documented in chapter 7. Proposals for statutory reform are suggested in the following chapter, which looks at the necessity for an independently funded and a structured advocacy system. Finally, recommendations for change are made in chapter 9, which proposes a radical change in policy and ideology in relation to advocacy for vulnerable disabled people in closed systems.

1.8 Conclusion

Fundamentally, Advocacy is a Rights Issue; it should be framed within constitutional and international human rights language and claimed within internal statutes. Vulnerable people within closed environments are international citizens and should be treated as equal citizens and accorded full citizen rights; including freedom of speech, expression, information and assembly. In an unequal system where some people have lesser rights than others, and legal protections are selective, advocacy is a necessary mechanism to name and claim those universal rights. Cooney suggested in 1994 that rights are neither self-inventing nor self-enforcing and if we really want people to know what their rights are, then we should spell out those rights. We should spell them out in a way in which all people can understand and benefit from.

1.9 Disabled people must take a leading role in their own empowerment process. That is not to say that professionals and friends cannot participate too – no person can operate alone – but support must be the support of solidarity, not oppression (Hurst, 1995). There is a necessity for anti-discrimination and pro-active legislation in relation to advocacy directed at those most vulnerable within our society.

2 The Concept of Advocacy

2.1 Introduction

2.1.2 The most common understanding of advocacy is the legal and trade union systems of representation on behalf of people by barristers, lawyers and union officials etc.. However, the concept of advocacy requires a broader understanding than the traditional formal models allow us. There is a danger that in calling for advocacy to be recognised in statute, it would be informed by a narrow formal focus and understanding. This could lead to an advocacy system being developed that is over professionalised and regulated, and could end up being elitist, exclusionary and overly intrusive in people's lives.

2.1.3 The aim of advocacy is not solely about the formal representation of others; it is equally about vulnerable people becoming empowered to become advocates in their own lives through training, education and life experience. Formal advocacy has a vital place, but should know its place as one cog in a large wheel. Systemic advocacy systems acknowledge the broader range of advocacy models and places the individual in the centre ('nothing about us without us') encouraging self-sufficiency and self-determination. If an advocacy system does not encourage these two components then it is not advocacy.

2.1.4 Any legislated advocacy system must be inclusive of all its members in multi-faceted ways. The Australian Advocacy system encourages systemic advocacy from a community developmental model. Effectively, this means promoting and supporting self-advocacy and local advocacy groups at grassroots level as well as the higher-profile patient, citizen and legal advocacy models. Local group advocacy and regional and national networks are all essential components in the development and evolution of systemic advocacy.

2.1.5 Poor definition of terms causes at least part of the confusion in any discussion on advocacy. Advocates and advocacy services need to be clear about what exactly they are providing and their advocacy roles. However, it is equally important, to know what advocacy is not.

2.2 Advocacy is:

I. Concerned with getting one's needs, rights, opinions and hopes taken seriously and acted upon. It allows people to participate more fully in society by expressing their own view points, by participating in management and decision making, and by availing of the rights to which they are entitled (A Strategy for Equality 1996:106).

II. Actively supporting a cause or issue; speaking in favour of; recommending; supporting or defending; arguing on behalf of oneself or on behalf of another.

III. Building the capacity of vulnerable people to develop the confidence, knowledge and experience base in which they can advocate for themselves, where possible.[3]

IV. Developing solidarity with other groups; especially those in more vulnerable situations whose voices are never heard or whose physical presence is never given expression.

V. Functioning (speaking, acting, writing) with minimum conflict of interest on behalf of the sincerely perceived interests of a person or group, in order to promote, protect and defend the welfare of, and justice for, either individuals or groups.

VI. Emphatic and vigorous and is actually, or is likely to be, costly to the advocate (Australian Advocacy Network).

VII. A political challenge to inherent systems and values, as it reasserts the power of the individual and collective who are often powerless within a system (Birmingham 2000:32).

VIII. Advocacy is both local and global, individual and collective, and a personal and political process.

2.3 Advocacy in basic terms:

I. Making informed choices, the right to say *'yes', 'no'* or *'I will think about it'*

II. The right to attend meetings about you.

III. The right to bring a person of your choice to a meeting, if you choose.

IV. The right to give and receive information.

V. The right to complain, speak up for yourself and/or others.

VI. The right to vote and to be registered.[4]

VII. The right to be heard.

VIII. The right to communicate in a manner culturally appropriate to you, and to have appropriate aids, equipment and interpreters if needed.[5]

IX. The right to formal or informal representation of your choice.

X. The right to have your presence and ideas respected.

XI. The right to participate in your own life and the life of your community, as an equal citizen and human being.

XII. The right to self-advocate and/or participate in groups.

XIII. The right to protest peacefully.

XIV. The right to freely express yourself in creative ways i.e. art, music, drama, body language or alternative mediums.

XV. The right to join a union, club or society.

XVI. 'Nothing about us Without us.'

2.4 What is an Advocate?

"An advocate would be a resource person, in enabling the client to name, blame and claim, if necessary, in the assertion of his or her grievance." (Cooney 2001:2).
However, Cooney emphasises it is important to be clear about what the elements of an advocacy relationship entail.

(a) The first element is the principal or client;

(b) The second is the advocate.

According to Cooney, the advocate does not replace the principle; but acts at the principle's direction. The principle's definition of these matters must shape the role and behaviour of the advocate. Clear conflicts of interests can become apparent where an advocate is an employee of a service organisation or a family member. The essential requirements of an effective advocate are ethical commitment to the client; diligent and fearless advocacy: independence; and appropriate knowledge and skills.

2.5 Broad Guidelines for Formal Advocates

I. The advocate should be carefully screened before appointment and receive adequate and ongoing training including experiential training as established by the relevant body.

II. Advocates must operate under a code of practice and receive ongoing structured support.

III. Advocates must have access to the people they represent (Rights of Entry) and with appropriate safeguards, their records. Closing off such access would quickly undermine an advocacy service (Cooney 2001:4).

IV. The advocate must be independent and objective.

V. Advocates should have no conflict of interest that may interfere with their ability to act on in the best interest of the person for whom they are advocating. An advocate must immediately remove himself or herself from a case or referral upon deciding objective and independent service may be affected.

VI. Advocates must be accountable to the person / group they represent.

VII. All advocates should acquire knowledge of the person / group's cultural, religious, social and ethnic backgrounds, as well as any extra or additional support requirements. Specific ethnic / minority groups should have their own advocates i.e. Traveller advocates, Deaf advocates.6

VIII. Advocates should have regular, face-to-face contact with the person and should communicate in an appropriate manner according to the person's requirements i.e. using language, special equipment /aids, sign, deaf advocates and language interpreters.

IX. The relationship between a client and his or her advocate must be confidential.

X. Advocates must be independent by statutory definition. The Act which sets up the Advocacy Service should contain a section which states that advocates are independent (Cooney 2001).

2.6 Standards of Practice for Advocates:

I. Wherever possible, the goal of an advocate is to enable the client to engage in self-advocacy.

II. Develop partnerships with clients to involve them directly in making decisions about advocacy activities and about advocating on their behalf.

III. Accountability to his or her client.

IV. Function in accordance with relevant legislation, policies, procedures, guidelines and directives.

V. Represent his or her client competently, responsibly, and in a timely manner.

VI. Act for the client in the least adversarial manner that is effective and adhere to the principle of least contest in the pursuit of advocacy activities.

VII. Take all necessary steps (including the use of an interpreter or alternate communication system) to communicate with people who are unable to communicate in the language of the advocate.

VIII. Maintain adequate records consistent with established documentation policy and which is agreed with client.

IX. Identify, and make the client aware of, individual, community, legal and family support systems as available when appropriate to the case.

X. An Advocate shall not assist a client to exercise legal rights, which the client does not have.

XI. Confidential information about a client or a former client should not be disclosed without the client's consent, except as required or permitted by law.

XII. Strive to improve his or her own skills, knowledge, and practice.

2.7 Three Overall Types of Advocacy (O'Sullivan,1987)

(1) Instructed Advocacy: Working with or on behalf of an individual person or group when instructed by the person or group.

(2) Non-Instructed Advocacy: Working on behalf of individual persons incapable of instructing an advocate, yet where there are reasonable grounds to believe there is a risk of harm to health, safety or rights of that person.

(3) Systemic Advocacy: Operates on an individual basis with groups to advance the systemic changes at governmental, economic, political and institutional levels. Systemic advocacy creates conditions in which disenfransised people can begin to assume ownership of their lives. It enables people to become active participants in their own life and the life of their communities.

2.7.1 Most people are aware of legal advocacy; which involves engaging with the legal process and its instruments i.e. judicial system, courts, barristers, lawyers and solicitors. However, as important and essential as formal advocacy is, it is important to lend equal if not extra weight to the lesser-known 'Social' model of advocacy,[7] or 'non-legal' advocacy, which entails speaking or pleading on behalf of others with vigour, vehemence and commitment, using non-legalistic resources. Unlike legal advocacy, social advocacy does not directly invoke or participate in the legal process to obtain the desired result.

2.8 The four principles of Social Advocacy (O'Sullivan, 1987):

1) 'Client-Centred' or 'instruction based.[11]

2) Administratively and fiscally independent of service providers.

3) Accessible and Accountable.

4) Not necessarily adversarial (working within a co-operative model where possible, rather than automatically engaging in an adversarial way).

The following chapter outlines different advocacy models, which are drawn from various sources in Ireland, US, Canada and Australia.

3 Models of Advocacy

3.0 Introduction

There are many different models of advocacy some of which overlap, including self-advocacy, peer advocacy, citizen advocacy, patient advocacy, legal advocacy, family advocacy, crisis advocacy, systemic advocacy, collective advocacy, and class advocacy. All advocacy models are political because they are about representing the interests of an individual, a group or a collective. Individual and collective advocacy types are not mutually exclusive. For example, a peer, citizen, patient or advocate seeking conscientiously to fulfil her/his role will endeavour to develop a person's ability to speak or act for themselves (i.e. to self-advocate).

Not everyone will wish or need to avail of advocacy and not everyone will be able to self-advocate. An older person with Alzheimer's, a very young child in care, a teenager with autism, a group of vocal disability activists or a very ill or vulnerable person may all require different models of advocacy: they may require citizen advocacy, legal advocacy, patient advocacy, collective advocacy or a specially appointed court advocate. It is important that not just one model of advocacy is promoted, recognised and resourced for this would exclude many for whom one particular model may not be appropriate.

3.1 Self – Advocacy:

3.1.1 Any self-determined action by any person, without the intervention of another person, no matter how small may be looked upon as self-advocacy. This means looking at self-advocacy and communication systems in a more broader and creative way, other than only through verbal communication systems. A person can self-advocate through a blink of an eye, by signing, moving their head or through art or music. One need not be a member of a group to self-advocate.

3.1.2 Self-Advocacy is where individuals use:

a) A process through which individuals represent their own specific needs and concerns to: Improve their own circumstances and establish their civil and human rights.[8]

b) Mechanisms to change the social attitudes that lead to discrimination against them.

c) The development of skills necessary for an individual to express their views to the fullest possible extent (A Strategy for Equality 1995:26).

3.1.3 The Benefits of Self-Advocacy are that:

(a) It allows people the space to name their own world and experiences in their own way.

(b) It can lead to employment / educational / economic / social & cultural opportunities.

(c) It can lead to a greater sense of self, increased confidence and can be a prerequisite for other models of advocacy.

3.1.4 It is important to recognise that support systems are vital for all forms of advocacy, and in particular self-advocacy. According to Cooney (1994:21), self-advocacy is vital but meaningless unless it involves a person being empowered to demand their rights and right to self-determination. Some people can become ill through stress, isolation and pressure if left to constantly advocate on their own; either within the public or the private sphere. Often the most prominent, articulate advocates are constantly called upon to speak, representing either themselves, or a particular issue, and this pressure can lead to burn-out and illness without a support network.[9]

3.2 Group Advocacy:

3.2.1 Group advocacy evolves from self-advocacy and is a prerequisite for the stronger and more political coalition and collective advocacy. It involves a process through which, individuals acquire and develop the skills and confidence to represent their own needs, concerns and interests within a group setting. An important aspect of this model is the resources of a group of advocates are stronger than an individual and thus can provide invaluable support systems for individual advocates.

3.2.2 For group advocacy to survive, support may be required in the form of:

a) Accessible premises (a safe place to meet).

b) Transport (if required).

c) Personal Assistants (if required).

d) Group-work skills (training and knowledge of group dynamics).

e) Funding.

f) Training and capacity building strategies for individuals and the group.

g) Support mechanisms & structures.

h) Administrative back-up.

i) A Facilitator (should the group require it – but the power dynamics should be firmly rooted and owned by the group).

3.2.3 Group Advocacy also requires:

a) A democratically elected chairperson, secretary and treasurer.

b) Ground-rules and a code of practice to ensure parity of esteem within the group.

These are all elements of the formation and maintenance of group life. Some groups function more informally and with less structure than others. It is up to the group members to decide what type of group they wish to have, and what works best for them. There have been many vibrant advocacy groups, which have fallen by the wayside, through a lack of support systems, human or financial (i.e. The Advocacy Ireland Movement). There are also many service-system and independent advocacy groups currently struggling to survive without resources or recognition.

3.3 Peer Advocacy:

3.3.1 Peer Advocacy is user-led and user-run only. This model is where one person advocates with / and on behalf of, another who has in the past, or is currently, experiencing similar difficulties or discrimination. Power dynamics are more equal in peer advocacy, because both parties have experienced and struggled through similar issues and experiences, have been in similar situations and shared similar labels. This is its greatest asset and can be a very safe and empowering model of advocacy. Peer Advocates are experts by experience.[10]

3.3.2 One practical example of peer advocacy is where a person may request Electro Convulsive Therapy (ECT) and ask a peer advocate to support them in their request. The psychiatrist may be reluctant to give this form of treatment and the peer advocate may be personally against ECT. However, the peer advocates role is to advocate what the person wishes, not what they themselves wish. An advocate's personal baggage must be left outside the door to represent the principle objectively. In this situation, the peer advocate can provide literature and information on ECT to the person, in order that they may make an informed choice. On reading all the relevant literature, and discussing it the person may still decide that they wish to have ECT. On this informed basis, the peer advocate can go into the meeting and support the person fully in their request. The aim is to provide support, not to judge or make the final decision.

3.4 Family Advocacy:

Family advocacy is an independent, community-based social advocacy model, which at its most effective can work at a State Level. NAMHI[11] is a powerful and effective example of collective family advocacy at this level. Most of the people involved in family advocacy are themselves parents or relatives of a disabled child or adult. They deal with the day-to-day issues which all families face. Other people involved are people who have a disability themselves or are allies to the empowerment of families.[12] Family advocacy can also operate at an individual level, where an individual family member/s advocate on behalf of, or represents another member of the family. This form of advocacy is very common especially in relation to people with learning disabilities[13,14] children and older persons but is extremely open to conflicts of interest within the family, especially in relation to dependency and asymmetrical positions of power.

3.5 Citizen Advocacy:

"Citizen's Advocates, independent of service providers, should be trained to help people not in a position to defend their rights"
(A Strategy for Equality 1996:98)

3.5.1 Citizen advocacy is a partnership between two people; the client and the independent Advocate. It refers to the persuasive and supportive activities of trained selected volunteers and co-ordinating staff, working with and on behalf of, people with disabilities who are not in a good position to exercise or defend their rights as citizens (A Strategy for Equality, 1996:106). Citizen Advocacy aims to increase the number of people who choose to relate to people voluntarily and without any pay. According to Hemphill, (Wertheimer 1998:8) it is connecting with someone who is devalued helping to ensure that the person is not lost in 'the system'.

3.5.2 Citizen advocates should be independent of service providers, potential service providers and families in order to avoid any conflicts of interest in terms of loyalty. Working on a one-to-one basis, citizen advocates attempt to foster respect for the rights and dignity of those whose interests they are representing. This may involve helping the person express his or her concerns and aspirations, obtaining day to day social, recreational, health and related services and providing other practical and emotional support to him or her (A Strategy for Equality1995:106).

3.5.3 This model links people with advocates who will help them to communicate for themselves or communicate with them on their behalf (Wertheimer 1998) and should be supported by, but independent of, the advocacy network, ensuring that the primary loyalty and accountability is to the person they represent. With its mission to empower disadvantaged individuals and groups, citizen advocacy presents a challenge to the power, role and status of professionals (Simons 1993). As challenging that power can be viewed as undermining the raison d'être of the professional, it is not surprising that a range of negative responses are often called into play such as:

1. The refusal to recognise the right of citizen advocates to represent people on the grounds that they lack the necessary knowledge and expertise to offer appropriate assistance.
2. The adoption of strategies designed to subvert the effective working of citizen advocate programmes (e.g. exclusion from relevant meetings, reviews etc).

3. The claim that the advocacy role is already being adequately covered by existing services (Simons 1993:52). This can take the form of key workers or other service-professionals who ‘have advocacy’ as an appendage to their role.

It is important to note that the above negative responses are also applicable to peer advocates when *presenting* in powerful systems.

3.5.4 Abandoning the Volunteering Principle in Citizen Advocacy (Jackson 1991)

An alternate view of citizen advocacy challenges the fundamental core concept that citizen advocates are unpaid and work voluntarily. Jackson proposes that the volunteering principle should be abandoned for the following reasons:

3.5.5 The original role envisaged for citizen advocates (writing letters, making phone calls, accompanying people to meetings) were relatively straightforward. However, in practice, the problems brought to a citizen advocacy service are extremely complex in nature. This in turn means more time is needed to disentangle the various strands, establish the facts as far as they can be accurately determined and to identify the key issues. Due to time pressures, few citizen advocates are able to take on more than two or three cases. This in turn means it is difficult for volunteers to acquire expertise in any one area.

3.5.6 There can be difficulties in finding volunteers with the ability and time to pursue lengthy and involved cases, and who are available to attend meetings and reviews during the course of the working day. If volunteers do not have the knowledge, experience or time required, and have to constantly refer back to the advocacy service, it leads to delays in processing cases quickly. This is not in the best interests of the person or service, particularly in situations where there is a crisis and a need for a quick response. According to Jackson (1991), this may lead to a damaging and public perception of an amateurish organisation if long delays are evidenced and people have not the experience, knowledge or skills to proceed independently.

3.5.7 Critics of paid citizen advocates will argue that a more professionalised service flies in the face of orthodox views of advocacy. However, Jackson (ibid) argues that purists have underestimated the extent to which some statutory services are prepared to frustrate and subvert the effective operation of lay advocacy services. The simple truth is that no professional group will ever willingly relinquish power – especially the medical profession, through which many referrals and queries are traditionally made. The argument for paid citizen advocates is that, only by becoming more professional will advocacy services successfully empower clients. Jackson ends his thesis with the argument that, 'realpolitik and not ideology should dictate the future shape of advocacy services'.

3.5.8 Usually within established citizen advocacy systems, there is a paid co-ordinator and administrator, and the advocates are fully trained, supported and accountable. While acknowledging Jackson's theory, there is a danger that if all citizen advocates are paid the service will become another meritocratic, credientialised service and will eventually alter the power dynamics of the citizen advocate relationship.

3.5.9 Citizen Advocacy is not:

- A befriending scheme: The advocate's role is to represent their partner's interests.
- Professional Advocacy: It is not part of the hospital / institutional care system.
- A Campaigning group: The focus of citizen advocates will be on fostering individual partnerships although where appropriate, an individual advocate may want to campaign on behalf of the person they are representing.

3.6 Service System Advocacy:

3.6.1 The 'service system model' is based within the services in which people live and work (institution, residential centre, hostel, workshop, day-centre, hospital, nursing home). This type of advocacy is initiated and supported by the service system. It is therefore, largely dependent on the service, the staff, resources and support of the service.

3.6.2 Limited available research has shown that this is the most common model of advocacy for people with learning disabilities, in the UK and Ireland (Travis 1994, Crawley 1988). Ten to twelve members within a service, meet for one-two hours a fortnight, with minimal staff support and no resources typify it (ibid). There are many problems inherent with this model, apart from its dependence on the service. It is generally exclusive and selective in its membership. A common characteristic is that members reflect the more able and articulate service users, and knowledge and experience are centralised on a particular few. When members or staff leave or groups end, the knowledge and experience base is depleted.

3.6.3 As this model is dependent on the service, the staff, resources and support of the system, it is compromised in terms of neutrality and autonomy. There is also an issue as to how a service and its staff prioritise advocacy; it is up to the service provider to fund and resource this model. Advocacy in Ireland in 2001 is not a right within services, but seen only as an extra option for staff to provide. It is often the case with service-system advocacy that, if a member of staff who was primarily involved in the group's formation and maintenance leaves, the group can be open to fracture and disolvement. Advocacy as a system must be more secure than the individual staff players on which this model is dependent.

3.6.4 Power dynamics are weighted heavily in favour of the service system as opposed to the advocates. There is a sense that services are able and willing to respond positively to the views of service-system advocacy groups in "softer areas", such as social activities and less progress in "harder" issues including a Charter of Rights (Travis 1994:3). Because of all these factors, the dominant service system model of advocacy can both de-politicise and colonise both advocates and the advocacy movement because of their dependency.

3.7 Professional Advocacy:

People who are paid to provide a particular advocacy service (this can apply to formal advocacy enshrined in statute, where advocates are appointed by an Advocacy Commission (ref. 7.24, chapter 7) and an Advocacy Commissioner) They are experts by training and not necessarily through direct experience.

Professional advocates can also be lawyers, barristers, elected representatives, ombudsmen, and the large variety of non-legal professional advocates attached to public and private services.

3.8 Service Professional Advocacy:

3.8.1 Service professionals represent the nurses, doctors, social workers, para-medics, caseworkers and others who have advocacy as part of their role and intertwined with their occupation. This model of advocacy is open to major conflicts of interest. The majority of service-professionals answer to their managers, and therefore can not be partisan, which is the core essential ingredient of an advocate.

3.8.2 An example of role-conflict within service professions is a caseworker presenting a case at a meeting in the absence of their client or the principal person, and without prior consultation or feedback afterwards to the client. It is not advocacy when the client is not at a meeting – either by their physical presence or through their ideas – during which they are being discussed. Advocacy is not a service professional's opinion on a client, or how they perceive the best way forward for them. Advocacy is about what the principal person wishes and believes.

3.8.3 It must be acknowledged that there are many good service staff, who advocate or attempt to advocate on behalf of the people for whom they work. It is important to acknowledge this and their imput, which is often at a personal cost, in terms of building a community of allies. However, advocating an unpopular stance within a powerful organisation on behalf and with a client can lead to a lack of promotion or being sidelined. Advocates themselves can become ill through stress when not supported or if continually operating in situations of conflict. It is important to note that a service professional advocating on behalf of a client in a closed system, can be seen as a whistle blower and treated as such. Therefore, apart from conflicts of interest and stress, advocacy is not generally seen as a 'career-enhancing role' within hierarchical environments, excepting where it is explicit, independent and central to the professional's role i.e. legal or union advocacy.

3.9 Crisis Advocacy:

Tends to be a one-off involvement centred upon a particular task or specific situation.

3.10 Complaints Advocacy:

Assisting individuals to pursue complaints within and about particular service. According to the Commission's Final Working Report (1996:26), the provision of advocacy is essential to the effective operation of complaint procedures.

Both crisis and complaints advocacy can be formally undertaken in their own right, or informally as part of other models of advocacy. It is helpful to classify what form of advocacy is being undertaken, for clarity of purpose and practice.

3.11 Collective /Class Advocacy:

Collective advocacy is where people come together to campaign on issues relating to a specific group of people and is sometimes referred to as ‘systems advocacy’. This model often develops out of a number of individual advocates from small advocacy groups joining together. The main aspect of this model, is that the groups act in a collective manner rather than in an individual or an isolated group way. This form of advocacy gains political strength and bargaining through its collective power. Black Power, Gay Pride, the Women’s Liberation Movement, The Civil Right’s Movement, The Traveller’s Movement and The Disability Movement are all forms of collective advocacy, which involve target audiences who experience similar oppression or discrimination. ‘People First’ is a practical example of international collective advocacy, specifically made up of people with learning disabilities.

The positive outcomes of collective disability advocacy organisations can be observed at all levels. The benefits include provision of accurate grass-roots level information on issues pertaining to everyday life for disabled people and at State level in terms of policy formation. Another benefit is that collective advocacy groups are more effective numerically in campaigning and in being involved with direct action.

3.12 Coalition advocacy:

Coalition advocacy brings together groups to share diversity to promote a greater sense of solidarity and a stronger power base for campaigning. It provides for a larger and more diverse group, which adds legitimacy, increases political power and improves the ability to generate funding. Solidarity and support from the common experience of being oppressed is what different groups can offer, both theoretically and politically through their presence. Partnerships can be defined in this way.

A critique of coalitions is the danger of a group being overpowered or sidelined within a powerful coalition (A Strategy for Equality)

3.13 Patient Advocacy:

3.13.1 There are occasions where a person resident in a hospital whose thinking may be disordered, and whose assertiveness may be impaired through illness or unequal power dynamics, who may wish or require the support of an advocate in raising concerns. It is crucial that the patient advocate is independent of the health care facility so they can, without conflict of loyalties, assist the person in putting forward their view, and not be compromised because they are funded through the health service or departments of health.

3.13.2 According to Lowson, (MIND, the mental health charity UK in NDA 2001:33) there are five basic stages or elements to the advocacy process. These are:

1. Regaining a right and capacity to exercise choice (sometimes lost through illness and associated experiences)
2. Exploring options
3. Making a choice
4. Finding a voice
5. Getting a response

The primary task of the patient advocate is to facilitate the person in moving through the five basic stages, in relation to any one or number of things that may be of concern to her/him. These can range from matters concerning treatment, therapies, medications, detention, commitment, release, discrimination, aftercare, denial of rights, choice of doctor, to social welfare or income benefits, family (or other) relationships, sexuality and domestic concerns. The second task of the independent patient advocate is to help redress the power disparity between the patient and the other stakeholders in the mental (or general) health service (ibid). These tasks can be generally applied to all advocates and not specifically patient advocates. However, specialist knowledge and information is essential in specific areas.

3.13.3 In relation to mental health an advocate must have knowledge and training about the service system. For example:

I. Categories and principles of Admission whether voluntary, temporary or under a person of unsound mind category (PUM).

II. Admission procedures.

III. Detention rights.

IV. Statutory rights and rights under the Mental Health Act (patient has no statutory right to be told of such).

V. The right to information.

VI. Doctors and certification.

VII. Consent to treatment.

VIII. Treatment and Medications.

IX. Transfer to other hospitals.

X. Discharge.

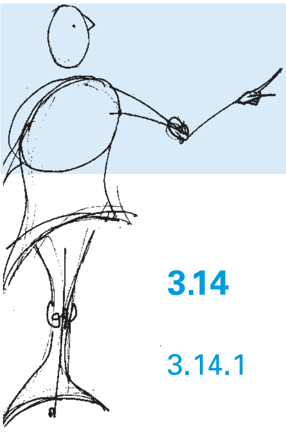
XI. Civil action in connection with detention (Keys, Advocacy in Action: A legal Perspective, 2001).

3.13.4 Promoting patient's rights must inevitably mean an adversary approach on occasion with administrators and carers. The importance of an adversarial function would be diminished without independence (Cooney 2001). Therefore, the emphasis must be laid on the independent nature of a patient advocate. This form of advocacy is usually derived from a patient's charter or through legislation i.e. within a Mental Health Act. To its complete shame, the new Irish Mental Health Act, signed by the President on 8 July 2001, to be known as the Mental Health Act 2001, contains no reference to patient or peer advocacy, which is the statutory basis for advocacy within Mental Health Services.

3.13.5 Persons facing involuntary detention in a psychiatric hospital have vital human rights at stake. They may be deprived of their personal liberty and be subjected to unwanted intrusive treatment. They may lose their capacity to control their property or financial affairs. They may be forced to surrender their personal lives and experience disablement and stigma. In hospital they may become institutionalised and dependent, and have their assertive abilities undermined. The interests at stake are fundamental. Recognising them is the starting point because it is the need to safeguard basic human rights that justifies the creation of an advocacy service (Cooney 2001:4).

The advocate would require statutory guarantees of access to information about the policies, procedures, and programmes in hospitals and units (ibid). The advocate would need complete access, on the individual's instructions, to the medical and social records of the individual, and an opportunity to participate in discussions of the individual's case, especially when decisions affecting the individual's care and treatment are to be made. The advocate would require statutory rights of access to be heard by decision makers[15] (ibid).

3.13.6 Many disabled people within general hospitals, nursing homes and other residential centres and institutions (private and public), are also vulnerable in relation to treatment, discharge and procedures (albeit non-legal) as highlighted by Cooney. This is especially true for the more vulnerable older person, without family or direct relations, or people with learning disabilities who are warehoused within psychiatric hospitals and residential centres. Even in situations where people have family, there can be conflicts of interest in relation to personalities, roles, property or interests. If the person in question is frail or vulnerable and unable or unwilling for various reasons to assert their rights and views, an independent advocate is essential in safeguarding their interests.



Independent advocacy should not be restricted to Mental Health facilities but accessible to all vulnerable persons, in all types of hospitals, residential centres and institutions.

3.14 Ethnic Disability Advocacy:

3.14.1 Specific ethnic disability advocacy is vital because this doubly disadvantaged group can experience marginalisation and isolation as a result of disability, language and cultural differences. There is an increasingly hostile environment of racism in Ireland and emphasis on assimilation as a public policy. Ethnic disability advocates would assist in terms of cultural identity.

3.14.2 This model is relatively more expensive because of the needs of its constituency, because it requires additional resources to cover extra costs in translations, interpreting, public and community promotions etc. (National Ethnic Disability Alliance (NEDA) Australia)

3.15 Traveller Advocates

3.15.1 Travellers with disabilities can experience multiple folds of discrimination, and can have particular difficulties with service providers. This can be due to a failure to understand Traveller's culture and background (Cousins 1995:36, submission 502). Service provision for Travellers can be delivered in a very racist manner and advocacy can be a determining factor in instilling a sense of pride in people who have been damaged badly by a system (Mc Donagh, 2001).

3.15.2 There is a need to abandon the assimilationist approach because it has failed (Collins 1997:18). A Disabled Traveller child who has been within residential care may have identity problems when they leave and feel they belong to neither the Traveller nor the settled community. Traveller advocates are one way for this minority group to safeguard their own rights and cultural identity and are essential in addressing the lack of Traveller representation within services. Advocacy can also be linked to in-service and anti-racist training for service providers (McDonagh).

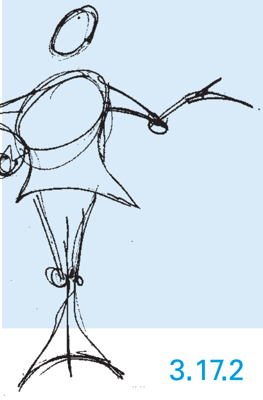
3.15.3 The working papers of the Commission suggested the development of programmes and provision of earmarked funding for the employment of Traveller advocates, which would be provided and controlled by Traveller groups (Final Report 1995:36)

3.16 Legal Advocacy:

3.16.1 Legal Advocacy is the most well known and familiar model of formal advocacy. This is where lawyers, barristers and other legally trained individuals assist persons to exercise their rights through the courts and legal system. This can involve getting new legislation passed, representation before tribunals and agencies (including criminal and civil courts) and monitoring compliance with existing laws and regulations i.e. the Constitution, the Equal Status Act, 2000 and the Employment Equality Act, 1988. This kind of representation may also be referred to as 'Formal Advocacy'. Informal systems of advocacy and representation should never replace the formal legal systems. The Forum of People with Disabilities suggests that both systems should compliment each other and co-exist to their mutual benefit and to the benefit of those most vulnerable.

3.16.2 The Commission's report (A Strategy for Equality 1996:107,4.49) recommended that funding should be provided to the Legal Aid Board to ensure that people with disabilities can employ an advocate to access expert legal representation, where necessary. However, the progress report diluted this *to consideration in the context of the Board's annual funding* (Towards Equal Citizenship 1999:46).

3.17 Guardianship



3.17.1 The law relating to consent is of fundamental importance to advocacy as a concept, as it serves as a means of protecting and preserving the right of a person to decide what is to happen to him or her.[16] In some circumstances the consent issue is complicated when, due to varying factors, a person is unable to consent on their own behalf. This is a fundamental issue for advocacy and the development of an advocacy service. The role of a guardian and the role of an advocate need to be clear; they are not mutually exclusive, but are also not necessarily mutually compatible.

3.17.2 In the case of minors, the common law provides that the parents or guardians have decision-making power, to be exercised in the context of the child's constitutional rights. In relation to those with a 'mental incapacity' however, the position is less clear. The fact that a person is assessed as being competent to make certain straightforward decisions does not necessarily mean that they are competent to make a more complex decision (Madden 2000).

3.17.3 However, it is possible to improve an individual's ability to satisfy a capacity assessment if action is taken to work with them. This is very important as developing a person's capacity gives due respect to their right to self-determination and to self-advocate. Gunn (1999) has demonstrated (through a research project in the UK) that for certain individuals who are unable to consent on their own behalf, their capacity may be improved by the use of simple language and non-verbal presentations. This indicates in terms of advocacy provision and the right to self-determine, alternative strategies for determining capacity ought to be developed. The use of pictorial representations can enable some participants to move from being labelled 'incapable' to being 'capable' (Madden, 2000). This would have cost implications as extra and additional resources are required in terms of time and developing alternate processes. It is one example of where differing models of advocacy could and should co-exist effectively (i.e. legal and social models). An advocacy system should not be territorial, but operate generically to the benefit of the person at the centre.

3.18 Alternatives to personal consent

3.18.1 If a person is assessed and deemed not to be competent, then there are a number of advocacy alternatives that may be applicable. A person who is made a ward of court establishes the President of the High Court or the Circuit Court as the person's legal guardian. This means that no important decision in relation to that person may be taken without the permission of the Court. The court will appoint a wardship committee to secure the day-to-day welfare of the person, including giving consent to medical treatment (ibid).

3.18.2 It appears from some of the case law in the area of guardianship, that the individual's best interests may have been confused with the needs and desires of the carer's (ibid). This conflict of interest may be around areas of sexuality, parenting, medical procedures as well as choice of living space and independent care arrangements. It is clear that conflicts of interest may also arise with legal guardians in relation to capacity and advocacy. Social advocacy in these situations has an important role to play in protecting and promoting the civil rights of an individual and in complimenting the legal system and Guardians.

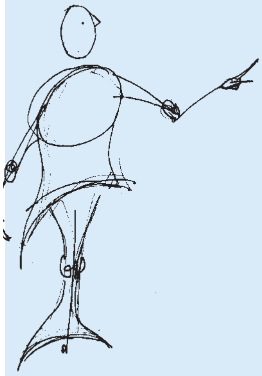
3.19 Advocacy for Children

Some examples of legal advocacy specifically for vulnerable children in care are explored in this section:

"One of the many shocking findings is the frequency of inappropriate and destructive intervention by the state...We are the state, we are responsible. We have failed vulnerable children and families in the past and we are failing them now. We are all on trial and we must do the honourable thing and plead guilty."

Ref: John Lonergan (Governor of Mountjoy Prison, commenting on the report in Focus Ireland 2000 '*Left Out On Their Own*')

3.19.1 Lonergan in the opening quote; acknowledges that we all have a part to play. We are all agents of power by design or default. An oppressive system is only as effective as the agents who work within it, and who collude in their silence. Often the children we as a society have failed can end up as adults, within the prison system with mental health difficulties[17], addiction problems and in poverty.[18] It is also the case that we as a society are still failing disabled children educationally,[19] socially and culturally, through a lack of equality in educational provision and support systems.



3.19.2 The issue of representation is currently hot on the political table in the light of the Nice Treaty referendum (2001), the EU and increasing levels of societal political apathy. In terms of recognition, and advocacy, where children are not afforded or given an equal, independent voice or space, society can not be surprised when as adults they are disenfranchised politically. Children, especially those vulnerable within care and legal systems require an independent voice. They require a systemic advocacy system, which includes both formal and social advocacy. Children should have equality of access to the same models of social advocacy as adults to articulate and/or express their own individual views and opinions. They must be given resources to develop and nurture as individual human beings, not as appendages; or viewed as the property of parents or care or legal systems. The next section will explore the formal representation of children in legal proceedings:

3.20 Guardian Ad Litem (GAL)

A Guardian Ad Litem (GAL) is someone who is appointed 'a guardian for a law suit'. This is a temporary appointment, which ends when the court's proceedings are finished. Currently, there are no parameters to guide the Irish courts or individuals appointed as guardians ad litem, and no supervision or accountability.[20] The Guardian Ad Litem Groups report (Giving Children a Voice, 2001) is very welcome in the sense that it recognises that children must be afforded separate independent legal representation in legal proceedings just as their parents are. It acknowledges that children are separate independent legal entities in their own right. This report recommends amending Article 41 of the Constitution, which lacks a child focus and fails to recognise the child as a juristic person with individual rights to which separate representation must be given (ibid:11).

3.20.1 Legal advocacy is distinct from family advocacy, and during adversarial proceedings, parents are not neutral. Advocacy as suggested by the report (ibid) in the form of GALs, would be a welcome event in an adversarial system. A child faced with any bureaucratic system, whether in welfare, residential care, school, hospital or detention centre requires someone to guide them through the complexities. In essence, the child needs an independent advocate to compliment other mechanisms. However, the GAL has no authority and no role in a continuing involvement in child welfare or family law cases, beyond a hearing and resolution of the legal solution (ibid: 36). This reinforces the need to look upon advocacy systems as broader than the purely formal. A generic advocacy system would allow an independent advocate for the child, with a GAL if required, during legal proceedings and after they end. The two forms of advocacy, social and legal, could co-exist to the benefit of the child and each other.

3.20.2 This point feeds into the larger and controversial issue of family advocacy, guardianship and vulnerable people – including adults – in general. In situations, (where the custody of a child is in question; or the suitability or ability of the parents to care for an adult is in question) a separate independent advocate is necessary. They could aid the child / adult through a quagmire of emotional conflict and an extremely difficult legal process. Parents and services are not neutral in these situations; both have their own vested interests as well as the child's / adult's interests. What is needed therefore, is a person(s) capable, accountable and neutral to focus on the child / adult, and what they want and need.

3.20.3 The lack of advocacy and representation for children can contribute to a legacy of inequalities as highlighted in research from the Focus Ireland report *'Left Out On Their Own'* (2000)[21]. It is very difficult to break the cycle of poverty and deprivation that children who are neglected find themselves in, especially in the case of disabled children, because support systems, including advocacy, are not in place.

3.20.4 Advocates (GALs) and an Autonomous Accountable Advocacy system would help redress the unequal representation of all vulnerable children and by default systemic power bases and operational policies within services. Purely on a developmental level, the cycle of neglect has to be broken.

3.21 CASA (A Court Appointed Special Advocate)

3.21.1 A CASA is a lay volunteer that is selected, trained, supervised and who is appointed to advocate for the best interests of the child. CASAs undergo extensive training and background checks to become certified to work with children who are involved in court proceedings. After the training and certification is completed, the volunteer is sworn in by the Court to serve as an officer of the Court. The CASA should be appointed as soon as possible in the proceedings and should remain involved until the child is in a legally sanctioned permanent placement and the case dismissed by the court system.

3.21.2 The CASAs role during the initial stages of a case, prior to adjudication, is to gather facts related to the child's past and current situation. The

CASA shall have the same access to information related to the child and the child's situation, as would the GAL for the child. The CASA is also allowed to interview the child, parents, social service staff, law enforcement personnel and any other individuals who have knowledge of the child. When it is time for a trial or hearing in court, the CASA can be a friendly, neutral person that the children can rely on for comfort in the unknown setting of the courtroom.[22]

3.22 Office of Ombudsman for Children

An independent Office of Ombudsman for Children is yet to be created, with responsibilities to promote the welfare and rights of children generally, to investigate complaints, consult with children and promote awareness of the UN Convention on the Rights of the Child.

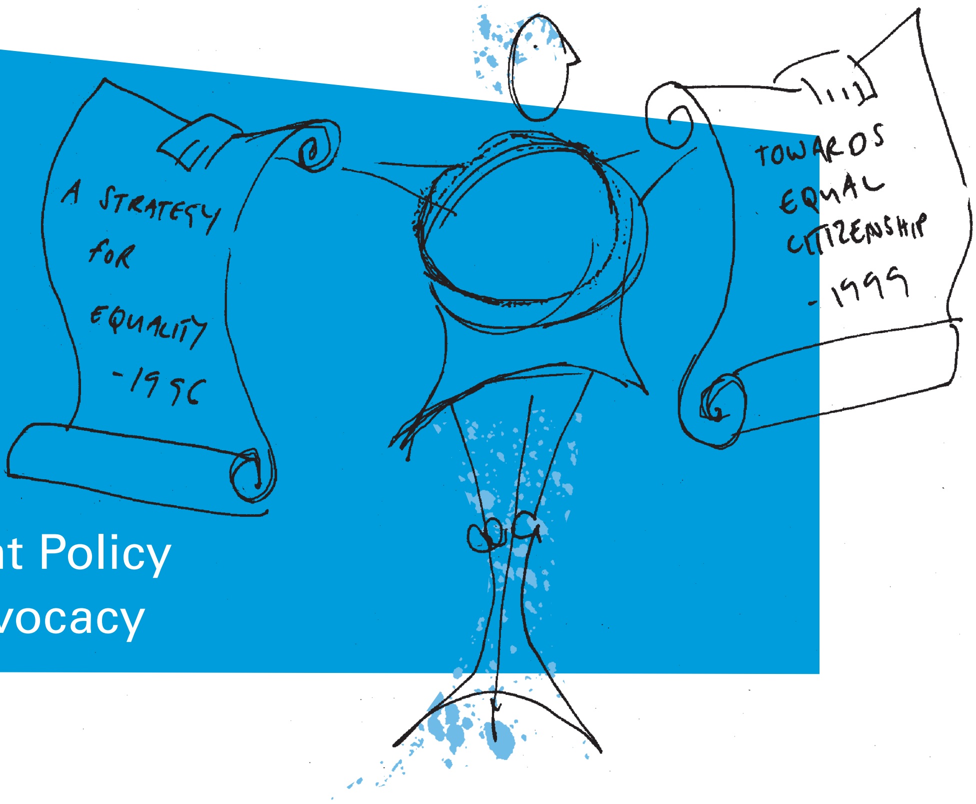
3.22.1 Government Commitment on Children's Rights: Following the launch of the National Children's Strategy in November 2000, an initiative intended to progress implementation of the UN Convention on the Rights of the Child in Ireland, a number of new structures have been created. These include a Minister for Children, a Cabinet Sub-Committee, a National Children's Office and a National Children's Council. These three structures are welcome and will serve to promote and safeguard the rights and representation of children in Ireland. However, more work remains to be done to ensure that all children, and particularly those most vulnerable[23], realise their rights under the UN Convention (Dooley 2001c). Comprehensive advocacy systems are a fundamental tool in ensuring this process.

The UN Committee on the Rights of the Child has recommended that Ireland incorporate the terms of the UN convention into Irish domestic law and implement the recommendations of the Constitution Review Group to amend the Constitution in relation to children's rights[24]. In response, the Irish Government has asked the All Party Oireachtas Committee on the Constitution "*to prioritise its consideration of the issue of the constitutional underpinning of individual children's rights*" (Dooley, 2001b).

3.23 Accessing advocacy systems for children

3.23.1 To conclude, there has been enough media coverage of the mistreatment and injustices meted out to children in care in Ireland, (including disabled children) past and present, to indicate the need for advocates who are independent of service providers, families and other interested parties. Legal representation alone does not cover daily life within hostels, detention centres, institutions, hospitals, families and schools where problems and conflicts of interests can occur. There is a fundamental need for Government to look to a model of Autonomous Accountable Advocacy, in which GALs and/ or CASAs play a fundamental part but are only one advocacy component. Children should have equality of access to the full range of advocacy models proposed throughout this document. What is required is a generic system of advocacy, within which, specialist models can co-exist and operate.

The next chapter explores current policy on advocacy, drawing upon statutory reports, making recommendations for effecting change.



4

Current Policy on Advocacy

4.0 Introduction

This chapter refers back to the 1996 report of the Commission on the Status of People with Disabilities *(A Strategy for Equality)*; the working papers that informed it, and the progress report in 1999 *(Towards Equal Citizenship)*. As these reports are statutory, they provide invaluable guidelines; for both government to progress social policy, and for NGOs to monitor progress. Clear recommendations were established for advocacy in 1996, after the consultation process. This document is animated by a concern about the absolute political failure to turn the recommendations of the Commissions report into reality.

This chapter explores in 2001, what progress has been made on those recommendations to date in relation to advocacy.

4.1 Background to the Commission

4.1.1 The Commission on the Status of People with Disabilities was established in November 1993, with much hope and optimism. Its remit was to advise the government on the practical measures necessary, to ensure that disabled people could exercise their rights to participate, to the fullest extent of their potential in economic, social and cultural life. One term of reference within the consultation process, was to make recommendations setting out necessary changes, in legislation, policies, organisation, practices and structures to ensure that the needs of disabled people are met in a cohesive, comprehensive, and cost effective way (1996:iii). *A Strategy for Equality*, the report of the Commission, received 600 written submissions from disabled people. It held 30 listening meetings at ten centres around the country, as well as locations in and around Dublin. The report contains 402 recommendations, nine of which directly relate to advocacy. The Commission submitted its Report to Government in 1996. These recommendations, as well as the Governments progress and response to the Report are detailed in this chapter.

4.1.2 The progress report (*Towards Equal Citizenship*, 1999) is a useful tool and indicator in examining what model of advocacy (if any) is being applied or that government and /or the legislature is striving to apply, from the 1996 Commissions report. Both reports provide a tangible barometer for disability rights-based organisations such as The Forum of People with Disabilities, to act as a watchdog for legislators and policy makers in areas of progress or indeed lack of progress on issues. However, these reports were compiled in 1996 & 1999, and times have changed. While this section chases up most of the recommendations from the report, it also suggests the inclusion of additional ones drawn from other statutes and legislatures.

4.2 A Strategy for Equality (1996)

4.2.1 The report of the Commission (1996) took on board most of the proposals from the submissions in the working papers, which detailed the results of the consultative process. It recognised the independence of advocacy services, acknowledging self-advocacy, citizen advocacy, patient advocacy and legal advocacy. The Report also stated that proper implementation of many of the Commission's recommendations is dependent on the availability of effective advocacy services.

4.2.2 As a reminder, the main recommendations in relation to advocacy were as follows:

- Advocacy Services should be independent of service providers (*A Strategy For Equality*, 1996: 106,4.47).
- Independent advocacy services should be mandatory in residential care settings or similar services (ibid: Recc.33, pg.19:4.7).

- The provision of advocacy should be incorporated into any legislation dealing with particularly vulnerable people in residential settings (ibid: Rec. 48, pg.20:4.49).
- The recognition of different forms including self-advocacy, citizen's advocacy and patient advocacy. Representation is taken to mean representation by a professional advisor, such as a lawyer (ibid: pg. 106:4.43).
- Education and training in self-advocacy should form an integral part of the curriculum followed by people with disabilities (Rec. 32, pg. 19:4.7) This should be linked to other measures such as representation in management and decision making. Funding for such measures should be included in the budget of all publicly funded education and training schemes (ibid: Rec. 32, pg. 107:4.49).
- Self-advocacy, should, where appropriate, be supplemented by the provision of citizen's advocacy and Funding for such a service should be provided by the Department of Health / Social Services (ibid: Rec. 47, pg. 20:4.49).
- The commission suggested a range of measures should be adopted under a proposed charter of rights, which would include the right to advocacy and representation.
- The post of advocate needs to be established by statute (ibid: Rec. 382, pg.32).
- Funding should be provided by the Legal Aid Board to ensure that people with disabilities can employ an advocate to access expert legal representation, where necessary (ibid: Rec. 49, pg., 20:4.49).

The above recommendations were compiled out of a two-year consultative process, which produced a broad range of working papers. Most of the advocacy recommendations from these papers were taken up within the main Commissions report, as outlined in the previous section. However, three recommendations, from the working papers, not included in the report are recalled in the following section:

4.3 Recommendations Recalled from the Working Papers 1995 (Cousins: 1995)

4.3.1 *'A well resourced independent citizen advocacy movement' (ibid:33, 28)*

While Citizen Advocacy was recognised in the 1996 report (*A Strategy for Equality*), the words 'well resourced' were omitted. This effectively removes a commitment, for funding, from government. It is therefore a recommendation without any teeth. Also, the working papers did not specify placing citizen advocacy under the Dept. of Health and Social Services remit as the Commissions report suggested. This goes against the fundamental principles of Autonomous Citizen Advocacy.

4.3.2 *'The provision of funding for Traveller advocates and developing links with Traveller groups' (ibid 1995:36)*

Through its omission, the Government has once again taken the assimilist approach, and denied Travellers an advocacy role for the development and maintenance of cultural identity. This must be addressed, especially in terms of multiple identities e.g. for Disabled Travellers.

4.3.3 *'The introduction of a proper guardianship law (ibid 1995:28)*

This proposal was not included in the 1996 commission's report. The issue of guardianship is particularly important for people who are mentally and / or physically incapacitated, within vulnerable situations and without family.

One submission (ibid) recommended the introduction of a proper guardianship law to include four principles, i.e. that it would only be invoked where the person was unable to handle his or her affairs without support; that the guardianship court would determine the sphere of guardianship and this would be the least restrictive alternative; that the person (or advocate) would be consulted in relation to all decisions; and that the guardian would make an annual report to the court on all decisions made.

There are also people whose thought processes cannot express what they wish, but who may be technically competent i.e. people with head injuries / stroke. There are disabled people with high support needs i.e people with Alzheimer's, dementia and / or people who require other people to advocate for them in all aspects of their lives. For these people advocacy mechanisms require to be found in a broader system where all voices are heard equally. A generic system of advocacy incorporating legal, formal and social advocacy is one vital component in protecting and ensuring their rights.

The following section details the most recent progress report available (1999), by the Government from the commission in relation to what work has been undertaken on advocacy.

4.4 Towards Equal Citizenship (1999): Progress Report on the Implementation of the recommendations from The Commission on the Status of People with Disabilities

4.4.1 *'The Department of Health and Children will continue to support the development of further advocacy services*
(Chapter 4:47)... where appropriate' (4.45)

The department does not specify how this will be done or what human, financial or legal resources will be provided for this support. The aspirational tone could be interpreted solely in terms of moral support or endorsement. Details of commitment are required, in terms of funding and resources. It is inappropriate for the Department of Health and Children to develop advocacy services, for reasons outlined in this document. It is also inappropriate for a Department, often at the centre of complaints and working to the medical model, to determine when Advocacy is appropriate.

4.4.2 *'Independent advocacy services continue to be developed and are provided by local and national user groups active on behalf of people with mental health difficulties and their relatives'*
(Chapter 4:47)

This continues to leave the responsibility of advocacy work to local and national user groups without any real commitment of resources from central government. It also narrows Advocacy systems; in terms of recognition and resources, to that of Mental Health which excludes other disabled people. Developing an impairment-based advocacy system is undesirable because it is too narrow; informed through the medical model, and helps to create unnecessary hierarchies of oppression among disabled people.

4.4.3 *'The issue of provision of funding to the Legal Aid Board to ensure that people with disabilities can employ an advocate to access expert legal representation, where necessary, will be considered in the context of the determination of the Board's annual allocations '*
(Chapter 4:46)

The Legal Aid Board is struggling to meet its current commitments. It is unacceptable that the right to legal representation for people with disabilities has not been given a firm commitment; or that resources are dependent on the fluctuant, fiscal nature of annual allocations and budgets. Rights cannot be dependent on resources.

4.4.4 *'The Eastern Health Board is at present, working towards provision of a patients advocacy service'*
(Chapter 4:45)

It is disappointing that patient advocacy or peer advocacy is not referenced within the Mental Health Act, 2001. The 2001 Act only recognises a patient's right to legal representation. However, The Eastern Regional Health Authority has sanctioned funding for Peer Advocates to be trained in the area of mental health but there are no indicators as to who will manage any future advocacy service. The North Eastern health Board are open to funding peer advocacy in the area of mental health, in the region and have provided premises in Monaghan for the Irish Advocacy Network. The Western Health Board established a patients Advocacy service funded through the National Lottery. The Southern Health Board initially allocated funding for the Kerry Advocacy Network and the Cork Advocacy Network. Contributions by Health Boards are welcome in the sense that they recognise the legitimacy of patient and peer advocacy. However, it is of vital importance, that advocacy services be totally independent of service providers, including funding, in order not to compromise the independence of a future advocacy system.

4.4.5 *'The group recommended the merging of the National Rehabilitation Board (NRB) and the National Social Services board (NSSB) into a new Organisation under the aegis of the Minister for Social, Community and Family Affairs'*
(Chapter 4.45)

The organisation now known as Comhairle, has responsibility for the provision of independent information, advice and advocacy services throughout the country, through the existing network of 85 Citizens Information Centres, more than 400 third party information providers and, as appropriate, facilities currently operated under the aegis of the NRB at 18 regional centres (Towards Equal Citizenship, 1999: 41-42)

4.5 COMHAIRLE

4.5.1 Advocacy, as defined and outlined in the Comhairle Act, 1999[25], is as follows:

"Advocacy services" includes services in which the interests of a person seeking a social service are represented in order to assist such person in securing entitlements to such service but does not include legal representation.

4.5.2 The functions of the Comhairle Board according to the act, shall be:

(a) To support the provision of or, where the Board considers it appropriate, to provide directly, independent information, advice and advocacy services so as to ensure that individuals have access to accurate, comprehensive and clear information relating to social services and are referred to the relevant services.

To promote greater accessibility, co-ordination and public awareness of social services and of information, advice and advocacy services provided in relation to such services whether by a statutory body or a voluntary body.

4.5.3 According to this Act, individuals are entitled to advocacy services under its terms of reference. However, to date (December 2001), Comhairle has no comprehensive Advocacy policy or delivery system, which will access disabled people and those to which this document is most concerned.

4.5.4 Comhairle's function and remit is to support the provision of independent information advice and advocacy services, which it does by acting as a resourcing agency (Comhairle 2001). The agency views advocacy as part of the continuum of information, advice and advocacy, depending on the individual's requirements (ibid). The Forum of People with Disabilities suggests that Comhairle, according to the 1999 Act as outlined above, has a responsibility to support the direct provision of advocacy where appropriate, as well as acting in a resourcing role. Direct provision means directly funding advocacy workers, operating under a code of practice who are paid, named and trained workers.

4.5.5 Comhairle indicates it has a small advocacy fund of £100,000 for 2001, to support a number of projects that will contribute feedback and learning in terms of a range of approaches to the delivery of advocacy services which, will help to inform Comhairle, as it implements its new Strategy 2001-2003. The Forum suggests that this allocation of funding is totally insufficient for the development and provision of national advocacy services, and should be viewed in the context of Comhairle's annual budget of £9.26 million in 2001 (Strategic Plan 2001-2003).

4.5.6 Comhairle and Citizen Information Centres (CICs)
Comhairle aims to provide access to information, advice and advocacy, which should be of a high quality and which is customer focused. It also acknowledges that access to information is a basic right of all individuals (ibid: 1.2). Comhairle partly provides this access through the capital funding of the 36 full-time key Citizen Information Centres, and 50 part-time local CICs (staffed mainly by volunteers) which make up the national network of CICs. Comhairle funding to CICs provides for the delivery of general information, advice and advocacy services but does not currently provide funding for named and trained (specialised) advocacy workers with the exception of a new pilot scheme based in Sligo CIC in partnership with others, which is currently recruiting an Advocacy Resource Worker.

4.5.7 The provision of services to date within CICs centres on information and advice[26]. Some CICs have access to solicitors and legal professionals who give their services voluntarily, without pay, at certain times; this would be in terms of legal advice, as opposed to direct representation.

4.5.8 There are variations in terms of operational procedures in CICs, 31 of the key CICs provide information outreach services, for example to local clinics in their catchment area. These outreach services are dependent on budgets and the particular staffing levels and expertise within a CIC.

4.5.9 In terms of access, most of the Citizen Information Centres are placed within town centres and respond to a direct need on their doorsteps; people who come into their offices from the street. For vulnerable disabled people to which this document has particular concern, access to the CICs is either difficult, or absolutely out of the question, unless they have access to a phone[27]. How can an older person who is unable to leave the house, a prisoner, person/s sectioned or resident in psychiatric hospitals or people with learning disabilities living within residential care access information, advice and advocacy? Unless there are independent advocacy workers providing direct outreach work to those within closed environments, those most vulnerable will be unable to access information, advice or knowledge on their rights and entitlements.

4.5.10 Comhairle, in the context of its new Strategic Plan 2001-2003, is currently at the time of printing this document developing a policy on Advocacy. One of the questions posed within the plan is "how can Comhairle work effectively… to ensure the delivery of high quality information, advice and advocacy services?" The Forum of People with Disabilities suggests that Comhairle allocates a substantial percentage of its £9.26 million annual budget for the development of advocacy mechanisms, and in particular for paid, named and trained advocacy workers, who can deliver and support advocacy. Disabled people need to know how to access advocacy workers, where to access them, and that they operate under a code of practice and ethics. The Forum also recommends that specific advocacy mechanisms, including advocacy workers target vulnerable disabled people living within closed environments. Unless there are paid, named and trained advocacy workers operating on the ground, under a code of practice, advocacy will remain theoretical.

4.6 The National Disability Authority (NDA)

4.6.1 The National Disability Authority (NDA) was established in June 2000 as an independent statutory body operating under the aegis of the Department of Justice, Equality and Law Reform.

4.6.2 The National Disability Authority Act (1999) defines the principal function of the Authority as to advise the Minister and keep him or her informed of developments in relation to any disability of persons, which concern issues of policy and practice. One of the principle functions of the NDA is to act as a central, national body, which will assist the minister in the co-ordination and development of policy relating to persons with disabilities (NDA, *Disability in the Mainstream*)

4.6.3 The NDA's first Strategic Plan "A Matter of Rights 2001-2003" states that the Authority will promote and help secure the rights of disabled people through influencing public policy and legislation by developing, co-ordinating and advising on policy. It will also undertake and commission research.

The Authority has "*committed itself to proactively adopting a civil and human rights perspective in the development of policy and practice for disabled people*" (ibid) and seeks to:

- Ensure that the needs and rights of disabled people are enshrined in all aspects of Irish life.
- Promote the empowerment of people with disabilities and their participation in decisions that affect their lives.
- Underpin the promotion of an inclusive vision among all constituencies in Irish society.

4.6.4 The language and aspirations of the NDA fit easily into the rights-based, social model of disability which does not focus on a person's impairment but rather on changing a disabling society. The Forum of People with Disabilities suggest that an independent, generic advocacy system in which specialist advocacy models could co-exist, which is inclusive of all disabled people regardless of impairment, would fit into the NDA's mandate under its Strategic Plan.

4.6.5 The initial advocacy focus within the Authority to date, has been on mental health, which arose in the context of follow-up work in relation to the NDA's submission to the Mental Health Bill. The Forum of People with Disabilities acknowledge that people with mental health issues encounter particular violations of their rights, especially in relation to involuntary detention and procedures in psychiatric hospitals. However an advocacy process which addresses rights violations – including advocacy mechanisms – must be reflected in an analysis which is broader than impairment (Toolan, D: 2001)

It is therefore to be welcomed that the NDA has recently stated *"While it is keen to see an informed debate take place on how best to progress the development of independent advocacy mechanisms which addresses the needs of* **all** *disabled people. It does not want to pre-empt the outcome of the discussion and consultation, which needs to take place among key stakeholders"* (NDA, 2001)

4.6.6 The Forum of People with Disabilities suggest that the National Disability Authority could use its prime position of influence to promote and work towards an independent generic, systemic model of advocacy. In such a system, specialisms could operate (i.e. peer, patient, Traveller, citizen, group and legal advocacy) which all disabled people could access regardless of impairment. It would be a useful opportunity for the NDA to actively promote advocacy mechanisms in which, the interests of all those most vulnerable within closed environments, could be named, protected and ensured. The NDA have welcomed the Forum's initiative in preparing this reflection document, and views it as a significant contribution on how best to progress the development of effective independent advocacy mechanisms in Ireland (ibid). On the basis of this, advocacy organisations, advocates and NGOs should play an active role with the NDA in progressing this development. As the Statutory Body responsible for formulating policy and having an inclusive vision, it is fundamentally important that the NDA follow through in progressing policy for the development of comprehensive advocacy services for **all** disabled people.

4.6 The Programme for Prosperity and Fairness (PPF)

"The Department of Health and Children will support initiatives to provide independent advocacy services for people who are involuntarily detained under the provisions of the new Mental Health Bill." (PPF 1999:94(8).

4.7.1 One of the challenges that the PPF faced in its negotiation process was ensuring that everybody could feel the benefit of social partnership, and recognising that, for many people social exclusion is still a stark reality. It also promised that the PPF would substantially increase the resources allocated to social inclusion (PPF 1999: Foreword). Some of those most socially excluded are disabled people living within closed environments. People within such environments have not benefited from the PPF; some are still sleeping in large dormitories, sharing wheelchairs, living in poverty, unable to participate in wider society due to inaccessible infrastructure and unable to obtain personal assistants or independent advocacy services to ensure that their interests are safeguarded.

4.7.2 The new partnership agreement, which commences negotiation within the next twelve months, should widen the current remit to promote and make financial provison for a generic advocacy system, targeting **all** disabled people and in particular those within closed environments. This would recognise and help address the high levels of exclusion that disabled people experience daily within powerful closed spaces, and acknowledge the recommendations from the Commission (*A Strategy for Equality*: 1996)

4.8 Office of the Inspectorate of Mental Hospitals

4.8.1 The inspectorate of mental hospitals (Dr Dermot Walsh), is obliged under provisions of Section 247 and 248 of the Mental Treatment Act 1945, to inspect and report annually on the psychiatric services / hospitals in each health board.

4.8.2 The Inspectorate reports inequalities, deficiencies and developments within psychiatric services annually. Unfortunately, advocacy systems within psychiatric services are not a named part within the Inspectorate's remit. The Inspectorate's office would be a powerful vehicle for recommending in future reports, the necessity of introducing an independent advocacy system within the closed environs of the psychiatric services. The office could also be a useful statutory indicator to assist the monitoring of a future independent advocacy system. Any future independent advocacy system would only serve to compliment the office and works of the Inspectorates office, in the spirit of transparency and most importantly, the protection of vulnerable people's interests and rights.

4.9 Office of the Ombudsman

4.9.1 The office of the Ombudsman established under the Ombudsman Act, 1980 is widely respected and recognised. One of the critical elements of the office is its independence. Within the positions jurisdiction the Ombudsman acts as an arbiter between the citizen and the public service. The office does not make representations, but ensures that public service activities, and in particular, the exercise of decision-making powers, are carried out not only in a proper legal manner but in a manner consistent with fairness and good administrative practice (Murphy 2000).

4.9.2 According to the Ombudsman (ibid, 2001), examination of individual complaints often leads to the identification of systemic defects in procedures, approach or attitudes and at this level valuable feedback can be given to the bodies within remit. In this area, the Ombudsman has to some degree levelled the playing field for disadvantaged groups in our society (ibid).

This document suggests that an Ombudsman's Office might be utilised in monitoring a future independent Advocacy Commission / Authority, not in terms of direct representation, to ensure the offices neutrality. The Ombudsman's office would also be useful because part of the success of the Ombudsman's work can be attributed to the fact that there is no board and no political appointments (O' Connell: 2001) and the office is neutral and widely respected[28]. It is interesting that in the UK, there are a wide variety of Ombudsmen, i.e. for funeral parlours, canals, banks, building societies, prisons, hospitals etc. It is therefore quite possible and feasible, that an Advocacy Ombudsman could be appointed in Ireland to monitor and oversee a future independent advocacy service.

4.9.3 In the interim period, the established Ombudsman's office would be valuable in drawing the Government and the Oireachtas' attention in its next annual report to systemic inadequacies and inequalities in the law and policies in relation to advocacy. In particular, in the context of this document, the Office could recommend an Independent Advocacy System recognised in statute, for vulnerable disabled people in closed environments. This concept is fundamental to the office of the Ombudsman as disabled people may require access to an advocate in order to seek help, assistance or information on their rights, or about the Office.

4.10 The European Committee for the Prevention of Torture and Inhuman or Degrading Treatment (ECPT)

4.10.1 The Committee for the Prevention of Torture[29] (CPT) was set up under the 1987 ECPT.[30] Ireland is one of 41 member states of the Council bound by the Convention. The Committees task is to examine the treatment of persons deprived of their liberty. For this purpose, it is entitled to visit any place where such persons are held by a public authority. It may formulate recommendations to strengthen, if necessary, their protection against torture and inhuman or degrading treatment or punishment (CPT, 2001) under Article 3.[31]

4.10.2 The Committee are afforded complete freedom of speech and complete independence of their duties. Their function is to carry out visits and, where necessary to suggest improvements. Visits can be organised in all kinds of places (public and private) wherever people are deprived of their liberty for whatever reasons. The remit is wide enough to cover theoretically a section of people that this document is concerned with i.e. those in administrative detention, for medical, legal or social reasons, minors in a public authority or in a military authority. Where issues of the legal status of people are concerned, the CPT has the powers to satisfy itself as to whether the 'voluntary' status of a person is indeed their wish. This is an important Convention with wide ranging powers of investigation. It could be applied to people with learning disabilities, classified as 'voluntary' within residential care, who often have no choice or say in their placements, or older people in nursing homes.

4.10.3 This Convention and the Committee charged with investigative powers last visited Ireland in 1988, outlining various recommendations from their visits. The Irish Penal Reform Trusts most recent report "*Out of Sight: Out of Mind*" [32] reinforced the findings of the CPTs report,[33] which registered concerns re the lack of accountability of medical doctors in the men's prison in Mountjoy; compelling evidence of brutality to prisoners; medical services for prisoners were below standard; rogue prison officers – who are still working – within Mountjoy and Limerick prisons, who ill-treated prisoners. One recommendation was that the provision of prison psychiatric services be re-organised as a matter of urgency (ibid: 36).

4.10.4 The scope of the Committee's powers of investigation are wide and its role could be expanded and utilised in other areas. For example, NGOs could lobby the President of the CPT to visit other closed places i.e psychiatric hospitals, residential centres for disabled people and children's homes. NGOs could also lobby the President of the CPT to recommend the introduction of an independent advocacy system to compliment and ensure proper complaints & inspection procedures, to ensure the representation of those most vulnerable.

4.11 Conclusions

4.11.1 It is clear from reading the progress report "Towards Equal Citizenship (1999), The NDA Act (1999), The Comhairle Act (1999), the new Mental Health Act, (2001), the Programme for Prosperity and Fairness (1999) and outlining advocacy mechanisms currently in existence that:

I. Autonomous Accountable Advocacy provision for all disabled people has not been a priority for the Government and relevant departments.

II. (a) There are only five references to advocacy, within the progress report: *A Strategy for Equality*. None of the five references specify what '*supporting advocacy services*' means.

(b) There is no mention of funding advocacy with the exception that l*egal aid for people with disabilities will be considered in terms of annual allocations* within the progress report.

III. Only £100,000 has been allocated to advocacy (for accessing information in relation to benefits and entitlements, under the Comhairle Act, (2000) in 2001.

IV. The National Disability Authorities initial focus to date has been in developing a research proposal for independent advocacy services for people with mental health Issues. However, the NDA has stated that it is keen to see an informed debate on how best to progress an independent model of advocacy, which addresses the needs of **all** disabled people, but does not wish to pre-empt the outcome of the discussion and consultation, which needs to take place among key stakeholders (Whyte 2001).

V. Despite NGOs' submissions, the new Mental Health Act (2001) makes no reference to advocacy, only that of legal representation.[34]

VI. The Programme for Prosperity and Fairness only makes reference to advocacy for people with mental health difficulties who are involuntarily detained.

4.11.2 Judged in this light, the Government's commitment to advocacy is clearly lacking. Without a commitment by central government to recognise advocacy in terms of statute and funding it is relegated into the minor philosophical league of moral rights.

4.11.3 However, other avenues can be explored as instruments to recommend and effect change. For example, the National Disability Authority, Comhairle, the Office of the Inspectorate of Mental Hospitals, The Office of the Ombudsman, the Committee on the Prevention of Torture (CPT), the Human Rights Commission, and the Law Reform Commission could all be lobbied by NGOs. The lobbying could recommend the introduction of an independent, generic advocacy system to Government, to assist in the protection of the rights of disabled people, particularly those in closed environments.

4.11.4 The next chapter explores, what rights mean; the difference between moral and claim rights, and the importance of linking constitutional rights with International obligations under Human Rights instruments. It is time for change; a wake-up call is required in terms of rights and recognition, particularly for our most vulnerable citizens in closed environments. Rhetoric is not good enough, the rhetoric is insufficient, the language is limiting and the knowledge base is uninformed at both a legislative and statutory level.

5 Advocacy in Action in Ireland

5.0 Advocacy in Ireland

5.0.1 Advocacy is not 'formally' recognised in Ireland, except for the legal and Trade Union systems of representation, within the Programme for Prosperity and Fairness (for those involuntarily detained under the 2001 Mental Health Act), and within The Comhairle Act 2000 (in relation to clear information and accessing entitlements to social services).

5.0.2 There are no national statistics or available research on the practices and provision of advocacy systems for disabled people in Ireland.

5.0.3 Some groups with whom research has been carried out are now defunct (Advocacy Ireland Movement[1]) and others are struggling with little or no resources or support.

5.0.4 There are numerous voluntary advocacy groups around Ireland but no cross-fertilisation across services or disability groups. The Irish Advocacy Network based in Monaghan has been a significant development in mental health advocacy in Ireland.

5.0.5 There is no comprehensive statutory funding of systemic advocacy from grassroots level to policy development.

This section will outline five examples of advocacy initiatives either in existence or under consideration: it is not a comprehensive list, only an illustrative one. There are many innovative advocacy groups and services operating without recognition or resources who are not mentioned. Independent research is required to be carried out, but that is not the remit of this paper, which is a discussion document.

5.1 Mind Yourself & Foyle Advocates (Peer Advocacy)

Mind Yourself & Foyle Advocates is an example of an independent peer advocacy model in Derry with charitable status, for people with mental health difficulties. According to the 2000 report, Mind Yourself provides a full range of services to all sections of the community irrespective of social class, religion, gender, disability, colour or ethnicity. Mind Yourself is the umbrella organisation and Foyle Advocates is the peer advocacy project which operates within it. This advocacy organisation is in its fifth year in 2001, and has provided independent peer support to a growing number of people with mental health difficulties, both within the community and the local psychiatric hospital. Based in an office in Derry, which focuses as a drop-in centre, focal point and administrative centre, Foyle Advocates have steadily networked with staff and hospitals, which has resulted in referrals from staff. Part of their remit is education and training and their peer advocacy course is now accredited throughout the Northern Ireland Open College Network (NIOCN). Training is funded by the Health Boards in the Republic of Ireland, facilitated through Mind Yourself & Foyle Advocates and networked through the Irish Advocacy Network (IAN) in Monaghan. This model of advocacy is fundamentally important in ensuring that the principle person is centrally involved, in making decisions in their own lives. It is vital in the process of recovery for people who experience a loss of self-esteem and confidence through illness or impairment and who have been disempowered in powerful systems. It is also important in building a community of allies in which individuals can feel safe to talk to and deal with. According to McClelland, the Mind Yourself Peer Advocacy training model can be taken as a prototype and adapted for other groups[2]. Peer advocacy as an advocacy model is not particular to Mental Health.

5.2 Irish Advocacy Network (IAN)

The Irish Advocacy Network (IAN) is a national network of people and groups who have experienced, or are currently experiencing, mental health difficulties. AIN is one of the most significant developments in mental health advocacy in Ireland because it is rights-based and user led. The network was the product of a first ever service user conference which took place in Derry in 1999, hosted by the Peer Advocacy Organisation in Derry called Mind Yourself. IAN brings together people who have experience of mental health services throughout the island of Ireland. The organisation has assisted in setting up the Kerry Advocacy Network and the Cork Advocacy network which are still evolving. AIN is currently funded through the health boards, but operates independently of them. Peer Advocacy training is facilitated through Mind Yourself in Derry and supported by the Irish Advocacy Network. There is a recently appointed full-time national co-ordinator in the Irish Advocacy Network's national office based in Monaghan, who liases with Peer Advocates who have completed the training. This support and networking is vital in terms of support systems for advocates, and in ensuring that people operate through the established code of practice. Some of the IAN's activities are:

- Individual Advocacy – Peer advocates helping people to have their interests heard in hospital or in the community.
- A support network to groups affiliated to peer advocacy.
- Public relations with other mental health organisations.
- Provide Peer Advocacy Training along with Mind Yourself Peer Advocates in Derry.
- Providing training to health service staff on peer advocacy within mental health and the benefits of ensuring that peoples needs are heard and addressed.
- Builds partnerships with other agencies with a view to influencing the development of peer led individual advocacy mechanisms.
- Advocacy case management.
- Support the establishment of peer advocacy groups.
- Present at conferences etc., articulating the views of service users (ibid).

5.3 Galway Citizen Advocacy

A Citizen Advocacy service in the Brothers of Charity services in Galway (2001) has to date (December 2001) recruited five citizen advocates to work with particularly vulnerable service users within their service. The target of the co-ordinator, is to locate enough independent, voluntary, citizen advocates to act as partners for over 200 of the most vulnerable people living within their service. This trial project recruits, prepares and supports advocates on a long-term basis, specifically for people who have learning disabilities and high support needs. According to the Co-ordinator, the benefits of Citizen Advocacy will be reaped beyond those directly represented. It is hoped that a neutral person coming in from the outside will provide a watchful eye on things. The downside to this scheme is its lack of independence; in relation to funding and the co-ordinator. However, it is a sign of progress, which most other services have not yet indicated. It is, while imperfect, a sign of a closed system opening up to outsiders and introducing alternate advocacy models.

5.4 Community Advocates

The Equality Authority is in the process of developing a community advocacy programme designed in partnership with national organisations and given expression through local organisations. The community advocates will be named and trained individual(s) representing communities under the nine discriminatory grounds of equality legislation i.e. Traveller Advocates, Disability Advocates. The community advocates remit will involve assisting and advocating with and on behalf of persons, in relation to a persons rights under the Equal Status Act and the Employment Equality Act. The Equality Authorities aims are to mobilise, resource and give direction to this partnership.

Community advocates will be a named focal point for people to contact in assisting them in pursuing a grievance, complaint or interaction from within their own community. This is a recognition of grassroots advocacy by a Statutory body. It is mutually beneficial in the sense that the authority has limited resources in which to support and provide for an increasingly high level of claimants under the equality legislation. The Equality Authority has to its credit, identified a consciousness of rights, and a confidence in acting on rights within communities. The challenge for the Authority will be in identifying community advocates that can operate within and across splintered communities (i.e. the disability community is fragmented with many organisations representing the specific interests of their own members) which people will identify with and trust. Another major challenge is in accessing funding in which community advocates can be paid for their work.

5.5 Collective Advocacy

There are numerous collective disability advocacy organisations; such as the Forum of People with Disabilities (a rights based organisation), the Centre For Independent Living, People With Disabilities Ireland, The Disability Federation of Ireland and the Irish Advocacy Network, to give a few examples. Collective advocacy is a model where individuals and groups can feed their opinions and views, into a larger collective organisation with more bargaining power. Collective advocacy organisations are invaluable in taking on the role of watch dogs for state and semi-state bodies and in ensuring the rights and interests of their memberships are put on the bargaining table and realised. This model can be an effective example of systemic advocacy where the grassroots members have mechanisms, which are owned and controlled by disabled people themselves to feed into a larger political system.

5.6 State-Sponsored Advocacy Initiatives

The three Area Health Boards have a joint initiative to fund training in the three area health board regions and have contracted Mind Yourself & Foyle Advocates (Derry) and the Irish Advocacy Network (based in Monaghan) to facilitate and deliver this programme. This is specifically targeted at mental health users only. Funding is being provided for other advocacy initiatives also in the area of Mental Health.

5.5.1 There are also initiatives in the North Eastern Health Board for developing peer advocacy for Mental Health Users. However, it can be argued that a focus on one group of disabled people by State Agencies excludes other disabled people from accessing and participating in advocacy.

5.7 Conclusions

a) It is clear from antedoctal research (due to a lack of quantified, qualified, emancipatory or action research) that organisations, services and groups are all doing their ‘own thing’ in an ‘ad hoc’ way.

b) There are few examples of established advocacy groups with codes of practice, support systems for advocates or independent, resourced, named and trained advocacy workers / groups in place (i.e. Mind Yourself & Foyle Advocates, Derry and IAN).

c) Training and knowledge appears to be ad-hoc and transient; it is not on-going and systemic and it is usually centralised in a few people within an organisation.

d) Advocacy groups have disappeared (i.e. The Advocacy Ireland Movement) and the knowledge and experience base goes with the ex-advocates and ex-advisors.

e) A real deficit of advocacy in Ireland, is that there is no available research on the progress and achievements made; or on the obstacles faced by advocates, advocacy groups or movements. There is no historical advocacy record. This deficit highlights the need for comprehensive, action emancipatory research involving the researched in the process at all stages, who are in control of the process and have a real say in where the research goes.

f) Anecdotal evidence and research for this document suggests that advocacy is in an embryonic stage in Ireland and is not accessible to the majority of people who are vulnerable within closed environments.

Chapter 7 explores what rights mean; the difference between moral rights and claim rights and the importance of linking constitutional rights with International obligations under Human Rights instruments.

6 Taking Civil Rights Seriously

The Commission believes that advocacy is essential because it allows people to participate more fully in society by expressing their own viewpoints, by participating in management and decision- making, and by availing of the rights to which they are entitled
(A Strategy for Equality 1996:106 (4.46))

6.0 Introduction

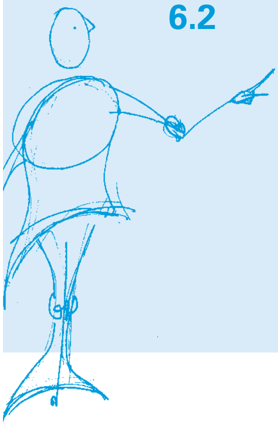
When rights are discussed, they can be understood widely as a certainty or type of insurance or assurance against discrimination and injustice. International and UN Declarations all emphasise the rights of disabled people; including freedom of speech, expression, opinion, information and assembly, which are directly related to advocacy. Though rights may be solely aspirational and of little value if there are no economic means to implement them, no information about them and a lack of political will to address them (Birmingham, D., 2000). As stated in the preface, to be meaningful in practice, rights must be enforceable. Confusion around the language of advocacy and rights is due in part to poor definitions. This chapter aims to clarify the difference between claim and moral rights and explore why we must take civil rights seriously in the context of advocacy.

6.1 The Meaning of Rights

A ‘right’ can be defined as any claim that is morally just or legally granted as allowable or due to a person, or as anything that accords with the principles of legal or moral justice (Final Report 1995:4).

6.1.1 Human Rights are often set out in international conventions or in national constitutions. They set out basic principles of moral justice. They may or may not also be legally binding. When “legal rights” are referred to, it means a claim that is justified by law and that can be enforced through the legal system. This would include rights set out in the Irish Constitution, in legislation i.e. acts of the Oireachtas, in ministerial regulations i.e. statutory instruments, or in judicial decisions (ibid). In the area of social services, many “rights” may not be legally enforceable, as they are not set out in legal documents. These “rights” have been accepted only as a matter of practice by the organisations involved because they have been set out in circulars or directives[3] or have simply been accepted as a matter of custom (ibid[4]).

6.1.2 This chapter focuses upon the position of disabled people in closed environments in particular. This group of people are particularly likely to have a very limited range of rights and/or find it difficult to exercise the rights they do have under constitutional and international law. People will argue for mainstreaming advocacy and not to direct or limit the focus on any particular group. This arrives from a fear of further labelling and segregation. However, Minow (1990) highlights that the moral policy of dealing with human differences (such as disability) where to ignore differences may help to prevent stereotypes and stigmatisation, but risks failing to do justice to the reality of difference4. This theory recognises that some people may require extra and additional resources to have equality of access, and participation to advocacy mechanisms due to their difference. This difference could be in terms of structures, policies, economics, environmental and attitudinal barriers, which preclude the participation of certain people (i.e. someone living within a total institution) from participating on an equal level with others.



6.2 Claim Rights Vs Moral Rights

When discussing civil rights in the context of domestic and international law it is useful to debate the difference between ‘claim rights’ and ‘moral rights’. It can be argued that disabled people are routinely denied both (Hudson 1988). Advocacy is an essential tool in giving direct representation to those who experience discrimination of both claim rights and moral rights.

6.3 Claim Rights

Claim rights deal with more ‘routine discriminations’, for example access to employment, accommodation, leisure and general services which can be claimed under specific pieces of legislation, for example, the Employment Equality Act, 1998 and the Equal Status Act, 2000. However, it must be noted that disabled people’s claim-rights to access services and employment are compromised in favour of property[5]. This can be an indicator of the low worth attributed to disabled people in relation to claim rights in this regard. Hudson (1988:28) argues that clarity and a more conceptual analysis are needed along with the enforcement and application of rights. If advocacy is to be enforced as a right, it needs to be one which people can both name and claim easily.

6.4 Moral Rights

6.4.1 Moral rights are more philosophical, aspirational and less absolute in nature than claim rights. Moral rights deal with fundamental discrimination. Those rights which are held prior to, or independently of, any legal or institutional rules, can be viewed as moral rights (Hudson, 1998:230), for example the right to life: the right to procreate: and the right to parent. Moral Rights by virtue of being moral, assume a philosophical role and therefore are open to subjectivity.

This subjectivity manifests itself when a group of people are discriminated against in a different way to the general population because they are perceived as having lesser human rights than the rest (ibid:1998). Disabled people, especially those within residential and institutional settings, have historically been denied equality in terms of reproduction rights; the right to parent, and to a family. This denial can be covertly applied under the guise of segregation of the sexes by state and religious organisations. Issues as to how society and governments view and accord moral worth are extremely important. This is especially true in the context of professional power and control versus disabled people.

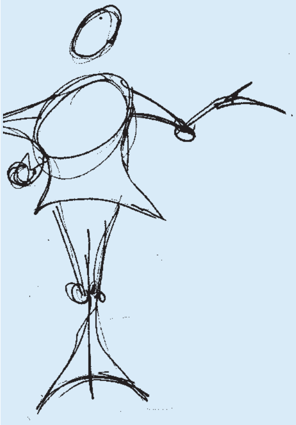
6.4.2 The debate about rights is central to advocacy if advocacy is to be referred to as a right. What is needed is clarity as to whether advocacy is an ambiguous moral right, or is enforceable as a claim right. If it is to become a claim-right, it must first be recognised as such in legislation. At present it appears from the lack of political will, legislation and recognition given to advocacy that it is not regarded as a right in any sense. This requires redressing the balance and stating clearly that advocacy is a right, and should be a claim right. Until an agreed legislated definition of independent advocacy as a claim right is enforced, it is clear that the representation of particularly vulnerable people will always be subject to question. Without a comprehensive, legislated advocacy movement to complement accountability procedures such as the Employment Equality Act, 1998 and the Equal Status Act, 2000, there are openings for current and future abuses in claim and moral rights, which might never be made public or addressed. Advocacy mechanisms give voice, expression and a direct presence to disabled people who are marginalised, vulnerable and socially excluded within closed systems.

6.4.4 Simply having moral rights is not enough: especially when they are subjective. In order to remedy the lack of advocacy provision, and to deter future discrimination, comprehensive advocacy legislation is vital as a claim right.

6.5 The Civil Rights Path

The most comprehensive legal approach to prevent and to protect against disability-based discrimination seems to be the civil rights path (Degener & Quinn 2000:49). Despite the fact that advocacy has not been ‘named’ as a specific right under Irish constitutional law or international law, there are articles of law, which directly and indirectly relate to the principle of what advocacy is. This document suggests that advocacy as a rights issue, should be informed through constitutional and in particular human rights language, in keeping with the civil rights path.

6.6 Defining Advocacy through Human and Constitutional Rights Language



The definition, context and language of advocacy is important, in giving due recognition to it; both in terms of human and constitutional rights. This document argues that:

I. Advocacy is a tool of self-determination.

II. Advocacy is the right to receive and impart information freely in order to be informed and to inform.

III. Advocacy is the right to express ones opinions freely and openly, in a medium appropriate to the individual / group.

IV. Group or collective advocacy is the right to assemble freely and peaceably. To join a union or a group of one's choice.

All the above definitions of advocacy can be mirrored both in international human rights law and Irish constitutional law and are in keeping with the civil rights path.

6.7 International Human Rights

6.7.1 Constitutional purists may argue that the Constitution super-cedes international law, without respecting international human rights obligations. It could also be argued that international human rights are only moral guiders in the form of ideas and principles and the Constitution is the supreme law of the land. However, the general comment No.5 (1994) of the UN Covenant on Economic, Social and Cultural Rights explicitly states:

> [The Covenant]...clearly requires Governments to do much more than merely abstain from taking measures, which might have a negative impact on persons with disabilities.
> The obligation in the case of such a vulnerable and disadvantaged group is to take positive action to reduce structural disadvantage and to give preferential treatment to disabled people in order to achieve the objectives of full participation and equality. This almost invariably means that additional resources will need to be made available for this purpose and that a wide range of especially tailored measures will be required.

This comment clearly signals an affirmative action approach is required in relation to meeting obligations under conventions for certain vulnerable and disadvantaged groups. It also calls for additional resources and special measures.

6.7.2 *All citizens shall, as human persons, be held equal before the law. This shall not be held to mean that the State shall not in its enactments have due regard to differences of capacity, physical and moral, and of social function* (Article 40.1 Irish Constitution)

It can be argued that Article 40.1 of the Irish Constitution in having due regard to differences acknowledges that sometimes unequal treatment is necessary to enact equality. This can be translated into some people requiring extra and additional supports to access and participate equally, such as the support of advocacy services. If interpreted in this way, Article 40.1 could also signal an affirmative action approach (such as the general comment No. 5 UNECCR) to assist the argument for unequal or positive treatment.

6.7.3 The UN Standard Rules on the Equalisation of Opportunities (1993) for Persons with Disabilities, and its broad statement also supports advocacy:

"The role of organisations of persons with disabilities could be to identify needs and priorities, to participate in planning, implementation and evaluation of services and measures concerning the lives of persons with disabilities and to contribute to public awareness and to advocate change."

Rule 15 (ibid) affirms that:
"States have a responsibility to create the legal basis for measures to achieve the objectives of full participation and equality for persons with disabilities."

Rule 15 could be used as a basis for the domestic legislation of advocacy for vulnerable disabled people, in order to participate equally and fully in the representation of their interests.

In addition, Rule 18 (ibid) gives further explicit support in declaring:
"States should recognise the right of organisations of persons with disabilities to represent persons with disabilities at national, regional and local levels. States should also recognise the advisory role of organisations of persons with disabilities in decision-making on disability matters."

Rule 18 (ibid) effectively endorses collective advocacy and by default systemic advocacy.

6.8 Human and Constitutional Rights

6.8.1 Human rights also include constitutional law, and according to Quinn, it is usually at this immediate level of relating to international law that the rather abstract formulae of rights language are located. The challenge is to ensure that the statute in constitutional law is not solely theoretical and does individuate itself in the lives of the people within the State, particularly those most vulnerable. There must be a synergy between human and civil rights (O'Connell 2001) to incorporate international moral vision into domestic law and statute.

6.8.2 The implementation of human rights must be concerned with the prevention of discrimination, which is the prevention of any action which denies to individuals or groups of people equality of treatment, which they may wish or to which they are entitled. Unfortunately, drafters of the International Bill of Human Rights did not include disabled people as a distinct group vulnerable to human rights violations. Even the European Convention on Human Rights Bill 2000 (Art 13.5) does not recognise disability as a distinct ground of discrimination in itself. According to Degener & Quinn (2000), none of the equality clauses of any of the three instruments of this Bill, the Universal Declaration of Human Rights (1948); The International Covenant on Civil and Political Rights (1966), and the International Covenant on Economic, Social and Cultural Rights (1966) mention disability as a protected category.

6.8.3 Although covered under the Human Rights Bill as human beings, specific rights were not detailed in relation to disability. This is where the Irish Constitution and internal law enters the debate. Advocacy should be referenced through human and constitutional law, but should be protected and resourced through a specific internal bill of its own. This would, in effect, create a binding law for advocacy instead of an ambiguous moral right. Advocacy would become a right to be named and claimed, with extra and additional resources, to cover the extra and additional supports necessary.

6.8.4 This document suggests that an adapted Advocacy Act similar to that of the 1992 Ontario Advocacy Act would be one legislative example to pursue in terms of advocacy claim rights. The Australian package, which places advocacy services and the development of advocacy as part of an overall package of measures, is another legislative option. Either one of these examples (outlined in Chapter 7) would signify that society and government were serious about the protection, vindication and progression of the right to advocacy for vulnerable people in Irish society. It would also signify a serious move towards a more progressive social policy as to how the interests of disabled peoples are represented.

6.9 References to Advocacy in International and Constitutional Law

'All peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development'
(Article (1) United Nations Covenants on Human Rights (UNCHR) (1948))

'Self-determination is the ability to make a decision for oneself without influence from outside' (Collins Dictionary). However, in the context of advocacy as a tool of self-determination, vulnerable persons may require support systems in arriving at this point. Internal self-determination via constitutions are gauged with reference to human rights. Violations of self-determination are violations of human rights. Human rights enshrined in the UN Declaration of Human Rights can direct attention to the organisation of the State as a whole, and how that State favours or disfavours human values and human rights to the benefit of all within the State. In this sense, Human Rights Law attempts to change the terms which the oppressed will demand justice and not just outlaw injustice. (Quinn: 2001)

6.9.1 The European Court has described freedom of expression as "*one of the essential foundations of a democratic society*" and it is this fundamental tenet that advocacy is based on. An important question to be asked here is; can Irish society call itself a modern democracy when a sizeable proportion of its most vulnerable citizens are denied access and supports to advocacy in order to freely express themselves and access their civil and human rights? This is meant in terms of access and supports to appropriate mediums of communication, aids and equipment, sign interpreters, brailling systems, drama, music, art and individual and systemic support advocacy systems.

6.10 International Human Rights Treaties

The Universal Declaration of Human Rights (1948-1998) sets out basic human rights and fundamental freedoms to which all persons are entitled to without discrimination. Ireland signed this declaration in 1973 and ratified it with reservations in 1989.[6]

...Both de jure and de facto discrimination against persons with disabilities have a long history and take various forms. For the purpose of the Covenant, "disability-based discrimination" may be defined as including any distinction, exclusion, restriction or preference, or denial of reasonable accommodations based on disability which has the effect of nullifying or impairing the recognition, enjoyment or exercise of economic, social or cultural rights.
(General Comment No. 5 (1994): Persons with Disabilities, U.N. ESCOR, Supp. No. 2, at 102, 11 15, U.N. Doc. E/1995/22 (1995)) in Quinn, 2001)

This is the only legal U.N. document to date that broadly defines disability-based discrimination and also emphasises the human rights approach to disability by including a clear demand for anti-discrimination legislation. It also importantly states 'recognition'[7] as a ground for disability-based discrimination, which is useful for advocacy.

6.11 International Covenant on Civil and Political Rights (ICCPR)

One of the most important international treaties in relation to human rights is the International Covenant on Civil and Political Human Rights (ICCPR) established by the United Nations. The ICCPR is a legally binding treaty and all signatories including Ireland, are subject to a five yearly review by the UN Human Rights Committee, which scrutinises the country's records against the standards laid down in the ICCPR. Governments are required to submit factual reports outlining how they are fulfilling these requirements and their representatives can be cross-questioned by members of the Human Rights Committee. In light of the lack of advocacy provision, the lack of independent representation for vulnerable people, who live within closed environments and the Lafoy Enquiry into institutional abuse, some of the rights outlined within this chapter, can and should be called into question.

6.12 The Irish Constitution and Advocacy

The Irish Constitution (1937) to quote Gerard Quinn (2001/04/01), pronounces eloquently but acts conservatively. This would appear to be the case, in particular, to the representation of interests of disabled people (i.e. freedom of expression, speech[8], opinion, information, and assembly) within closed environments.

6.13 Using Constitutional Law

According to Dagener & Quinn (2000:31-32), constitutional anti-discrimination provisions can be very broad and cover unfair direct and indirect discrimination. Some constitutions enable or entrust the legislator to take affirmative action to combat disability discrimination. Canadian and Australian statutes are two such examples. Unfortunately, McAteer (1999:5) suggests that within the parameters of our Constitution, there is little room for affirmative action policies[9].

Advocacy requires affirmative action to target the lack of representation of disabled people who are particularly vulnerable. With this in mind, advocacy must be located as a right within constitutional law, while being addressed formally under a specific bill. This would ensure equality of access, participation and outcome and enable the legislator to take affirmative action.

The following section explores how the Irish Constitution in conjunction with international instruments, may be used for naming and claiming advocacy.

"The State guarantees in its laws to respect, and as far as practicable, by its laws to defend and vindicate the personal rights of the citizen"
Article 40.3 (Irish Constitution)

Article 40.3 is the support mechanism for other representation rights such as:

6.14 Freedom of Opinion and Expression

"Everyone should have the right to freedom of expression; this right shall include the right to seek, receive and impart information and ideas of all kinds."
(Article 19 (ICCPR))

"Freedom of opinion and expression, the right includes freedom to hold opinions without interference."
(Article 19 (UNDHR) (echoed in Art.10 ECHR Bill 2000)

"The State guarantees liberty for the exercise of the right of the citizens to express freely their convictions and opinions."
Article 40.i (The Irish Constitution)

All of the above articles state and reinforce the basic principles of advocacy; freedom of speech and expression.

6.15 Freedom of Movement and Association

"Everyone shall have the right of freedom of association with others."
Article 22 (ICCPR)(echoed in Art.11 ECHR Bill 2000)

Article 22 has echoes in:
"The right of the citizens to form associations and unions."
Article 40.iii (Irish Constitution)

Group, collective or coalition advocacy can be viewed in light of these articles. However, for vulnerable groups such as those living within total institutions and residential care, practical support[10], may be required to facilitate the freedom of association and assembly with those of their choice. In terms of advocacy and associating with other advocates, advocacy groups or unions, affirmative action is also clearly required.

6.16 Conclusions

Advocacy must be identified and framed within human and constitutional language as this chapter has suggested. However it requires formal recognition, either within a specific Advocacy Act, or named clearly as a claim right within a legislative package. This chapter proposes that:

1) Advocacy is a right to which people are entitled.

2) Advocacy must be a claim right.

3) Comprehensive advocacy legislation is vital in naming advocacy as a claim right.

4) Advocacy must be framed within a civil rights context, using human rights language.

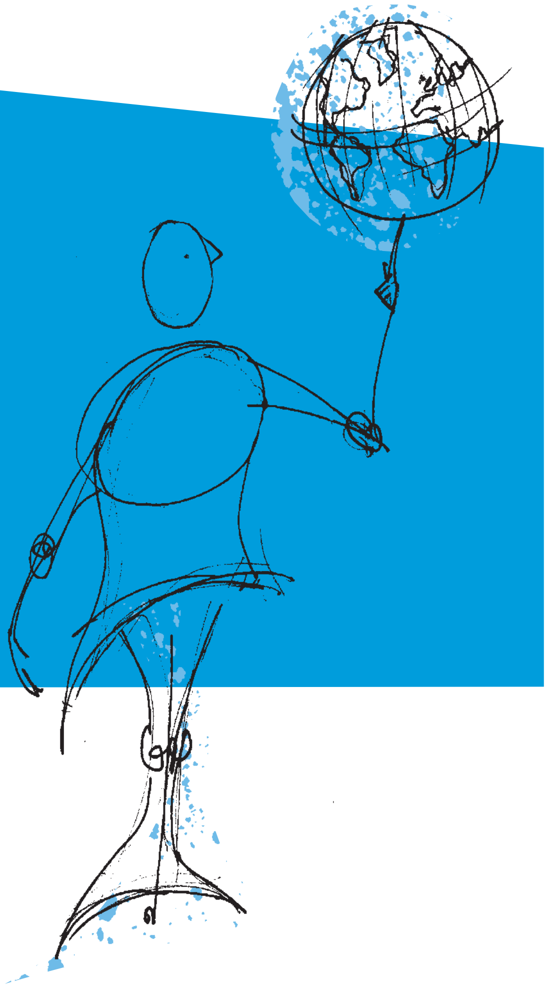
5) There must be a synergy between constitutional and international instruments.

6) Affirmative action is required in relation to Ireland meeting its obligations under international conventions for vulnerable and disadvantaged groups, in relation to the representation of their interests via advocacy. This is in terms of legislation and additional economic resources.

6.17 Comparatively speaking, the Irish Government's commitment to advocacy when viewed in the context of other jurisdictions is nothing less than an absolute disgrace. The challenge is to move forward and study progressive models internationally as a barometer of good tried and tested practice. Chapter 7 outlines two alternate systems of advocacy, in Australia and Canada, and the financial, legal and structural commitments given to them.

7

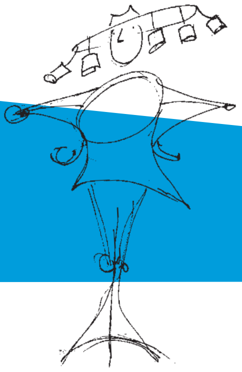
Advocacy: An International Perspective



7.0 Introduction

Two different operable systems and models of advocacy are outlined within this chapter; the first is from Australia where advocacy is part of an overall package of measures and statutes. The second model is Canadian, which explores the 1992 Ontario Advocacy Act and the reasons for its repeal in 1996.

7.1 The Australian Model – Introduction (http://www.csc.nsw.gov.au/)



This section details various pieces of Australian Statute; all of which are designed to complement one another, and progress the rights of disabled people. A selection are selected because many of their functions are part of a comprehensive, systemic approach, which places advocacy services and the development of advocacy as part of an overall package of measures (complaints, reviews, monitoring) and not as isolated functions. This section details the relevant statutes, which recognise and impact on advocacy.

The legislative package available to Australians with disabilities while not perfect, does provide for the basic rights of disabled people, especially those most vulnerable. Advocacy is included and named as one of those rights.

7.1.1 Included in this section are:

1. Federal and State Legislation.
2. Disability Discrimination Act (DDA)(1992).
3. Disability Services Act (1986).
4. Community Service Act (Complaints Appeals and Monitoring) (1993).
5. Disability Services Standards.
6. The NSW Disability Services Act (DSA)(1993).
7. Funding: The Draft Report of the Disability Advocacy Programme Review.
8. Community Service Commission (1994).
9. From individual to systemic.
10. Reviews.
11. Community Visitors.
12. Community Services Appeals Tribunal.

7.2 Federal & State Legislation

There are nine separate legal jurisdictions in Australia: the federal level, the six states and the two territories. Each has its own courts and Parliament. There is no Bill of Rights in the Australian constitutions and so advances in the protection of individual rights depend to a great extent on legislative initiatives[11] (MacDonagh in Quinn et al.,1983:120)

7.3 The Australian Disability Discrimination Act (DDA 1992)

The DDA established the *Human Rights and Equal Opportunity Commission* (HREOC), a specific *Disability Discrimination Commission* and a Disability Discrimination Commissioner.

The DDA (1992) provides a uniform standard of protection for disabled people across all States and territories. This Act's significance is the recognition given that disability is not the same as other forms of discrimination and therefore, requires different legislative treatment (Quinn: 152). This thinking is also reflected in Canadian legislation, which suggests a reversal of the traditional equal opportunities method of defining equality, which treats everyone the same.

This piece of legislation sets the rights of disabled people into a legal framework. It acknowledges that disability is a specific ground of discrimination and therefore requires specific remedies. It also:

- Prohibits discrimination on grounds of disability.
- Aims to ensure that disabled people get equal treatment before the law.
- Promotes understanding that disabled people have the same rights and opportunities as the rest of the community.

7.4 Disability Services Act 1986

(Part 11 Funding of services for persons with Disabilities. Division 1-General 7 Interpretation)

This act is important because it names advocacy as a specific area under its remit and provides statutory provision for affirmative action. The DSA 1986 is enabling legislation, which relates primarily to the funding of services for disabled people, advocacy being one area. The principles include systemic advocacy and the right for people to participate in decisions, which are central to their lives.

Advocacy Services described according to this act are:

(a) Self-advocacy services; namely, services to assist persons with disabilities to develop or maintain the personal skills and self confidence necessary to enable them to represent their own interest in the community.

(b) Citizen-advocacy services; namely, services to facilitate persons in the community to assist;

1. Persons with disabilities; or

2. Families of, and other persons who provide care for or assistance to, persons with disabilities.

To represent their interests in the community; or

(c) Group-advocacy services; namely, services to facilitate community organisations to represent the interests of groups of persons with disabilities.

These three references are interesting because the act recognises the formal value of systemic advocacy and self-representation.

7.5 Community Services Act (Complaints Appeals and Monitoring) (1993)

This legislation provides an independent mechanism to investigate complaints, reviews and monitoring in relation to the provision of community services in NSW, including advocacy services. It also:

- Provides for the establishment of the Community Services Commission, an independent body which monitors and investigates complaints about service providers.
- Ensures that the rights of disabled people are covered (including advocacy).
- Appointment of Community Visitors (to monitor services, including advocacy).

7.6 Disability Services Standards

This piece of legislation defines the rights and responsibilities of service providers in terms of service outcomes and was:

- Developed as a "working definition" of the Commonwealth Disability Services Act and the NSW Disability Act.
- Its aim is to empower disabled people in clearly defining their rights when accessing services.

7.7 The New South Wales (NSW) Disability Services Act (DSA) (1993)

The NSW DSA is similar to the Commonwealth Act, the legislation that supports equal rights for disabled people. The DSA Act sets out a set of principles and applicable principles for the provision of services for disabled people in NSW.

- Services funded and provided by the NSW government must enforce standards as set out in the Act in order to receive funding (this is a measure of accountability).
- Unfortunately, the DSA is currently being ignored. There are services that do not conform to the DSA, and the NSW government is doing nothing to address this.

7.8 Funding: (The Draft Report of the Disability Advocacy Programme Review[12])

7.8.1 The Australian Government provides funding to advocacy services to assist them in their work. This amounts to ten million dollars a year and there are 76 services that share the money. The National Disability Advocacy Program accounts for how well the money is used by services, how well the services are working and how Disabled People are represented. Some advocacy services also get money from the State governments. Advocacy services have contracts with the government: they provide advocacy services and the government gives them money.

7.8.2 Monitoring Mechanisms of the Disability Advocacy Program involve:

- The kinds of issues they deal with (for example, housing and public transport).

- The kinds of disability their clients have, and levels of support required.
- The number of people the service has helped or cannot help.
- Examples of best practice in certain situations.

Geographical breakdown: The part of Australia the advocacy services covers, and importantly, those that are not covered.

The DDP ensures that advocacy outcomes are equal and that the more vulnerable as well as the articulate, rural and urban, benefit from representation.

7.9 The Community Services Commission (1994)

7.9.1 The Community Services Commission was established in 1994, following legislation CAMA (Complaints, Appeals and Monitoring Act, 1993) (now CRAMA, Complaints, Reviews and Monitoring Act (1998)). The Commission provides an easy access point for complaints by consumers and advocates of community services and they provide a body of expertise to deal with all community services delivered by both government and non-governmental agencies. This Commission gives priority to people who are the most vulnerable and least able to protect their own interests, such as:

- Children and young people, especially those in child protection and substitute care systems.
- Disabled People in care, or in need of care.
- Consumers of government or funded home care services.
- Consumers of SAAP services (e.g. refuges).

7.9.2 The commission's remit includes 12 interlocking statutory functions, where advocacy is viewed as complimenting other roles and functions, such as education, standards, complaints, enquires, and reviews as described below:

1) To promote and assist the development of standards for the delivery of community services.
2) To educate service providers, clients, carers and the community generally about those standards.

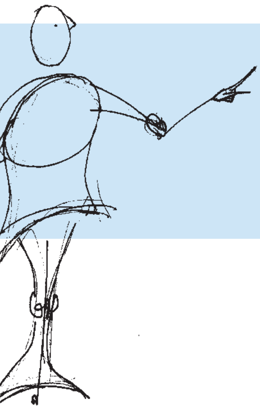
3) To monitor and review the delivery of community services.

4) To conduct inquiries.

5) To receive, assess, resolve or investigate complaints.

6) To assist service providers in improving their complaints procedures.

7) To assist in the making of complaints by persons receiving or eligible to receive community services.



8) To promote, liase with and assist advocacy services.

9) To support the development of advocacy programs.

10) To provide information, education and training in relation to the making, handling and resolution of complaints.

11) To review the cause and patterns of complaints, identify ways in which those causes could be removed or minimised.

12) To exercise and perform other functions conferred.

The 12 interlocking functions of the Commission are part of a comprehensive and progressive approach, which places advocacy services and the development of advocacy as part of an overall package of measures and not as an isolated function.

7.10 From Individual to Systemic

A unique feature of the CRAMA legislation was the ability to move from individual issues of concern through to an overview of systemic issues. This approach includes dealing with advocacy, complaints, information, education, accountability of service provision and the conduction of enquires. By having the same body dealing with individual complaints and collective issues, there is a system of one feeding into the other. There is formal recognition by the Commission as to how individual advocacy can feed into systemic advocacy.

7.11 Avoiding Duplication

The NSW parliament, in passing the CRAMA legislation specifically had regard to inter-jurisdictional issues particularly with the Ombudsman. This translates into a complaint made to the Community Services Commission would not also be investigated by the Ombudsman. Agreements have been entered into between the Ombudsman and the

Commission. Complaints to the Commission may be received orally, given the vulnerability and background of the clients. Complaints to the Ombudsman's office are required to be in writing.

7.12 Reviews

The Law Reform Commission in 1999 following a thorough investigation, assessed the CRAMA legislation[13]. Following this investigation, the Law Commission strongly supported the retention of the CRAMA legislation, subject to amendments to strengthen it and strongly endorsed the role and purpose of the commission. However, following advice from the Crown solicitor, certain functions have been redesignated to the office of the Ombudsman, relating to children in care in particular.

7.13 Community Visitors

Community Visitors are appointed by the Minister for Community Services under to Community Services (Complaints, Appeals and Monitoring) Act 1993 (CAMA) and (CRAMA 1998)

The visitors are co-ordinated by the Community Services Commission. However, they are independent from the Commission and responsible directly to the Minister for Community Services. Term of office is not to exceed three years or if qualified for consecutive terms of not more than six years. The composition of Community Visitors is specified and includes:

- People with a disability.
- Parents and relatives of people with a disability.
- Ex-State wards.
- People who were in care as children.
- Advocates.
- Professionals.

7.14 Where do they visit?

Residential Services for children, children with a disability, and adults with a disability throughout NSW

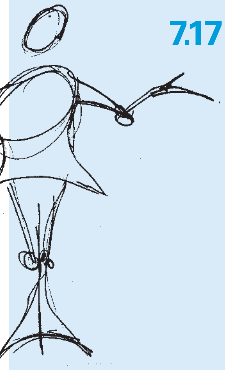
7.15 What do Community Visitors do?

- They promote the legal and Human rights of people using community services.
- They consider matters raised by consumers and staff of services and others.
- They give consumers information about advocacy services and help them get the service.
- They facilitate the early and speedy resolution of grievances or matters of concern.

Community Visitors are watchdogs for rights, they can identify issues or issues can be identified to them. Advocacy is named as part of their remit.

7.16 Community Services Appeals Tribunal

If a service provider does not take action recommended by the Commission, the person who made the complaint can ask the Community Services Appeals Tribunal to review the service provider's decision. In two decisions, the Tribunal said that two peak disability groups, Disabled People (NSW) and the Council on Intellectual Disability, could bring appeals against decisions by the Minister.



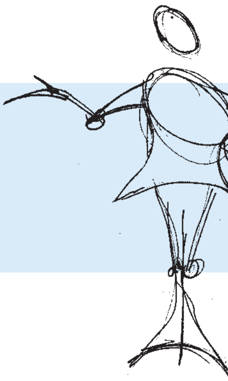
7.17 Conclusions

The Australian system (NSW) in relation to the protection of rights for Disabled People is comprehensive, updated and reviewed on a regular basis. Advocacy is named within various statutes, and resourced accordingly. A positive feature of the Australian model is the recognition of advocacy as systemic and not just a complaints and monitoring body. It recognises that advocacy needs resources, and that it is accountable to its members.

Advocacy in NSW Australia targets its resources particularly to those most vulnerable within closed systems. It is claim right enshrined within a legislative package and although it is not perfect, is a positive working example of an autonomous accountable advocacy model. The following section explores an alternate international system of advocacy, that of Canada. It will compare the legislative package of Australia to the specific 1996 Ontario Advocacy Act in order to present two possible alternatives for Advocacy provision in Ireland.

7.18 The Canadian Model – Introduction

7.18.1 Canada is a federal state made up of ten provinces and two territories. Each province has its own elected legislature, with its own government, and power is divided between the provincial and federal governments. It is similar in structure to that of Australia and very different to that in Ireland. Having said that it is possible and necessary to draw best practice, from different jurisdictions in relation to advocacy.



7.18.2 Laws and polices in relation to disabled people in Canada fall into two categories; those prohibiting discrimination on the grounds of disability, and those requiring that some positive action be taken. This means non-discrimination legislation and affirmative action.

7.18.3 The Australian system as outlined earlier is comprehensive in terms of rights and legislative redress for disabled people, in which advocacy is recognised as part of an overall package. The Ontario Advocacy Act (1992) repealed in 1996, differed from that of Australia because it addressed advocacy as a stand-alone issue. It was allocated a gravitas of place, as a cornerstone of human and civil rights. It was a comprehensive, progressive and detailed piece of statute in its design and Ireland can learn both from the mistakes that led to its repeal in 1996, and the idealism of its creation.

7.18.4 The 1992 Advocacy Act was clear in its remit. It laid the legal foundation for a formal advocacy service in which vulnerable people could be represented. One progressive and visionary aspect was the emphasis on real systemic changes with community development strategies. This was emphasised in the introduction of the Act

> *"...if the advocacy reveals widespread or chronic abuse, neglect or ineffectiveness...then changes will have to be made. This may involve systemic changes, including new laws, practices and policies in both the public and private sectors. We are fully prepared to see that happen."*
> (Hon. Ms Ziemba, Legislative Assembly of Ontario 1991)

7.19 The Ontario Advocacy Act (1992)

The 1992 Advocacy Act was the centrepiece of a legislative package. Its aims were clear and unambiguous. It gave rights with redress to advocacy. On introducing the Act, on 18/4/91 into the legislative Assembly, it was stated that:

"Society is judged in part on the basis of how it treats its most vulnerable citizens. Historically, many vulnerable adults have been silenced and deprived of the opportunity to exercise their fundamental rights. Such rights include the right to make choices; the right to participate in shaping one's owns future and the future of the community, and above all, the right to speak out for change. The Advocacy Act is the centrepiece of a legislative package to address this injustice."
(Hon. Ms Ziemba Legislative Assembly of Ontario)

7.20 Purposes of the Advocacy Act?

(a) To contribute to the empowerment of vulnerable persons and to promote respect for their rights, freedoms, autonomy and dignity.

(b) To provide advocacy services:

  (i) to help individual vulnerable persons express and act on their wishes, ascertain and exercise their rights, speak on their own behalf, engage in mutual aid and form organisations to advance their interests;

  (ii) to help individual vulnerable persons who are incapable of instructing an advocate, if there are reasonable grounds to believe that there is a risk of serious harm to the health or safety of those persons; and

  (iii) to help vulnerable persons to bring about systemic changes at the governmental, legal, social, economic and institutional levels.

(c) To ensure that community development strategies are applied in the provision of advocacy services.

(d) To take into account the religion, culture and traditions of vulnerable persons.

(e) To ensure that aboriginal communities (sic. T*raveller communities could be applied in the Irish context*) are enabled to provide their own advocacy services whenever possible.

(f) To acknowledge, encourage and enhance individual, family and community support from the security and well being of vulnerable persons. 1992, c. 26s 1

7.21 Who was covered under the Ontario Advocacy Act 1992?

The Advocacy Act prioritised vulnerable people.

7.22 Who is a 'vulnerable person?'

7.22.1 According to the act a 'Vulnerable Person' is a person, who, because of a moderate to severe mental or physical disability, illness or infirmity, whether temporary or permanent and whether actual or perceived:

(a) is unable to express or act on his or her wishes or to ascertain or exercise his or her rights, or

(b) has difficulty in expressing or acting on his or her wishes or in ascertaining or exercising his or her rights. ("personne vulnerable") 1992,c. 26,s.2.

7.22.2 An interesting facet is the scope of premises and services that this act covered. Under its definitions, a facility can be police detention facilities provided by a municipality under the Police Services Act or a detention facility maintained under the *Municipal Act.*

7.22.3 Bringing it back home, the 1999 Irish Penal Reform Trust Report detailed that 78% of prisoners with severe mental health difficulties receive inadequate or no treatment. Lock-up, strip cells and isolation are all used as a means of dealing with and containing their illness. These prisoners would benefit and should have access to independent advocates, but fall outside the traditional scope of services. Nursing homes for older people and children's homes, are other categories, where a persons right to representation can be neglected or totally absent. The advocacy act named specific categories, therefore affording people the right to redress within them.

7.23 What details did the Advocacy Act cover?

- General purposes of the Act.
- Definitions.
- Advocacy Commission.
- Delegation of powers.
- Advisory committees.
- Categories of organisations.
- Responsibilities of Advocates.
- Rights of Entry.
- Access to Records.
- Confidentiality.
- Miscellaneous including:
  – Offences in obstructing an advocate.
  – Unauthorised provision of advocacy services.
  – Improper disclosure by advocate or other.
  – Regulations.

The Advocacy Act was managed by An Advocacy Commission, which consisted of a chair and twelve other members.

7.24 Functions of The Advocacy Commission:

7.24.1 The 15 functions of the Advocacy Commission involved:

(a) Promoting respect for vulnerable persons and for their rights, freedoms, autonomy and dignity.

(b) Providing advocacy services,

(i) to help individual vulnerable persons to express and act on their wishes, ascertain and exercise their rights, speak on their own behalf, engage in mutual aid and form organisations to advance their interests, and

(ii) to help individual vulnerable persons who are incapable of instructing an advocate, if there are reasonable grounds to believe that there is a risk of serious harm to the health or safety of those persons.

(c) Providing advocacy services to help vulnerable persons to bring about systemic changes[14] at the governmental, legal, social, economic and institutional levels.

(d) Providing rights advice and other advocacy services required...{by 4 related acts}.

(e) Ensuring that community development strategies are applied in the provision of advocacy services.

(f) Ensuring that advocacy services are provided in a manner that takes into account the religion, culture and traditions of vulnerable persons.

(g) Ensuring that aboriginal communities are enabled to provide their own advocacy services whenever possible.

(h) Acknowledging, encouraging and enhancing individual, family and community support for the security and well-being of vulnerable persons.

(i) Conducting programs of public information and education about the Commission and the services it provides[15].

(j) Conducting programs of public information and education about vulnerable persons and their rights, freedoms, autonomy and dignity.

(k) Establishing minimum qualifications, standards and a code of conduct for advocates.

(l) Establishing criteria and procedures...(i),(ii),(iii).

(m) Establishing, subject to the approval of the Minister, and make available to any person on request, a written review procedure for dealing with complaints from any person relating to advocates.

(n) Providing training programs to advocates.

(o) Ensuring that advocates and community agencies comply with the procedures and standards established by the regulations made under this Act.
(Ref: Advocacy Act 1992:6,8)

7.25 The Repeal of the 1992 Advocacy Act

7.25.1 The 1992 Ontario Advocacy Act was viewed as an affirmative action measure in its time. The Act was repealed in 1996, because it was thought "*intrusive in the lives of vulnerable people, their families and care givers*"[16]. However, the legislative debates leading to its repeal, and the introduction of its replacement, were not without staunch opposition. Part of the debate on repeal was fiscal: revolving around the fact that the 1992 Advocacy Act's operating costs were approx. $30-50 million annually, including $18 million for the Advocacy Commission (Hansard). It was deemed too expensive and unwieldy. Some parliamentarians deemed the Advocacy Act adversarial and confrontational with an anti-professional bias. This was because the Act gave rights of entry into both private and public dwellings. It could be argued that it threatened the power and control of powerful players within systems.

7.25.2 Other parliamentarian's thought the assumption (for repeal) that families are the best placed to advocate on behalf of their members was misplaced. This view acknowledged that sometimes the family environment is extremely dangerous and the legislation acted as a strong protective measure[17]. The heated debates that led to its repeal are very interesting in terms of research for the development of an advocacy system in Ireland.[18]

7.25.3 However, the act was deemed to be intrusive into people's lives, and the lives of their families. Lessons can and must be learnt from this. Ontario learnt and (some would believe) moved on; introducing the Advocacy, Consent and Substitute Decisions Statute Law Amendment Act 1996 (Bill 19) in its place. It is debatable whether the new replacement is sufficient in safeguarding the rights of vulnerable people. Some parliamentarians[19] in Ontario believe it was wrong to repeal the Advocacy Act, and economics and professional power won out. In an interesting linkage to this document, Mrs Caplan (debate 1550[20]) recommended looking at the Australian Model as a "*do-able, affordable, possible alternative*". It is fundamentally important that in designing an advocacy system, Ireland learns from other models and practices from the best. An informed debate is required to prevent a quick fix solution; which would benefits few and leaves many behind, usually the more vulnerable.

7.26 Conclusion

This chapter outlined two alternate systems, Australian and Canadian, which could be tailored to design an Advocacy system in Ireland. The Australian model ensures advocacy is named and claimed within its legislative package; and each element designed to compliment one another and to progress the rights of Disabled People. An alternative system could be modelled on an Adapted Ontario Advocacy Act (1996). The Australian model takes a comprehensive, systemic approach, which places advocacy services and the development of advocacy as part of an overall package of measures (practical application, complaints, reviews, monitoring) and not isolated on its own. An adapted Advocacy Act appears attractive because it stands alone and may be quicker to implement.

The following chapter explores the possible structures of an advocacy service, funding arrangements, monitoring, accountability mechanisms and consultative processes in the design of an advocacy system.

8 Proposals for Staturory Reform

8.0 Introduction

According to Cooney (2000), before an advocacy service is established there needs to be a clear understanding of the constituency it is intended to serve. Many advocacy services in the UK are client specific, with a significant proportion serving clients with learning disabilities. Client specific advocacy, it is argued, makes sense in that it is likely to have a greater degree of clarity and consensus concerning its goals, operational procedures, etc. and to be better placed to develop a body of valuable expertise and case-lore. However, the provision of a service to one disadvantaged group in society at the possible expense of other disadvantaged groups (e.g. older people, mental health users, and children in care) can be questioned on moral and ethical grounds. It can be argued that a specialist advocacy service is undesirable because:

(a) The existence of separate advocacy services serving different populations is likely to confuse potential clients.

(b) It reinforces the damaging stereotypical image of disabled people as homogeneous populations distinct from the general population (i.e. a Traveller gay woman with a learning disability may have mental health problems and be an older retired person. To which specialist advocacy service should this person be referred? Which of the above multiple identities does this woman identify most with). Disabled people are not homogenous and they do not fit easily into a one-labelled box. Identities overlap and an advocacy service should reflect this.

(c) It is unlikely that any area will have enough specialist advocacy services to cover all client populations.

(d) There is a high probability of overlap and duplication of effort which would be wasteful.

8.1 Generic Versus Specialist (Advocacy Service)

The case for a generic advocacy service rests on the belief that an advocacy service should, as a matter of principle, be comprehensive and inclusive. It also acknowledges the importance of mainstreaming services as recommended in the Commissions report. The Forum of People with Disabilities favours a generic service, which is inclusive of all vulnerable persons in closed spaces regardless of a person's impairment or disability.

8.1.2 The Australian model highlighted in the previous chapter makes clear that numerous types of advocacy can co-exist effectively. According to Stewart (2001) this is a key element to which we here in Ireland could all constructively subscribe...the challenge is to develop a clear overall picture within which different systems of advocacy, with different mandates, can co-exist effectively.

However, it is essential for those vulnerable in terms of equality of access, participation and outcome that this overall picture is legislated and managed under the auspices of an independent Commission / Authority separate from state agencies.

8.2 The Structure of an Advocacy Service

How policymakers' structure an advocacy service is decisive for how the advocacy operates (Cooney 2000:2) It may be identified within a number of possible settings i.e.:

a) Placed within an existing authority structure i.e. (Health, Justice Equality and Law reform, Social Services).

b) Included as a separate office within a governmental department i.e. Department of Justice, Equality & Law Reform; Department of Health; Department of Social Services; Department of Justice;

Comhairle.

c) Included as part of an existing organisation/s, such as the legal aid scheme or NGOs.

d) Established as an Advocacy Commission and monitored under the jurisdiction of an Ombudsman.

e) Established as an autonomous, accountable Advocacy Commission.

f) Established as an autonomous, accountable private company / body.

8.3 Existing Government Structures

Advocates must be independent by statutory definition, permitting administrators or staff…sole responsibility for advocacy would be like letting the fox guard the henhouse.
(Cooney, T., 1996:297)

Placing an advocacy system within an existing government structure presents conflicts of interests and disadvantages. The conflict would arise as they involve decision makers whose decisions impinge upon the rights and interests of people within their own services whether this is psychiatric hospitals / services, general hospitals, residential or day services, prisons, children's homes or community houses / hostels.

Making the advocate answerable to the very decision makers whose decisions he or she may wish to challenge might compromise the advocate's partisan role. The advocacy in this sense may be perceived as someone whose primary responsibility is not to the individual but to the bureaucracy. (Cooney, T., and O'Neill, O (2000:2)

8.4 Government Departments

Placing an advocacy service within a Government Department would subject it to the control of the executive branch of government. The partisan character of the advocate’s role requires the elimination of any actual or apparent executive influence or pressure or manipulation (Cooney 2000:2).

What is clear from research, and practice is that advocacy must be independent and partisan if it is to be effective. Independent in the sense that it is independent from Departments of State including Health and Justice, Equality & Law Reform, General Services, Institutions, Courts or the voluntary sector. Advocacy must not only be independent in practice, but also be seen to be independent.

8.5 Legal Aid Scheme

The premise for locating the advocacy service within the legal aid scheme is the conviction that the best vehicle for guaranteeing a vigorous advocacy service is an independent non-political organisation possessing a tradition of representation. Use of the legal aid scheme would have the obvious advantages of management, advisory and litigation expertise. However, there are compelling reasons to avoid this option (Cooney, 2001:3). The legal aid scheme[21] is overworked and under-financed[22] Over 90% of the legal aid scheme’s business involves family law issues and few lawyers within the scheme have knowledge of disability issues, mental health law and bureaucracy (ibid: 2). In this context, the layers would not have the appropriate training for aggressively challenging psychiatrist / consultant / general practitioner’s opinions. Another compelling reason not to solely pursue this option is because it restricts advocacy to legal advocacy and does not recognise other forms of social or systemic advocacy. This is not to deny that advocates should have knowledge and training in some aspects of law relevant to their situation, but it does recognise that other forms of non-legal advocacy are equally important.

8.6 Funding

8.6.1 Careful consideration must be given as to how an advocacy service should be funded. This is perhaps one of the most crucial decisions facing an advocacy service as the nature of the funding will influence the extent to which the service can operate independently (Dunning 1995). Advocacy services should analyse the source its source of funding. It is important in the establishment of an autonomous advocacy service, that it avoids getting into a situation of 'biting the hand that feeds you' and conflicting interests.

8.6.2 Where advocacy services are funded by statutory agencies (i.e. Department of Health; Department of Justice, Equality & Law Reform) there is a growing trend to adopt service agreements. This trend is undesirable for the following reasons:

(a) The adoption of the purchaser-provider model places at risk the integrity of an advocacy service.

(b) If an advocacy service is contractually linked with the funder in the provision of its service then it will be directly answerable to that contractor. This relationship immediately breaches the independent position of the advocacy service.

(c) With service agreements, there is likely to be pressure to disclose information about the people represented, and how they are represented. This creates a risk of leakage of confidential information. It may also encourage doubts in the users of the service as to the extent the service can protect confidentiality. Some people may not wish to associate with the service around advocacy if the impartial nature of the service was in question.

(d) Service agreements are likely to lead to the bureaucratisation of the service provided (ie. increased paperwork and form-filling; constant demand for statistical returns; the perception of clients as units and not people and the power base remaining with the service managers).

(e) The obvious value of the service agreement for the funder is that it enables it to retain control and prevent professional encroachment. It places a check on the process of client empowerment and by default professional disempowerment.

(f) Funding which is filtered through statutory departments becomes diluted because there are more managers managing the money. More managers means that less resources reach advocates and advocacy services at grassroots level.

8.7 Recommendations for Funding

Funding could come through a variety of sources. An Independent Advocacy system requires to reflect carefully about who funds the service. Some options are explored within this section:

(a) There should be no direct funding link, nor contractual relationship between statutory agencies and advocacy services.

(b) Funds should be channelled through a central government agency i.e. Advocacy Commission / Authority.

Or;

(a) Funds should be provided through a free-market model, with advocates named as shareholders within the service or paying a subscription or fee similar to union membership (this would automatically exclude and discriminate against lower socio-economic and vulnerable groups).

(b) Public Funding should be made contingent on the adoption by the service (*advocacy*) providing organisation of an agreed programme to encourage the participation and representation of Disabled People in management and decision making (Final Report 1995:31).

(c) Funding should be monitored according to the representation of people similar to that within, the draft report of the disability advocacy programme review[23] in Australia.

(d) Funding Accountability should be managed through a properly worded, Autonomous Advocacy Service Agreement, which would allow it to be open to scrutiny, accountability and complaint to its central governing body.

(e) This document does not endorse the commissions recommendation (*A Strategy for Equality*, 1996:329) that for people with mental illness, the Patient Advocate should by funded by the Department of Justice, Equality and Law Reform. Patient Advocacy should be independent of state departments.

8.8 Criteria for Appointment – Advocacy Board

Disabled people should constitute a majority proportion of the Advocacy Board (*service*) to ensure that disabled people have a significant chance of influencing decisions and policy development. This requirement should be mandatory, a reasonable proportion being 60% minimum, inclusive of older people, minority representatives and a % of family members.

Records of the proportional criteria of membership must be open to the public and monitored. If it is deemed that a sizeable proportion of disabled people do not have the relevant skills or knowledge (through the inequalities of the educational system), then positive discrimination and affirmative action must be shown. This would be in terms of allocating funding for training and education for the target group to ensure the majority criteria.

8.9 The Monitoring and Accountability of an Advocacy System requires:

(a) The study of policy outcomes.

(b) Developing monitoring indicators and systems, specific guidelines and codes of practice for advocates, the advocacy system, funding, Commission and those represented.

(c) Undertaking focused reviews of policy and practice.

(d) Comprehensive equality proofing; evaluation of services with regard to equality of outcome.

(e) Comprehensive disability and equal opportunities proofing.

8.10 Conclusion

It is clear that an independent advocacy system must be independent of government departments and existing government structures. This lends the view to a completely new autonomous accountable Advocacy Authority. It is also clear that advocacy provision if it is to be credible and independent, must be centrally funded from Government, if it is not to be compromised in its integrity through departmental service agreements.

An accountable autonomous advocacy system must also be clear in its mechanisms to ensure equality of participation for disabled people in its management and decision making processes.

9 Recommendations & Conclusions

9.0 Introduction

> *"Our own great frustration is not that anybody says the wrong thing but that nobody does the right thing."*[24]

9.0.1 This quote seems apt in relation to advocacy in Ireland. Rhetoric has been around for a long time where official reports pay lip service to advocacy, referring to it only in aspirational terms[25]. One advocate's view is to "Stop messin' about with Advocacy" (McCormack 2001). This basically says it all. Government and state bodies and departments need to 'stop messin' about'. Advocacy requires affirmative action and governmental inaction in this area suggests legislation is the only route to take. It must be enshrined in statute as a claim right.

9.0.2 Some people require extra and additional resources in order to access their constitutional and human rights to self-determination in making rights enforceable. This is particularly true for disabled people within closed environments such as total institutions, hospitals, hostels, residential care, prisons, children's homes & workshops. Advocacy is an effective and necessary tool to access self-determination and so extra and so unequal treatment is required.

9.0.3 Systemic advocacy is vitally important in terms of developing the capacity of vulnerable people and marginalised groups. Start with people themselves and build up; not the other way about. It is about redressing the silence and silencing of disabled people within powerful structures. Systemic Advocacy is also vital in informing and developing social policy and practice.

9.0.4 In Ireland, there have been numerous enquiries into abuse and neglect both at a statutory and voluntary level. In the past there were no safety mechanisms in place for disabled people, either on an individual or a collective basis. It is questionable without a comprehensive advocacy system in 2001 as to whether this has changed in Ireland. It is not good enough to trust services and organisations (whether state or voluntary) to monitor and regulate their own services, when the central voices of disabled people are silent and silenced through inaction, lack of support systems and a lack of affirmative action policies on advocacy. This includes children, adolescents, adults and older people. What is required is a 'cradle to the grave' systemic advocacy system which targets in particular vulnerable people within closed environments.

9.1 Current situation

9.1.1 (a) In 2001, there is no Disability Act, Disability Commissioner, Disability Commission, Advocacy Act, and no accessible, comprehensive complaints and monitoring mechanisms in Ireland

(b) There is no independent agency / commission dedicated to promoting, assisting, monitoring and funding or developing advocacy initiatives, training, research or services in Ireland. There is sod all.

(c) There is no consistent investment made into advocacy provision in Ireland either on a regional or at a central level.

9.2 Legislative Alternatives for Advocacy could include:

(a) The development of an adapted Advocacy Act similar to Ontario, Canada.

(b) Creating and developing an Advocacy Authority/Commission monitored under an independent Ombudsman's department (the Ombudsman's office would not provide direct representation for the Advocacy Authority / Commission, only a monitoring role).

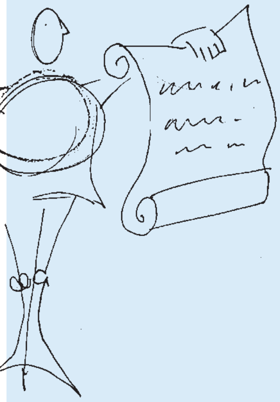
(c) Creating an Advocacy Authority and Advocacy Investigations Office similar to the Equality Authority and Department of Equality Investigations,

(d) Placing Advocacy Services, with its own Advocacy Authority monitored under the Irish Human Rights Commission.

(e) The Development of an Advocacy Commission monitored under an Office of The Ombudsman.

(f) Naming Advocacy as a claim right within a Disability Act, Mental Health Act, Disability Commissioners Act & Disability Commission Act within a legislative package similar to Australia.

9.3 The Forum of People with Disabilities makes the following recommendations for the development of an independent advocacy system, which is inclusive of all disabled people, and in particular those most vulnerable within closed environments. These recommendations are based on the information contained within the reflection document, the process of consultation and feedback in which it involved, and 11 years experience as a collective advocacy organisation. The recommendations are as follows:



(a) Action and/or emancipatory research needs to be undertaken by a neutral, competent body in order to research advocacy practices and provision in Ireland for disabled people. The NDA could under their legal remit, resource and tender this out to a relevant university department.

(b) Advocacy systems must be systemic and include affirmative action policies designed to develop the capacity of disabled people to represent themselves and their own communities.

(c) The term ‘vulnerable’ requires to be legally defined. The Forum suggests learning from the Ontario Advocacy Act in this regard.

(d) The term ‘closed spaces’ requires to be legally defined. The Forum suggests learning from the Ontario Advocacy Act in this regard.

(e) Advocacy must be framed within Human and Civil Rights Language as a Rights Issue. Advocacy requires to be a claim right which, people can name and claim easily.

(f) Affirmative Action is required in relation to Ireland meeting its obligations under International Conventions for vulnerable and disadvantaged groups, in relation to the representation of their interests via advocacy. This is in terms of legislation and additional economic resources.

(g) Advocacy must be named and detailed within a pro-active and anti-discrimination legislative package similar to that of Australia, which enables the legislator to take affirmative action.

(h) There should be a charter of rights and accessible information in relation to advocacy; detailing exactly what advocacy means, the role of an advocate, how to access an advocate and available support in becoming or being an advocate.

(i) Education systems must be established for the formal training and accreditation of advocacy workers linked to universities, and which are pro-actively accessible to disabled people.

(j) A code of practice on advocacy should draw on charters produced by the UN and should centrally involve consultation with disabled people. The code should inform best advocacy practice, protect and support advocates and those who they are advocating with or / or on their behalf.

(k) An advocacy system should include comprehensive monitoring and complaints procedures.

(l) The Offices of the Ombudsman, Inspectorate of Mental Hospitals, The National Disability Authority, Comhairle, The Law Reform Commission, The Human Rights Commission and the European Committee for the prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) should all be utilised and lobbied by NGOs to promote a generic, systemic advocacy system, within their annual reports, as defined within this document.

(m) Advocacy services should be independent of service providers (A Strategy for Equality 1996:106 4.47).

Independent advocacy services should be mandatory in residential care settings or similar services (ibid: recc 33 pg 19.47).

The provision of advocacy should be incorporated into any legislation dealing with particularly vulnerable people in residential settings (ibid: recc 48 pg20: 4.49).

The post of Independent Advocate needs to be established by statute.

(n) NGOs should re-negotiate the current terms of the PPF within the next twelve months to actively promote a Generic Independent Advocacy system, which prioritises advocacy systems for disabled people in closed environments. This would help address the unacceptable levels of social exclusion and poverty, disabled people experience and would acknowledge the recommendations from the 1996 Commission's report.

(o) The Law Reform Commission should be pro-active in:

- Recommending that independent systemic advocacy systems be enshrined in statute for vulnerable persons in closed environments.
- Assisting in the development of a package of pro-active and anti-discrimination legislation which recommends advocacy as a claim right.
- Playing an active role in monitoring an independent, generic advocacy system, in which specialisms can co-exist.

(p) Specific reform is urgent and necessary in relation to Guardianship, and new legislation with comprehensive regulations addressing the provision of a Guardian ad litem system must be put in place. A GAL should be an officer of the court and independent of all other parties (Giving Children a Voice, 2001).

- Specially trained solicitors should provide legal representation for children, working with or without a GAL (ibid:5).
- The government should establish and fund an independent guardian ad litem service (ibid:4).
- Section 25 &26 of the Child Care Act, 1991 should be repealed to include a new part of the Act drafted, headed '*Representation for Children*' (ibid:43).
- Article 41 of the Constitution should be amended to ensure that the right of children to have their welfare protected is given the prominence it deserves (ibid: 4).

(q) Statutory Departments who already have advocacy as a named part of their role under law (Comhairle) should be mainstreamed under an Independent Generic Advocacy System. This would ensure that advocacy funds are used effectively and would avoid duplication.

9.4 Conclusion:

This paper as stated in the introduction is not a legal or academic document. It is a discussion / reflection document designed to inform and stimulate debate and discussion on advocacy. It has taken the recommendations from the commissions report of 1996, updated and replaced them in the public and policy making arena for reflective, informed debate and action. It is clear that there is a need for independent action research in this area, in which disabled people are central to the process. There is also a need for affirmative action by disability activists and NGO's to lobby Government to legislate for the right to advocacy for disabled people in closed environments.

9.4.1 The Forum of People with Disabilities call immediately on Government to address advocacy as a human and civil rights issue, enshrined within a package of pro-active and anti-discrimination legislation, which all disabled people within closed environments can claim.

9.1.6 The Forum of People with Disabilities proposes that the Australian model of advocacy would best suit Ireland. This means naming advocacy within a legislative package i.e. a Disability Act; a Commission; a Disability Services Act and a Community Services (Complaints, Appeals and Monitoring) Act. What is required is the dual pronged approach of non-discrimination legislation and affirmative action. It is clear that the upcoming Disability Act in Ireland should name and detail advocacy within it, which recognises independent, systemic advocacy. However, a Disability Act is only one element within a future legislative package. It is also clear that a central system of substantial funding needs to be made available to implement the recommendations.

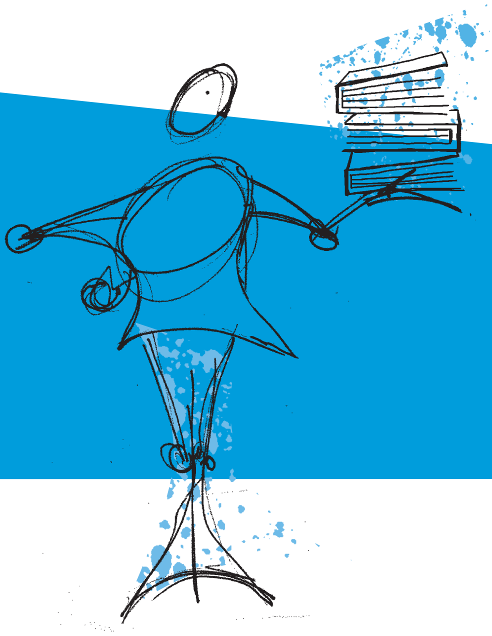
9.1.6 The Forum suggests that until an agreed legislated form of autonomous accountable advocacy is enacted as a claim right, advocacy and the representation of interests for disabled people will be tokenistic on the part of the State and service providers.

Appendix

Access to Communication – Recommendations (Cousins, 1995:15-16)

- All public documents should be provided in a range of appropriate formats, including large print, Braille, and on audiotape. The provision of a reader service is also an essential requirement in order to allow access to communication.
- In the case of people whose first language is not a spoken language or for those who do not communicate orally, appropriate interpretation facilities must be made available.
- People who are able to read sign language should be employed in all public services.
- Access to communication should be facilitated through the use of new technology and technical aids, including the internet.
- "Disability Proof" all information.
- Provision of a video information processing agency (such as that already established by the Irish Deaf Society).
- All those working with the deaf should have sign language and Irish sign language (ISL) should be recognised as an official language of the country and taught as a mainstream language option at all levels of the education system.
- Alternative communication strategies ought to be developed. The use of pictorial representation i.e. line drawings and photographs can enable individuals to self-advocate. Alternative communication strategies can also move a person's legal status from 'incapable' to 'capable'.

Bibliography



Advocacy Act
(1992), Statutes of Ontario, 1992 General (O.Reg. 33/95) Queen's Printer for Ontario.

Advocacy Ireland Movement (1994) Submission by the Advocacy Ireland Movement to the Commission on the Status of People with Disabilities (Dublin)

A Strategy for Equality
(1996), Report on the Commission of the Status of Disabled People. Dublin. Government Publications

Australian Advocacy Network
(http://www.ecu.edu.au/ses/research/disability/advocat/advocat.html)

Birmingham, D.,
(2000) *The Politics of Advocacy: An Egalitarian Critique.* An Exploration into the Representation of Interests for people with Learning Disabilities. Unpublished Ms. Thesis. Equality Studies Dept. University College Dublin.

Brandon D.,
Brandon A., and Brandon T. (1995), *Advocacy, Power to Disabled People.*
Birmingham: Venture Press

Bresnihan, V.,
(2001), *The Politics of Prison Medicine:* Follow-up discussion paper to Out of Mind, Out of Sight, Solitary Confinement of Mentally Ill Prisoners. Irish Penal Reform Trust, Dominic St, Dublin 1.

CAIT
Citizen Advocacy Citizen Advocacy Information & Training, 162 Lee Valley Technopark, Ashley Road, London N17 9LN Tel: 0288804549
Disabled Peoples' International (1981)

Collins, M .,
Minority Ethnic Groups (1996) (Eds) Proceedings of Conference held on 27 September 1996, St. Patrick's College Maynooth. Printing Office, UCC. Cork.

Comhairle Act,
(2000). Government Publications. Dublin.

Comhairle
Strategic Plan (2001 - 2003). *Hume House Ballsbridge, Dublin 4.*

Comhairle
(2000) *Entitlements for people with disabilities. Nov 2000. Hume House Ballsbridge, Dublin 4.*

Comhairle (2001)
Unpublished feedback on document 'Advocacy: A Rights Issue' to Birmingham 9/11/01 at Forum of People with Disabilities

Cooney, T., O'Neill, O (1996),
Psychiatric Detention: Civil Commitment in Ireland. Delgany Co. Wicklow: Baildonur. Kritok: no 1.

Constitution of Ireland, Bunreach na hÉireann (1937). *Government Publications Office, Dublin.*

Cooney, Tom.,
(2001), *Advocacy*. Unpublished paper presented at a working group for the Forum' of People with Disabilities (16-05-2000). Impact.

Cooney, Tom.,
(1994), *'Empowerment & the need for legal guarantees'* in Frontline. May-July 1994:20-21. Wordwell Press.

A Reflection Document On A Cost of Disability Payment (2001), Rahaheen Ltd & The Forum of People with Disabilities.

Cousins, Mel.,
(Jan 1995) *Policy Analysis of Submissions*. Commission On the Status of Disabled People.

Crawley, B.,
(1988), *The Growing Voice: A Survey of Self-Advocacy Groups in Adult Training Centres and Hospitals in Britain.* London: CMH

Degener, T., Quinn, G.
(22-26 Oct 2000), *A survey Of International, Comparative and Regional Disability*

Law Reform. Paper presented at the 'From Principles to Practice' Symposium Washington *D.C.*

Dooley, Raymond.,
(2001a:3-7) *Meeting Children's Needs, Safeguarding Children's Rights.* Childlinks: The quarterly Journal of Barnardo's National Children's Resource Centre. Dublin. Millennium Publications.(Spring Ed.)

Dooley, Raymond,
(2001b) Unpublished Feedback on Document "*Advocacy: A Rights Issue*" to Birmingham 15/10/2001 Forum' of People with Disabilities

Dunning A., (1995),
Citizen Advocacy with Older People: A Code of Good Practice, Centre for Policy on Ageing, London.

Final Report,
(June 1995), *Working Group On The Rights of Disabled People*. Commission On the Status of Disabled People.

Focus Ireland
(2000), "*Left Out on Their Own: Young People Leaving Care In Ireland*" Executive Summary. Focus Ireland.

Foucault. Michel
(1997) (Eds), *Madness and Civilization: A history of Insanity in the Age of Reason.* London. Tavistock Press, first published as Folie et Deraison (1961).

Frontline
(1996:3)(Eds), *'The Triumph of Accountancy over Compassion',* Frontline. Dublin. Wordwell Press.

Giving children a voice
(May 2001), A report by the Guardian Ad Litem Group "The case for the independent representation of children". Dublin. Law Society, Blackhall Place.

Gunn, Wong, Clare, & Holland
(1999), '*Decision-Making Capacity'* Medical Law Review. Autumn 1999 269-306

Hansard
Reporting & Interpretation Services regarding the Advocacy Act, 1992.
www.ontla.on.ca/
http://hansardindes.ontla.on.ca/hansardiessue/36-1/1030.html 2nd reading of Bill 19, Advocacy, Consent and Substitute Decision Statute Law Amendment Act 1995.

Hurst, Rachel.,
(1995), *"Choice, Empowerment-Lessons from Europe".* Disability and Society. Vol 10. No.4. (529-534)

Irish Deaf Society
(1999), "*Advocacy & Public Relations Techniques to Promote Equal Opportunities for Deaf People*" in partnership with 'Associacao Portuguesade Sourdes', 'Deutscher Gehorlosen-Bund V', 'Ente Nazionale Sordomuti'. Supported by European Commission DGV and EU of the Deaf.

Kennedy & Grubb
(1994), *Medical Law, Text with materials*. London at 87.

Keys, Mary
(2001) Unpublished Comments on "Advocacy: A Rights Issue" Document (feedback) to Birmingham at the Forum of People with Disabilities.

Keys, Mary.,
(Feb 2001) "*Advocacy in Action: A Legal Perspective*" Paper given at Conference of Kerry Citizens Information Service and Kerry Network of Disabled People in Killarney

Marchese, Rosario
(1620) in http://hansardindes.ontla.on.ca/hansardiessue/36-1/1030.html

NDA
(2001) Disability in the Mainstream: Moving Forward Together. National Disability Authority. Dublin.

NDA
(2001-2003) A Matter of Rights: Strategic plan 2001-2001. National Disability Authority. Dublin.

Hudson, Bob.,
(1988), 'Do People with a Mental Handicap have Rights?' *Disability, Handicap & Society.* Vol. 3, No. 3: 227-334.

Hurst, Rachel.,
(1995), *Choice, Empowerment-Lessons from Europe"* Disability and Society. Vol 10, No.4. 1995 (529-534)

ICCL
(Irish Council of Civil Liberties) (26-06-01) European Convention on Human Rights Bill: submission to Joint Oireachtas Committee on Justice, Equality.

Irish Penal Reform Trust Court. Report
(2001), '*Out of Sight, Out of Mind; Solitary Confinement of mentally Ill Prisoners'*
Irish Penal Reform Trust. Dominic 41 Lower Dominic Street., Dublin 1. Email
info@penal-reform.ie

Jackson J.,
(1991), Learning Disability and advocacy: Obstacles to client empowerment. Journal of Learning Disabilities, Vol. 3, No. 1 Mar. Churchill Livingstone.

Madden, Deirdre.,
(2000), *'Capacity and Consent'* Unpublished paper presented at NAMHI conference. 12th May 2000.

Mc Ateer, Teresa
(1999), '*The Varying Perspectives on Equality in Irish Law*'. Unpublished paper presented at equality workshop. UCD

McCormack, Rory.,
(2001), Unpublished communication (28/09/01) re: "*Advocacy A Rights Issue"* to Birmingham D., Forum' of People with Disabilities

Mc Donagh, Rosaleen.,
(2001) Unpublished communication (9/10/01) re document "*Advocacy: A Rights Issue*" to Birmingham D., Forum' of People with Disabilities.

Minow, Martha.,
(1990:18-79), *Making All The Difference: Inclusion, Exclusion, and American Law In Degener &Quinn (*2000)

Murphy, Kevin.,
(2001) Unpublished feedback from the Ombudsman re: Document "*Advocacy: A Rights Issue*" 27th September 2001 to Birmingham, D., Forum' of People with Disabilities.

NDA
(National Disability Authority) (2001) Submission to the Department of Health and Children on The Mental Health Bill 1999.

NDA Act
(1999) *National Disability Authority Act.* Government Publications Office. Dublin.

NEDA National Ethnic Disability Alliance
http://members.ozmail.com.au/~neda/main.html

O’Connell, Donnacha
(21-07-2001), Quote from unpublished speech @Annual Human Rights Forum. Department of Foreign Affairs. Dublin Castle.

O’Connell, Donnacha
(2001), Unpublished feedback on Document ‘Advocacy: A Rights Issue’ given at 2nd working group 17th September 2001. Forum of People with Disabilities in The Equality Authority. Dublin.

O’Sullivan, Sean
(1987), “You’ve Got a Friend”. Report on advocacy cited in Hansard debates. Ontario. Canada. 36-1/1030html
http://hansardindes.ontla.on.ca/harsardiesur/36-1/1030.html

Phillips, Anne.,
(1993), *Democracy and Difference.* Polity Press. Cambridge. UK.

Phillips, Anne.,
(1995), *The Politics of Presence.* Polity Press. Cambridge. UK.

P.P.F.,
(1999), *Programme for Prosperity and Fairness*. Government Publications. Dublin.

Power, Kevin
(2001) (Ex-Advisor to Advocacy Ireland Movement), Personal Communication to Birmingham D., Forum’ of People with Disabilities.

Quinn, G.,
(2001-21-July), *Towards a UN Convention on the rights of Persons with Disabilities.* Keynote address given at the Department of Foreign Affairs Annual Human Rights Forum. Dublin Castle.

Quinn, G.,
(20-21 –2001) “Toward Principle in Politics: seeing NAMHI as a Human Rights Defender” paper presented at the AGM of NAMHI, Kilkenny.

Quinn, G., McDonagh, M., Kimber, C.,
(1993) Disability Discrimination Law in the United States, Australia and Canada. Oaktree Press. Dublin.

ECPT Report (1999)
Report to the Irish Government on the visit to Ireland carried out by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) from 31 August to 9 September 1998. Strasbourg/ Dublin, 17 December 1999
Relevant Web sites: http://www.cpt.coe.int/en/refdocs/ecpt.htm
& http://www.cpt.coe.int/en/press/20000518en.htm

Report of the Inspector of Mental Hospitals
(2000), Government Publications. Dublin.

Scheerenberger R C
(1987) A History of Mental Retardation: a quarter century of promise. Brooks Publishing, Baltimore.

Simmons K.,
(1993) Citizen Advocacy: The Inside View. The Norah Fry Research Centre. Bristol.

Stanley, Kevin.,
(2001) Unpublished feedback on Advocacy: A Rights Issue. Forum of People with Disabilities

Strichart S, Gottlieb J.,
(1980) Advocacy through the eyes of citizens.

Sullivan, Sean
(1987), '*You've Got a Friend'* Report on advocacy cited in Hansard debate, Ontario, Canada. http://hansardindindes.ontla.on.ca/hansardiesur/36-1/1030.html

Steward, Jiff.,
(2001), unpublished personal comments on Advocacy: A Rights Issue document given to Birmingham, D., (05/09/01) Forum' of People with Disabilities

Toolan, Donal.,
(2001) Unpublished personal comments on *Advocacy: A Rights Issue document Forum'* of People with Disabilities

Towards Equal Citizenship
(1999), Progress Report on the Status of Disabled People. Dublin. Government Publications

Travis, D.,
(1994), '*Report on the results of a survey into self-advocacy in Ireland, Power to the People!.* May-July. Frontline. Dublin: Wordwell Press.

United Nations Declaration on the Rights of Mentally Retarded Persons
(20 Dec 1971)(Resolution 2865), United Nations. New York.

WertheimerAlison.,
(1998), '*Citizen Advocacy: A Powerful Partnership*', CAIT. Printed Intertype, 307 Aberdeen House, 22 Highbury Grove, London. N52EN.

Information on why the Ontario Advocacy Act 1992 was repealed,
check:www.ontla.on.ca/

36th Parliament, 1st Session	Issue no.	Date
1st reading	L023	15 Nov 1995
2nd reading	L028	22 Nov 1995
3rd reading	L030	27 Nov 1995
4th reading	L044	20 Mar 1996
5th reading	L045	21 Mar 1996
6th reading	L046	25 Mar 1996
7th reading	L047	26 Mar 1996

Useful Links

Comhairle: Independent information, advice and advocacy services on entitlements and social services. Hume House, Ballsbridge, Dublin 4. Ph; 6059000 Fax: 6059099 Email: comhairle@comhairle.ie Web: www.comhairle.ie
Citizens Information Database www.cidb.ie OASIS-www.OASIS.gov.ie

Citizen Advocacy
Citizen Advocacy Information & Training, 162 Lee Valley Technopark, Ashley Road, London N17 9LN Tel: 0288804549
www.citizenadvocacy.org.uk Email:cait@teleregion.co.uk

Partners in Advocacy (http://www.partners.dabsol.co.uk/aboutadvocacy.html)
webmaster@partners.dabsol.co.uk

Galway Citizen Advocacy Project, Josephine Flaherty. Failte House, Castlepark Road, Ballybane, Co Galway. Ph: (091) 593286

The Forum' of People With Disabilities (A Rights Based Organisation) 21 Hill Street, Dublin 1. Ph: 8786077 Fax:(01)-8786170 Email: Inforum@indigo.ie Website: www.inforum.ie

'*The Union on Hill Street'*: Self Advocacy Group. c/o 21 Hill Street, Dublin 1 Ph: (01) 8786077 Fax: (01) 8786077 Website: www.inforum.ie

Age Action Ireland: 30 Camden Street, D. 2 Ph: (01) 6779892 Fax: 4756011 Email ageact@indigo.ie

Arts and Disability, City Arts Centre, 23/25 Moss Street, Dublin 2 Ph: 6770643 Fax: 6770131 Email: cityartcentre@eircom.net

Ombudsmans Department: Kevin Murphy, 18 Lower Leeson Street, Dublin 2. Ph: (01)6785222 Fax; (01)6610570

National Disability Authority, 25 Clyde Road, Ballsbridge, Dublin 4. Ph: 6080400

Equality Authority, Clonmel Street, Dublin 2. Ph: (0104173366 Fax: (01)4173366 Email infor@ equality.ie Web www.equality.ie

NAMHI, 5 Fitzwilliam Place, Dublin 2. Ph: (01) 6766035

FLAC (Free Legal Aid Centre), 49 Sth. William Street, Dublin 2. Ph (01)6794239 Fax: (01)6791554

Irish Council of Civil Liberties, 40-41 Lower Dominic Street, Dublin 1.
Ph:(01)8783136/7 Fax: (01)8783109 Emai iccl@iol.ie www.io.ie

High Commissioner for Human Rights. www.unhcr.ch

Human Rights Commission. 17-19 Lower Hatch Street, Dublin 2.

Human Rights Commission. Northern Ireland. Ph: 048 90243987.

Children's Rights Alliance, 13 Harcourt Street, Dublin 2 Ph: (01) 4054823 cinfo@cra.iol.ie

Disability Federation of Ireland. John Dolan. 2 Sandyford Office Park, Dublin 18. Ph: (01) 2959344/5 Fax: (01) 2959346 Email: info@disability-federation.ie Web http://ireland.iol.ie/~dfi/

People with Disabilities Ireland (PWDI) Richmond Square, Morning Star Avenue, Dublin 7 Ph:(01) 8721744 Fax (01) 8721771 Email: info@pwdi.ie

Disabled Peoples' International (DPI) 11 Belgrave Road London SWIV IRB Ph: 00441718340477 Fax 00441718219539

Irish Deaf Society, 30 Blessington Street, Dublin 7 Ph: (01) 8601878 Fax: 8601960 Email: ids@indigo.ie Web Site: www.irishdeafsociety.org

Ahead – Association for Higher Education Access and Disability, Newman House, 86 St Stephen's Green, Dublin 2 Ph: (01) 4752386 Email: ahead@iol.ie

Enable Ireland, Sandymount Avenue, Dublin 4. Ph (01) 2867543

Centre for Independent Living, Carmichael House, North Brunswick Street D.7. Ph: (01) 8730455 Email cildub@iol.ie

Carers Association, Metrepole Centre, James Street, Kilkenny Ph: 1800 240724 Email information@carersireland.com

SIPTU Services Industrial Professional & Technical Union Liberty Hall, Dublin 1 Ph: (01) 8749731

The Office of the Ombudsman, 18 Lower Leeson Street, Dublin 2 Ph: (01) 678522

GROW, Mental Health Movement, 11 Liberty Street, Cork. Ph 021 277520 Fax; 02127350

Irish Penal Reform Trust, Dominic Court, 41 Lower Dominic Street, Dublin 1. Ph (01) 8720344 Fax: (01) 8720399

Irish Traveller Movement, 4-5 Eustace Street, Temple Bar, Dublin2 Ph: (01) 6796577 Fax: (01) 6796578

Lights Disability Action: Contact Peter Kearns, Coolock Development Centre, Bunratty Drive, Coolock, Dublin 17 Ph: (01) 8470160

Disability Awareness in Action, 11 Belgrave Road 0044 1718340477 Fax: 00441718219539

Mental Health Advocacy Links

Mind Yourself & Foyle Advocates: 15 Magazine Street, Derry. Tel: 048 71263461, Fax: 048 71263318

Mental Health Matters (formally Mind Matters): Unit 1b 26/17 Portland Street North, North Circular Road, Dublin 1. Ph: 01 8658293

Irish Advocacy Network: Old Rooskey Building, Rooskey, Co. Monaghan Ph: 04738918 Mobile: 087-9800445

Patient Advocacy Services: Margaret O'Connor, The White House, St. Mary's Hospital, Castlebar, Co. Mayo Ph; 086 8141788

ACORN: Brendan Core, c/o Tus Nua Resource Centre, Unit G, Ballymun Shopping Centre, Dublin 11

Cork Advocacy Network: Jean Hamilton, Dromina, Charville, Co. Cork, Ph: 063 70435

Kerry Advocacy Network: Ciaran Crowe, 79 New Street, Killarney, Co. Kerry PH: 066 7123655

Schizophrenia Ireland, 38 Blessington Street, Dublin 7. Ph: (01) 8601620 Fax: (01) 8601602 Helpline 1890–621631 Home Page: http://www.iol.ie/lucia email schizi@iol.ie

Mental Health Association of Ireland, Mensana House, 6 Adelaide Street, Dun Laoghaire, Co. Dublin Ph: (01) 2841166 Email:mhai@iol.ie Website: www.mensana.org

[1] Barnes, C., Oliver, M., (1995) *Disability Rights: Rhetoric and Reality in the UK. Disability & Society, Vol. 10. Barton, L., (1996) Disability and Society: Emerging Issues and insights. US: Longman.* Oliver, M., (1990) *The Politics of Disablement. London: MacMilan Education LTD.* Oliver, M., (1996*), Understanding Disability, From theory to Practice.* Morris, J., (1991) *Pride and Prejudice,* The Women's Press: London.

[2] Degener & Quinn (2000:22) found anti-discrimination laws in the following countries: Australia, Austria, Bolivia, Brazil, Canada, Chile, China, Costa Rica, Ethiopia, Finland, Fiji, France, Gambia, Germany, Ghana, Greece, Guatemala, Hong Kong (SAR), Hungary, India, Ireland, Israel, Korea, Luxemburg, Madagascar, Malawi, Mauritius, Namibia, New Zealand, Nicaragua, Nigeria, Philippines, South Africa, Spain, Sri Lanka, Sweden, Switzerland, Uganda, United Kingdom, United States, Zambia and Zimbabwe.

[3] Power differentials in advocacy and the representation of people need to be identified, for example, is it fair for an individual to partake in a forum on a 'perceived' equal basis with doctors and an array of credentialised professionals if that person has had unfair advantage in education, training, life experience and the accumulation of cultural capital? Is the presence of a self-advocate in this example, without addressing power and structural imbalances, simply tokenism? According to Phillips, representation as currently practiced rests on what most practitioners will admit is a pretence (Phillips, 1995:53). Can proceedings be equal when one party may not understand or is unable to partake in the language and established rules because of societal disadvantage and unequal privilege? Issues of some people feeling disempowered and at times humiliated in such proceedings are left un-addressed unless the fundamental question of power within advocacy and representation is addressed. In the words of one advocate "*people from services would sometimes get someone with learning difficulties and disabilities on the media who could not speak up. People with learning disabilities should be taught to speak up for themselves and should not be afraid*" (Lawlor, Rita in Birmingham 2001:62). Mechanisms of advocacy must not humiliate the advocate or those they represent. There needs to be a commitment of independent resources and mechanisms to build the confidence and capacity of disabled people. This means in terms of education, training and experience in order that advocates can participate equally, either directly in person or if unable to self advocate, through an accountable other.

[4] The Forum of People with Disabilities successfully organized its first campaign in 1990 on the most basic of all civil rights: the right to vote. Up until 1990, disabled people who wanted a postal vote in an election had to go through a process of having a doctor declare them SANE. The Forum successfully organized a campaign to force the Government to change this offensive law. However, in 2001, despite the success of the 1990 campaign, many disabled people within closed environments are not registered and are not supported to exercise their vote.

[5] The right to communication and information available in a medium appropriate to the individual is essential in order to enable full and independent participation in society (Rule 5b of the Standard Rules of the Equalisation of Opportunity). This right underpins the exercise of all other constitutional and Human rights. Communication is essential to advocacy, to communicate in a medium appropriate to the individual, which enables them to get their opinions and views understood. The submissions made to the commission have made clear that, this right to communication is severely limited (Final Report, 1995:15, Recommendations for Communication in appendices no. 1) According to the chairperson of the Irish Deaf Society, the interpreters service is in a near obsolete situation at the moment. There are far too few sign interpreters – only 15 registered nationwide. Ideally, there should be more than 300 to cater for the demands of the deaf community nationwide. There is a need for permanent State funding for the interpreters agency Irish Sign Link to boost its resources and staffing levels. The Irish Deaf Society strongly feels that the Department of Justice, Equality and Law Reform should take this responsibility as opposed to it being that of the Department of Health. It requires more funding, and permanently. The Irish interpreters service currently is the worst in Europe. There is a need for a code of ethics, code of practice and the accreditation of interpreters as there is in Europe and USA (Stanley 2001)

[6] Deaf people view themselves as a cultural and linguistic minority. Cultural because they are part of the Deaf Community and a minority because they live as a minority in a society of hearing people. Advocacy is the process where deaf people are empowered to represent the Deaf Community by choice, i.e. Deaf Advocates (Irish Deaf Society: 1999).

[7] O' Sullivan, Sean., (1987) *You've Got a Friend* report on advocacy cited in hansard debate, Ontario http://hansardindes.ontla.on.ca/hansardiesur/36-1/1030.html

[8] In 1971, A United Nations Declaration encouraged self-advocacy groups to develop worldwide, which stated principles of equality and natural justice for people with learning disabilities.

[9] Acknowledgment to the Dublin Mental Health Matters Group (formally Minds Matters)

[10] ''Mind Yourself' and Foyle Advocates Derry, Mental Health Matters Dublin, and the Irish Advocacy Network, Monaghan are examples of Peer advocacy with mental health users. They explain Peer Advocacy as a process of empowering people experiencing mental health related difficulties.

[11] National Association of the Mentally Handicapped in Ireland

[12] (Family Advocacy http://www.family-advocacy.com/whoweare.htm).

[13] NAMHI and Parents and Siblings Alliance are two examples of collective family advocacy for people with learning disabilities.

[14] A high profile example of family advocacy, in 2001, is that of Cathy Sinnott who advocated in the Irish High and Supreme Courts for the education of her son Jamie and who is continuing with her high profile campaign for the rights of her son on his behalf

[15] Rights of access to records and Rights of Entry were enshrined in Canadian Statute in 1992 (ref. chpt. 6)

[16] Kennedy and Grubb, *Medical Law, Text with Materials* (London 1994) at 87

[17] The 2001 IPRT Report (Out of Mind, Out of Sight) reveals that 78% prisoners who are mentally ill, within the Irish penal system are put into solitary confinement (strip cells) and isolation as a way of containing their illness and as a substitute for appropriate care.

[18] *'Left Out On Their Own: Young People Leaving Care In Ireland'* (2000) Focus Ireland.

[19] This was proven in 2001 in the Case of Sinnott Vs the State.

[20] Ref: Giving children a voice (May 2001) A report by the Guardian Ad Litem Group. Law Society Blackhall Place, Dublin. This report makes twelve recommendations in terms of regulating and up-grading the current guardian ad litem role in Ireland. One recommendation is that

the government should establish and fund an independent guardian ad litem service and the Irish Constitution (art. 41) should be amended in order to recognise the child as a juristic person with individual rights to which separate representation.

[21] This report confirms that one-third of young people leaving the care of health boards, and over 50% of those leaving special schools for young offenders, experience episodes of homelessness or spend time in detention centres. The figures become more gruesome two years down the line including statistics of addiction, prostitution and sexual abuse.

[22] Central Missouri Child Advocacy Law Center

[23] The Disability Federation expressed concerns that Health Boards are not required to inspect and register center's for children with disabilities nor staff volunteers with substantial access to children. Registration with Health Boards for children with physical and learning disabilities are excluded by part v111, section 59 (c) of the Child Care Act 1991 and called for an advocacy movement as exists in England (Eds.), Frontline. 1996:3)

[24] After reviewing Ireland's performance in implementing the UN Convention on the Rights of the Child in 1998

[25] This act may be cited as the Comhairle Act, 2000

[26] 30% of queries dealt with by CICs in 2000 were by telephone. Comhairle recognise that there are people presently unable to access services as they do not have access to a CIC (or CIC outreach), to a telephone, internet or to information, advice and advocacy services.

[27] Information is provided on topics like social welfare, health services, redundancy, income tax, housing, family law, consumer affairs and local organisations and services. Citizen Information Centres assist people to get entitlements by helping to fill in forms and if necessary, by contacting government departments or other agencies on their behalf. The centres also help people who are appealing against decisions. The centres assist in the early stages of exploring an issue, it has not the resources to date of providing direct advocacy services from the early exploratory stage to direct formal representation.

[28] The Ombudsman does not consider that any proposed Advocacy Authority or Commission would fit naturally within the functions of the office. There would be a conflict between the role of independent arbiter and the representative role of the advocator. In these circumstances, the

Ombudsman considers the critical competence of independence would be compromised (Murphy 2001)

[29] The committee is composed of persons from a variety of backgrounds; lawyers, doctors, prison experts, persons with parliamentary experience and are elected by the Committee of Ministers of the Council of Europe by an absolute majority of votes (http://www.cpt.coe.int/en/refdocs/ecpt.htm).

[30] The 1987 European Convention for the prevention of torture and inhuman or degrading treatment or punishment.

[31] "No one shall be subjected to torture or to inhuman or degrading treatment or punishment" (Article 3)

[32] The IPRT Report, 'Out of Mind, Out of Sight' highlighted that padded cells are widely used in the Irish Penal System, with 78% termed 'mentally ill'. One prisoner spent 25 days out of 33 there and 78% were certified 'insane'. It is clear from the report and the IPRT summary findings (Bresnihan 2001:2,4) that 'a turf war' exist between the Department of Justice, Law and Equality and the Department of Health as to who will do least for mentally ill prisoners, in particular those with personality disorders and an inter-ministerial agreement between the departments of health & justice is needed.

[33] Report to the Irish Government on the visit to Ireland carried out by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) from 31 August to 9 September 1998. Strasbourg/Dublin, 17 Dec 1999.

[34] Keys (2001) notes that although not specifically mentioned in the Mental Health Act, 2001, Section 16 on information rights may provide an avenue for an independent advocate. This section notes that the patient will be given notice in writing concerning the detention order and a statement will be included outlining the patient's rights. There is no reference to the patient's capacity to understand, perhaps due to illness, whether the patient can read or whether it is in their first language. There is provisions for individualised care plans and goals, to be drawn up where possible in consultation with the person themselves, possibly creating a role again for an advocate. However, this all falls within the medical models remit. It fails to acknowledge systemic advocacy or to actually name advocacy. Relying on the arbitrariness of the good will of staff is unacceptable for people in vulnerable positions. Voluntary patients who are incapacitated have no protections or special attention under the law (ibid). They require Independent Advocacy as a right.

[1] In 1993, Advocacy Ireland Movement was formed and the Chairperson Mr. Colman Patton was appointed as a Special Advisor to the Commission with an independent advisor. It made a submission to the Commission. Despite its laudable aims to improve education, training, benefits, involving itself in State and national activities, ensuring a national strong voice for people with learning disabilities and representing those with severe learning disabilities it no longer exists. According to a key advisor, its inception in 1993 brought hope, challenges and a political consciousness to the advocacy movement, for people with learning disabilities. It failed due to a lack of money, resources and support (Power, K: 2001).

[2] Personal communication with Martha McClelland (28/4 /2001) @ Peer Advocacy Information Seminar. Dublin

[3] In some cases, it is arguable that entitlements set out in guidelines and circulars may indeed be legally enforceable but the legal position is somewhat unclear (Final Report June 1995:4)

[4] In the discussion document '*The Cost of Disability' (2001),* it was argued that extra and additional resources are required for the extra and additional costs of disability. It is argued here that unequal treatment for certain groups, in this case, disabled people is necessary in order to access a level playing field.

[5] The Employment Equality Bill, (Dept. of Equality, 1996) (section 6(2)(g), section 16 and 35) was found to be in conflict with the constitution with regard to articles 43 and 40.3.1 relating to property and access for disabled people. The courts determined in the challenge that provisions dealing with disability and access were repugnant to the constitution because of the right of property owners to carry on a business and earn a livelihood. This is an example of the disproportionate value property rights are placed over the individual's claim rights (Birmingham, 2000:40)

[6] Ref: www.UNHCR.ch (website of the High Commissioner for Human Rights)

[7] The politics of Recognition and difference in discussed in Phillips, A., (1995) & Phillips, A.,(1993)

[8] One recent Australian landmark case (which might have relevancy to advocacy in Ireland) has established that the Australian Constitution provides an *implied* right to free speech: *Australian Capital Television Pty Ltd v. Commonwealth of Australia (*No.2) (1992)108 A.L.R. 577. This decision has prompted speculation as to whether other human rights could be implied into the Australian Constitution (McDonagh, M in Quinn et al., 1993:120)

[9] Ref: A.G. [1984] I.R. 277; [1984] I.L.R.M.643 a case where, the lack of provision of postal voting facilities for disabled voters was not found unreasonable, unjust or arbitrary in the case of Mrs. Draper. In this case the Irish Supreme Court relied heavily on the presumption of constitutionality and did not indicate to the legislature that reform was necessary.

[10] Transport, personal assistants, accessible premises, education, administrative back-up and financial assistance may be some practical measures that people may require.

[11] (ref. footnote 13, Pg.100)

[12] (http://www.facs. gov.au/disability.ood/advocacy/advocacenglish.htm)

[13] Investigation included the establishment of an expansive reference group, 96 written submissions, seven public seminars in Sydney and selected country areas, focus groups and surveys of the Community Visitors Scheme to look at all elements of the Commission's operation and the legislation under which it operates.

[14] An advocate under the 1992 Act, could with the authorisation of the Commission "*access records if there were reasonable grounds to suspect the existence of systemic policies or practices that may be detrimental to vulnerable persons; and...is necessary for the purpose of an investigation into the existence of the systemic policies or practices*" (Advocacy Act 1992:18 25 (1)).

[15] The programs of public information and education were targeted to (a) vulnerable persons, (b) family members of vulnerable persons; and the general public in that order. (Advocacy Act 1992:8).

[16] The Advocacy, Consent and Substitute Decisions Statute Law Amendment Act, 1996 (Bill 19) was introduced to repeal the Advocacy Act of 1992, amend the Substitute decisions Act of 1992 and repeal the Consent to Treatment Act of 1992 replaced with the Health Consent Act. The aim was to reduce government interference in the private affairs of individuals and ensure that decision-making is in the hands of families (Hansard Reporting, 2000)

[17] During the course of research for this document, this issue came up frequently for advocates across the disability spectrum. Some people with learning disabilities, acknowledged that families "*tried to do their best*", while others felt their families "*were a health hazard to them*". One advocate (anonymous) expressed that the Advocacy Act was attractive from the viewpoint of a person with a mental illness living within the family home, who may feel vulnerable to being involuntarily signed in by a member of the family. An independent advocate in this case, would be reassuring in ensuring their human rights were not being violated.

[18] Text of Advocacy Act can be accessed through the office of the Forum of People with Disabilities, 21 Hill St, Dublin 1.

[19] Ref: Mr. Rosario Marchese (debate1620)

[20] http://hansardindes.ontla.on.ca/hansardiessue/36-1/1030.html

[21] The Civil Legal Aid Act of 1995, by which legal aid services are provided to persons of modest means at little or no cost through legal centres based throughout the country

[22] The Human Rights Committee emphasized in a 1993 report on Ireland that access to legal assistance is an essential right under the (ICCPR) Covenant, and noted that, under the current restrictive system, a proper legal defense could not be ensured for many persons.
http://www.unhcr.ch/tbs/doc.nsf/

[23] (http://www.facs. gov.au/disability.ood/advocacy/advocacenglish.htm)

[24] Coalition of Provincial Organisations of the Handicapped and the Canadian Disability Rights Council, *Omnibus Legislation:* A Strategy for the Nineties, December 1990/Jan 1991, Vol. 9,1 Arch-Type ar 17 in Quinn et al 1993:165

[25] Five reports in relation to the planning and recognition of advocacy at a statutory level were explored for references to advocacy, because the resourcing of service provision have been made and social policy formulated, based on recommendations within them. 1.*Enhancing the Partnership* (Dept. Of Health, 1997). 2. *Needs and Abilities,* (Dept. of Health 1990). 3. *Annual Report* National Intellectual Disability Database (The Research Board 1996). 4. *An Assessment of Need* (Dept. of Health 1997-2001) 5. *Building a Future Together* (Dept. of Health 1998) in Birmingham (2000:52-55)