NATIONAL DISABILITY AUTHORITY

ÚDARÁS NÁISIÚNTA MÍCHUMAIS

Exploring Advocacy

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The views and opinions expressed in this report do not necessary reflect those of the National Disability Authority (NDA), the Centre for Disability Studies, UCD, nor of the National University of Ireland, Dublin.

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EXECUTIVE SUMMARY

Advocacy is emerging as a powerful tool for individuals with disabilities in exercising their rights. In the Netherlands, the United States of America, and Australia, persons with disabilities have influenced legislation through advocacy. In its various forms, advocacy has two central goals: to safeguard the rights of our most vulnerable citizens, and to empower these citizens, thereby contributing to the creation of a more equitable society.

This research report into advocacy was commissioned by the National Disability Authority (NDA) and undertaken by the Centre for Disability Studies, National University of Ireland Dublin. The research aimed to examine what legislation, systems, and models of advocacy would best serve people with a range of disabilities in Ireland today. While the research carried out was mainly documentary, interviews were also conducted with umbrella organisations, involved in advocacy in Ireland.

Findings

The findings of this study suggest that current advocacy services in Ireland take many forms: self-advocacy, parent advocacy, peer advocacy and citizen advocacy. However no services are mandated and advocacy organisations have emerged with few resources. Expanding advocacy provision in Ireland will involve similar difficulties to those encountered in other international models. It is likely that the primary problems will arise from a failure to regard advocacy as a human and civil right and the lack of guaranteed funding. The findings also suggest that clarity is required on the meaning of advocacy and education is needed to clear up any confusion regarding the legal jurisdiction of advocacy.

Recommendations

Taking these consultations into account, this report concludes that: advocacy in Ireland must be established as a legally-binding right; an independent advocacy commission should support local groups to expand existing advocacy provision; funding for these organisations must be long-term and secure; and more detailed research is needed from a national and international perspective.

Chapter 1

INTRODUCTION

> ***'Advocacy is concerned with getting one's needs, wants, opinions, and hopes taken seriously and acted upon. 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

Persons with disabilities regularly experience powerlessness in their lives, particularly when taking life decisions about where and with whom to live, or where to work. Being unable to make decisions regarding their lives leaves people with disabilities at the mercy of professionals and family members. However, this vulnerability is not an inevitable consequence of having a disability. Rather, it is a product of society and thus can be changed by society – through advocacy (Jenkins and Northway, 2002). Advocacy takes many different forms and is used by many different groups in society. Self-advocacy, peer advocac*y* and citizen advocacy are some variations. What is important is that advocacy allows the most vulnerable individuals in society to be heard – people with disabilities, members of the travelling community, children and the elderly – to have impact on policy and legislation. However, in the light of sparse advocacy provision, Irish services and policies have often been designed and implemented without the direct involvement of the above groups (Forum of People with Disabilities, 2001).

This study was commissioned by the National Disability Authority (NDA) and was prepared by the Centre for Disability Studies, National University of Ireland, Dublin. It draws on work previously carried out by the NDA, which focused on a number of groups providing advocacy to those with mental health difficulties. Subsequently, the NDA consulted further with mental health organisations and other groups in the disability sector to find suitable methods of including the provision of advocacy in future legislation. In the light of these consultations a research question was developed, and thus this study aimed to examine:

> *'What legislation, system or systems, and model or models of advocacy, would best serve people with a range of disabilities (including physical and sensory, intellectual, mental health, and acquired disabilities) in Ireland today?'* (NDA Research Tender, 2002)

The main objectives were:

- to build on, rather than duplicate, the publication 'Advocacy - a Rights Issue' (Forum of People with Disabilities, 2001)

- to identify and provide information on current active legislation and models of advocacy within Ireland and other specified countries

- to propose value-based criteria for selecting examples for future exploration of advocacy

- to identify and provide contact details of examples of Advocacy in Ireland, enabling further evaluation by the NDA

- to make recommendations for further research.

Methodology

Literature Review
A literature review was completed, drawing on both Irish and international sources on advocacy. Key international sources included: Department of Family and Community Services, Canberra, Australia; The Scottish Executive; The United Nations Declaration of Human Rights; and the Council of Europe.

Interviews
Relevant bodies of advocacy provision in Ireland were contacted. From the outset of the report, it was agreed between the Centre for Disability Studies and the NDA, that providers of advocacy in Ireland would not be visited. This was agreed for three reasons:

1. Time limitations restricted data collection to secondary sources, precluding direct contact with providers.

2. A detailed review of advocacy provision would involve the duplication of the document published by the Forum of People with Disabilities (2001).

3. Comhairle – the national support agency responsible for the provision of information, advice and advocacy to members of the public on social services – is also carrying out a detailed review of advocacy in Ireland. A specific part of the Comhairle project is a comprehensive review of service provision within Ireland – the results of which were not available at the time of completion.

Due to time restrictions, not all those contacted were available for interview. Representatives from the following organisations were consulted: The Irish Advocacy Network; The Forum of People with Disabilities; The Federation of Voluntary Bodies; and Brí. The latter is a newly founded advocacy organisation for people with Acquired Brain Injury on the east coast of Ireland. It was decided to consult a representative from Brí, as an initial review of the literature found very little evidence of advocacy for those with Acquired Brain Injury. Interviews took place in September and October 2002.

Outline of the Report

This report examines the different models of advocacy and the required legislative accompaniments necessary for people with disabilities from Irish and international perspectives. Chapter Two suggests that advocacy is a set of strategies that help to answer the question “How may people with disabilities exercise equal opportunities in society?” Chapter Three adopts an international perspective on advocacy and focuses on issues of funding and legislation. Chapter Four presents the outcomes of advocacy in Ireland, bringing legislation and structural models under the spotlight. Finally, Chapter Five proposes recommendations for advocacy provisions and future research. Each chapter concludes with a brief critical review.

Chapter 2

ADVOCACY & EQUITY

Introduction

Recently, practitioners in law, politics, health, social development and many other fields have embedded the term *advocacy* in their vocabularies. As a way of enabling the hitherto silent voices to emerge and be heard, advocacy may be seen as a crosscutting issue in the public domain. Individuals with disabilities and their allies have embraced advocacy in their efforts to achieve equal opportunities for inclusion in society. Yet, these efforts have not always succeeded in effecting change: there is a difference between advocacy and leadership. While advocacy can be seen as a useful strategy of leadership on some issues and in some contexts, advocates are often constrained because they are not expected to engage multiple perspectives on the issues being explored. Some problems require the employment of different values, perspectives, and dialogue. While resolution may be reached through advocacy, many problems require diverse groups or factions to make adjustments in values, perspectives, and behaviours.

This chapter suggests that advocacy is a pathway, not a destination. It is a set of strategies that help to answer the question, “How may people with disabilities exercise equal opportunities in society?” The chapter comprises five sections: (1) defining terms related to advocacy; (2) the goals of advocacy; (3) policy implications; (4) access to advocacy; and (5) advocacy strategies to achieve equity.

Defining Terms

Definitions reflect rather than inform the conceptualisation of an entity or model. Consensus on the nature of disability remains elusive, in spite of spirited debate. However, two related approaches to disability – one based on *rights* and a second characterised by *self-determination* – inform current definitions of advocacy.

Disability

Debates are rife about what disability is, what words should be used to refer to people with disabilities, and what means – if any – should be applied in the measurement of various impairments or losses of function. Consensus is still emerging on these and other issues. Eschewing simple ‘social’ or ‘medical’ models of disability, disablement may be construed as a complex, interactive set of relationships between an individual, family, society and the wider political, economic and physical environment (Bickenbach *et al.,* 1999). The United Nations *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (1994) adopts a universal approach to disability, stating that each country should strive to achieve equal opportunities for all citizens – including those with disabilities – to participate fully in society. The *Standard Rules* states that every

citizen is equal by right. However, it acknowledges that those with disabilities have difficulty in both knowing and exercising their rights as citizens (1994). While it expresses moral and political values, the *Standard Rules* document is not legally binding (Michailakis, 1999). The European Union has endorsed the document and has adopted a rights-based approach to disability. This model supplants earlier welfare or accommodation models (Council of Europe, 1998).

Advocacy & Rights

In recent years, the view that advocacy is no longer an aspiration in society – rather a right – has emerged. This conclusion follows from an assumption that people with disabilities have a right to full societal participation. Thus, advocacy may be seen as a means for individuals, family members and other allies to achieve equal opportunities. Diverse groups in society may require advocacy to support their efforts – for example, frail elderly people, those without families, or people who have mental health difficulties. According to Forster (1990: 156), a 'new legalism' has developed. This emphasises that individuals with mental health issues are citizens with moral and *legal* rights. Contrary to *de jure* civil and legal equality, people with disabilities are often treated as second-class citizens. Such mistreatment is reflected by inadequate service development (van Loon & Van Hove, 2001). In some cases, the needs of the consumer are superseded by those of the service provider: while poor service provision is often attributed to bad management and funding shortages, the true cause may be a disregard for the rights of people with disabilities (Hurst, 1995).

Self-determination

Self-determination has emerged as a core element in models of quality of life. This characteristic reflects the way individuals become competent in directing the course of their lives. It is expressed in self-regulation, psychological empowerment, self- realization, and autonomy (Wehmeyer, 1996). In the case of advocacy, a model of active self-determination expresses itself as making one's views heard in the pursuit of autonomy. *The Strategy for Equality* (Commission on the Status of People with Disabilities, 1996: 106) describes advocacy as being 'concerned with getting one's needs, wants, opinions and hopes acted upon'.

Goals of Advocacy

Advocacy may be said to have two central themes:

1. The safeguarding of vulnerable individuals

2. The empowerment of people to ensure that their voices are heard, either through themselves, or by someone on their behalf (Scottish Executive, 2001; ADACAS 2002; NHS, Orkney and Orkney Council, 2001).

The Safeguarding of Vulnerable Individuals

Very often, vulnerable individuals who lack the support of family and friends are at greater risk of exposure to substandard services and/or injustice (Scottish Executive, 2001a). Advocacy is necessary because those who are vulnerable in our society - particularly individuals with disabilities, the aged and children - are often unaware of, or ill-equipped, to access the civil and political rights that they hold in common with other citizens (ADACAS, 2002). Through the information and support provided by advocacy, vulnerable individuals can exercise a degree of self-determination in the attempt to establish control over their lives and to secure the receipt of equal treatment (Inclusion International, 1994: 9).

As stated, individuals most likely to require advocacy are those who have been 'in the system' for many years. With few social supports, such individuals become more susceptible to abuse and injustice (Scottish Executive, 2001a). However, through advocacy these individuals are succoured in services, which could otherwise 'disempower, neglect or abuse them' (Advocacy 2000, 2002: 10)

The Empowerment of Individuals

The empowerment of individuals is a central theme in advocacy, and is necessary so that individuals can make their own decisions (Inclusion International, 1994). Advocacy also encourages equality, and aims to foster a society where each individual has the same access to information, to services and an equal ability to exercise their rights (Inclusion International, 1994).

> *'Advocacy is about stating a case, influencing decisions, ending assumptions, getting better services, being treated equally, being included, protecting from abuse, redressing the balance of power [&] exercising rights'* (Dunning, 1995: 11)

Brandon (1995) emphasises the importance of empowering individuals through advocacy. Empowerment is concerned with enabling people to speak up for themselves, in order to 'play a part in the construction of their own life and destiny' (Forster, 1998: 158). By increasing the individual's sense of power, his or her confidence and assertiveness flourishes (Brandon, 1995). This newfound belief in oneself results in an increased ability to make choices. Connected to such an increase is the expansion of individual hopes and abilities, such as, the ability to make one's opinions heard, the ability to access the information necessary to make effective choices, and the ability to guarantee improved treatment at the hands of others (Advocacy 2000, 2002; Brandon, 1995).

The essence of advocacy is that it is part of everyday life. It is an ordinary activity (Scottish Executive, 2001b). Some people find it hard to express what they need. Others find it difficult to be heard. Both issues infringe upon an individual's ability to take part in ordinary life. This is especially true for individuals who have spent large amounts of time immersed in service systems or institutions, in particular

individuals with disabilities (Scottish Executive, 2001a). This exclusion hinders the development of the social networks that would ordinarily support an individual in fighting his or her cause. As a consequence, socially marginalized individuals are dependent on advocacy for the exercise and knowledge of their rights (Scottish Executive, 2001a). Advocacy is needed to enable disempowered people to control their lives (British Deaf Association, 2002).

Advocacy provides support for the ideas and opinions of individuals and groups that may previously have been ignored (Advocacy 2000, 2002). It helps to give credence to people's concerns (Scottish Executive, 2001a). It enables people to influence decisions 'individually and collectively at a local or national level' (British Deaf Association, 2002).

The practice of advocacy also connects individuals in the community through a common cause. It enables vulnerable and excluded individuals to become involved in ordinary activity (Advocacy 2000, 2002). This connection promotes a more cohesive society and encourages the social inclusion of individuals previously on the margins of society. Advocacy heightens awareness across wider society to the oppression faced by people with disabilities. As an element of the social rights movement, it facilitates collaboration between disability organisations and other marginalized groups in the fight against discrimination (Cone, 1999). On a larger scale, advocacy is about redressing the balance of power (Dunning, 1995; Forster, 1998). It allows individuals previously mute in society and overlooked in terms of their specific needs to voice their concerns as equal citizens. Thus advocacy expresses an important element of self-determination. Some individuals may already act in a self-determined way, while others may need to learn effective strategies, such as goal setting or choice-making.

Policy Implications

Policies favouring advocacy on behalf of people with disabilities or other groups reflect national priorities. Advocacy not only addresses the needs of individuals and groups, but according to the Scottish Executive (2001), it can also address policy goals. These may include health improvements, equity, social exclusion and partnership (Table 2).

Such policy goals can only be achieved if consumers can clearly voice their needs and opinions (Department of Family and Community Services, 1999). It is often taken for granted that all citizens have an equal ability to gain inclusion to use rightful entitlements to equal effect. This is rarely the case (van Loon and van Hove, 2001). Advocacy facilitates the consideration of all voices and opinions in the development of services and policies and the achievement of a fairer society. Advocacy ensures that service providers and policy structures are challenged to meet these needs (Department of Family and Community Services, 1999).

Table 2: Advocacy and Policy Goals: A Perspective from Scotland

Health Improvements
The onus of the nation's health is placed largely on the shoulders of health boards and local authorities. It is their duty to promote the health and welfare of its citizens. Through the principle of empowerment advocacy plays a key role in the attainment of such goals. Empowerment enables patients to gain greater access to information on the treatments they receive. Such knowledge has been shown to stimulate a faster, more successful recovery. Therefore, improvements in the nations health can be achieved through providing citizens with appropriate information and involving them in their own health and rehabilitation.

Equity
Advocacy aims to mediate on behalf of individuals and groups most susceptible to substandard services. By voicing the needs of the most vulnerable, broader social causes are advanced, and equity in service provision is realised.

Social Exclusion
The prevalence of social exclusion and institutional care is reduced through advocacy. The social networks that it creates and sustains protect the most vulnerable from drifting towards the fringes of society and ultimately 'disappearing'.

Responsiveness and Partnership
Achieving real partnership between consumers and service providers involves a change in the culture of service provision. Advocacy facilitates such collaboration. Furthermore, partnerships between community and policy makers, is also made possible through advocacy, allowing local communities to regain their power.

(Scottish Executive, 2001: 11)

Access to Advocacy

If advocacy is a rightful form of support aimed at achieving equity, who should have access to it? If it is a scarce good, how will it be rationed? Will the system of allocation be transparent? It seems that, once government has accepted the need for advocacy, it must decide whether to target the specific needs of certain groups or to address core social domains such as education, health or employment with a view to participation on the part of people with disabilities. In the United States, activist and advocacy organisations may be said to vary in approach: 'Organisations can vary on many dimensions. One of these is whether the focus is on a single issue or multiple issues. Organisations can also vary on a dimension that might not have an analogue in other social movements – that of how many types of impairments they appeal to or recruit from' (Barnartt et al., 2001: 443).

For example, an organisation may appeal to people who have a variety of types of impairment on a single, narrow issue such as public transportation. Both kinds of provision have respective benefits and drawbacks. The development of a specialist service allows expertise to develop for that specific area, encouraging a more efficient and effective service (Scottish Executive, 2001b). However, individuals who do not fit the specific criteria — for example, having mental health difficulties — are excluded from the service. Individuals with multiple disabilities, for example, intellectual disability and an additional mental health difficulty may find it difficult to access an advocacy service. On the other hand, a generic advocacy agency is, in theory, open and accessible to all (Scottish Executive, 2001b). However, this type of provision requires a large body of staff with an extensive general knowledge of all relevant areas (Scottish Executive, 2001b; Dunning, 1995). Furthermore, a larger body of consumers requires a prioritisation of needs, which may cause difficulties in attending to each individual's needs (Scottish Executive, 2001b).

In some cases, the above difficulties have been overcome through the development of generic advocacy provision with smaller specialist divisions (Dunning, 1995). The employment of several staff with specific focuses all working under the same auspice of independent advocacy 'actively recognises the importance of a relationship between different forms of advocacy' (Dunning, 1995: 28). There are several successful examples of generic advocacy provision in Scotland – the Scarborough Advocacy Alliance provides citizen advocacy and recruits individuals to work with individuals with mental health difficulties and intellectual disabilities (Simons, 1993). In the Argyll and Clyde Health Board area, an independent professional advocacy for people with mental health difficulties is currently merging with two other mental health advocacy providers (SHS Trust, 2001). It is hoped that the three organisations will collectively provide community advocacy services to all individuals in the Argyll and Clyde Health Board area (SHS Trust, 2001). The Scottish Health Services Trust advise that there is no one best model of advocacy (SHS Trust, 2001). Through an individual's life span various changing support may be required (SHS Trust, 2001). Those who devise advocacy services must take this into consideration (SHS Trust, 2001).

Strategies

Fundamentally, advocacy is a practice executed by or on behalf of an individual or a group, which aims to redress the imbalance of power in society. The forms in which it is applied reflect cultural expectations and practices. Some dominant applications are outlined in this section.

Independent Advocacy

Independence has emerged as the most important aspect of advocacy. Advocacy providers must have independence of mind, place and funding – this first element being most important (Scottish Executive, 2001b). To achieve this, advocacy organisations should avoid all connection with particular services providers, local authorities, and health (Scottish Executive, 2001a). Reports from Ireland and elsewhere recommend that advocates must be both structurally and

psychologically independent (Kerry Advocacy Network, 2001; Meade & Carter, 1990; Advocacy 2000, 2002). The independence of an advocate and advocacy organisation is vital in order to ensure that all those involved know exactly where their loyalties lie (Scottish Executive, 2001a).

Professional Independence

The advocate has to be entirely clearly that he or she is accountable only to the represented individual or organisation and not to service providers, or the government (Scottish Executive, 2001a). Professionals working in the healthcare area often speak up for the individual as part of their job. However, they cannot be completely independent of the concerns of the service provider. Conflicts of interest may arise where a professional working in a service agency must consider the wishes of employers and those of the individual they represent (Ibid). Independent advocates are in a position to pursue the needs of the individual, without having to 'compromise the well being of the people they represent' (Scottish Executive, 2001: 10).

Financial Independence

Advocacy efforts may be compromised by pressure from funding bodies: while unconditional funding to independent advocacy is desirable, it may be infrequent (Kendrick, 2000). The Scottish Executive suggest that the independence of advocacy organisations can be achieved through the provision of government funding 'at arms length' with some degree of security (2001b: 2). As advocacy organisations become more mainstreamed, and receive more local and health authority funding, their independence may be compromised (Valios, 2002). This author suggests that replacing 'local funding streams', from local authorities, for example, with direct government funding is a way of overcoming the difficulty (2002: 32). Once structural independence is assured, the following models of advocacy can thrive.

Self-Advocacy

> ***'It is important to us as individuals with developmental disabilities that we be partners in decision making throughout our lifetime'*** **(Levitz 1999: 279)**

Self-advocacy is different from advocacy in that it is the individual speaking up for his or her own rights (Godley, 2000, see Table 1). According to Campbell (1990), self-advocacy is concerned with power and powerlessness. It enables disempowered people to regain control over their own lives, and 'express their own needs…and represent their own interests' (Dunning, 1995: 20). *London People First* states that 'self-advocacy enables us to make choices and make our own decisions and control the way our lives should be' (Brandon, 1995: 68). The activity of self-advocacy came to the forefront initially with the development of *People First*

in the United States of America (Simons, 1993). This organisation emerged as people with intellectual disabilities began to fight for their rights as citizens. According to Miller and Keys (1996), self-advocacy organisations have three core goals:

- To teach individuals with intellectual disabilities to speak out
- To teach individuals with intellectual disabilities about their rights and responsibilities as citizens
- To teach individuals with intellectual disabilities how to make choices that affect their lives (see *How to Advocate*)

How to Advocate

To advocate means to speak up or defend a cause or person. By definition, instruction to promote self-advocacy will focus on two common themes: how to advocate and what to advocate. The strategies for the "how to advocate" side of self-advocacy include instructional emphasis on being assertive but not aggressive; how to communicate effectively in one-on-one, small-group, and large-group situations; how to negotiate, compromise and use persuasion; how to be an effective listener; and how to navigate through systems and bureaucracies. It is evident that each of these is tied closely to the acquisition and emergence of other self-determination skills' *(*Shalock and Verdugo, 2002:301). Furthermore:

- Self-advocacy acknowledges that people with disabilities have both rights and responsibilities as citizens (Brandon, 1995)
- Through individual development, people gain the confidence to articulate their own views (Simons, 1993)
- It is through the expression of his or her needs that an individual ultimately takes responsibility for his or her own life (Connolly, Molloy & Walsh, unpublished): achieving self- actualisation
- Through these processes, individuals expand their awareness of themselves and their society, and educate the wider community about current discriminatory practices (Miller and Keys, 1996)
- Self-advocacy is the goal for all forms of advocacy. It is what advocates strive towards - the self-representation of the individual (Brandon, 1995)

Collective Self-Advocacy

Self-advocacy can also take the form of collective advocacy. This involves individual advocates uniting to fight for their rights as a group of citizens. Such collaboration offers mutual support in achieving a common goal. According to

Godley (2000), a mutually inclusive relationship exists between the individual and collective self-advocacy. Collective advocacy is an essential part of the democratic process and enables the views of previous voiceless groups to influence policy and legislation (Scottish Executive, 2001a). Issues are raised not only for personal improvement, but also for political and economic gain (Connolly, Molloy & Walsh, unpublished). The most common collective is that of a local action/pressure groups who may call upon the structural support of paid or volunteer advocates (Campbell, 1990). Alternatively, members themselves may be exclusive managers (Scottish Executive, 2002). Despite the obvious benefits of self-advocacy, caution is advised on two aspects of its provision – tokenism and service design:

First of all, as with other forms of advocacy, there is a danger that self-advocacy can be *tokenistic.* The service provider may encourage staff to run 'self-advocacy groups', regardless of their potential to impact (Brandon, 1995). The individuals who attend such groups are often faced with a limited range of discussion topics. Self-advocacy is reduced to conversations on meals or weekly activities, rather than an arena for efficacious debate on citizens' rights (Brandon, 1995). Secondly, over the last few years, self-advocacy has become a tool for evaluating services managed by non-disabled people (Dunning, 1995). Rather than a 'mouthpiece' for service users, self-advocacy is increasingly concerned with service design (Dunning, 1995). In fact, the Scottish Executive states that the long-term benefit of advocacy is that it will shape services in such a way that advocacy is no longer be needed (Scottish Executive, 2001a). This calls the primary focus of advocacy into doubt: is it for the service provider, or the represented individual?

Citizen Advocacy

According to the Strategy for Equality (1996), citizen advocacy comprises the supportive activities of trained volunteers who are unpaid and independent, working on behalf of people with disabilities that are not in a position to exercise their own rights (see Table 1). It involves helping a person to express concerns and aspirations, obtaining day-to-day social, recreational, health services, etc, and providing practical and emotional support. Citizen advocacy has three core elements, which distinguish it from other forms of advocacy:

1. The citizen advocate is an ordinary unpaid citizen (Scottish Executive, 2001a), and therefore, free from conflicts of interest (Dunning, 1995). The advocate is an independent volunteer who articulates and represents the views of the individual as if they were his or her own (Meade and Carter, 1990).

2. Citizen advocacy is about the development of a supportive relationship with someone who is vulnerable or at risk of isolation (Simons, 1993). This one-to-one relationship with the individual, often long-term, and occasionally life-long (Scottish Executive, 2001a; Dunning, 1995; Simons, 1993; Advocacy 2000, 2002).

3. Citizen advocacy is concerned, not only with the central goals of advocacy, but more specifically, with the empowerment of the individual through communal integration facilitated by the advocate's local contacts and power (Brandon, 1995). Therefore, the advocate is often well established in the local community having the ability to integrate the individual using his or her contacts (Simons, 1993; Advocacy 2000, 2002). The rights and interests of those with less power are safeguarded by more powerful community members (Brandon, 1995).

According to Meade & Carter (1990), the above principles provide a powerful channel through which the disadvantages and inequalities faced by an individual with a disability can be addressed. This is the central ethos of citizen advocacy. Dunning (1995) however highlights the possibility of 'role blurring' in citizen advocacy, which is aimed at providing practical and/or emotional help of the vulnerable individual (Dunning, 1995). It is not mediating, counselling, befriending or advising, as none of these pertain directly to the goal of addressing inequalities (Dunning, 1995). The principles of citizen advocacy are present in other forms of advocacy, particularly crisis advocacy. While often only needed as a 'one-off' involvement, crisis advocacy is based on the same principles as citizen advocacy (Dunning, 1995). Brandon (1995) advises that as most crisis cases approach a citizen advocacy organisation, it is necessary for the organisations to have a pool of crisis advocates with the potential to engage immediately with a needy individual. Often these individuals need instant help with issues of homelessness, sudden sickness, etc. Unfortunately the availability of such advocates seems difficult to achieve (Brandon, 1995). Another variation of citizen advocacy is highlighted in *A Strategy for Equality* (Commission on the Status of People with Disabilities, 1996) – patient advocacy. However, the question of independence is especially compromised here, as the hospital or institutions where the individual resides, is often the employer of the advocate (Commission on the Status of People with Disabilities, 1996).

Peer Advocacy

Peer advocacy has emerged as an essential tool for those with mental health issues (see Table 1). Peer advocacy involves the provision of support for individuals with mental health difficulties by those who have experienced similar difficulties (Dunning, 1995). Such relationships enable a level of trust to develop on the basis of shared experiences (Scottish Executive, 2001b). Peer advocacy fosters a supportive and empowering relationship and is linked to peer support, for example, Alcoholics Anonymous (Brandon, 1995). The development of the relationship between the individual and his or her peer allows for shared negative experiences to be seen in a more positive lights (Brandon, 1995). By placing a value on his or her experiences, empowerment of the individual is instigated. It has proved invaluable for sufferers and their families in the attempt to dissolve the stigmatic labels often associated with mental health difficulties (Foulks, 2000). As with other forms of advocacy, peer advocacy can develop on a one-to-one basis, or within a collective.

Professional Advocacy

This type of advocacy can take many forms, but is generally concerned with advocates who have expert knowledge on legal, health, or welfare systems (Scottish Executive, 2001a). The advantages are that advocacy can be simultaneously linked to several individuals, and that advocates often hold expertise and knowledge in specific areas (Scottish Executive, 2001b). Furthermore, the reliable availability of such advocates, allows them to be more responsive to crisis cases (Scottish Executive, 2001b). Professional advocates may either work for, or volunteer their services for, an agency (Scottish Executive, 2001a: 6).

Family Advocacy

Families are an integral part of the provision of advocacy for people with disabilities (Department of Family & Community Services, 1999) (see Table 1). Intimate knowledge of the individual, and a passion for justice, makes family members strong and effective advocates (Department of Family & Community Services, 1999). The influence of families should not be overlooked because they play a crucial role in the life decisions for the individual (Barnes & Brandon, 2002). In fact, families are very often the only support people with disabilities have (Barnes & Brandon, 2002). The success of family involvement in the provision of advocacy is evident from the role families have played in the development of services for people with disabilities, in particular, those with developmental and physical disabilities (Department of Family and Community Services, 1999).

In the Russian Federation, parent organisations working on behalf of children with disabilities, have formed a collective which liases with the Ministry of Education and maintains an information database on these children (Smith-Davis, 2000). These families advocate on behalf of their children so they can live a 'normal life', and improve their opportunities within society (Smith-Davis, 2000). However, in India, it is more difficult for parents to achieve improved services for their children with disabilities. Cultural and economic factors severely hamper the advancement of the cause of people with disabilities: The family is the locus of care for people with disabilities, '*the promotion of inclusion, citizenship and self determination…begins with the family* ' (Goel, 2000:236). Disability is commonly interpreted as punishment for wrongdoing. Parents not only have to advocate for better services for their children, but also involve themselves in the provision of these services (Goel, 2000). Parent Organisations in Ireland such as NAMHI (National Association for Mentally Handicapped in Ireland), have played a key role in advocating for improvement in services for those with disabilities. NAMHI is part of Inclusion International, which is a global network of family-based organisations. Inclusion International works towards a more inclusive society by promoting the human rights of persons with developmental disabilities.

The Australian *National Disability* advocacy *Program* (1999) recognises the importance of families in advocacy and proposes the following:

- As part of the National Program, recognition should be given to the significance of family involvement in advocacy provision
- The principle of support for people with disabilities and their families should be included in a code of practice
- Any future research on advocacy should include consultation with families.

Nonetheless, family member advocates and self-advocates can come into conflict (Brandon, 1995; Barnes & Brandon, 2002). What a family want for the individual and what is best for the individual is often a matter of contention (Dept. of Family and Community Services, 1999). Brandon (1995) believes that as more and more individuals demand to speak up for themselves, conflict may increase (1995). Consequently, the author questions whether it will become necessary to replace family member advocacy with self-advocacy (Brandon, 1995)

Children & Advocacy

A discussion on advocacy would not be complete without the inclusion of advocacy for children. However, the provision of advocacy for children is a specialist area, which requires a more detailed exploration than is possible in this paper. The following is a brief overview of what advocacy provision means for children.

The UN *The Convention on the Rights of the Child (1989: Article 1), states that:…'a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier'*. The convention also deals specifically with the rights of children with disabilitiesas outlined in Article 23:

> *'State's parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions, which ensure dignity, promote self-reliance and facilitate the child's active participation in the community'*

Ireland has signed and ratified this convention, which provides children's groups with the tools to campaign for the domestic provision of advocacy for children (Quinn, undated). In the same light, it is accepted that children require an independent advocacy system, built on the same principles that shape advocacy provision for adults with disabilities. Specifically, advocacy is necessary for children within the care system, as history has shown how vulnerable children in institutions can be (Ryan, 1999). Recent social history reinforces how essential advocacy is in child protection.

Table 1: Advocacy Models and Group Involvement

MODEL	GROUP	BENEFITS
Self-Advocacy	Has a long tradition for those with intellectual disabilities, but is of use to all groups	Through empowerment, enables individuals to shape their own lives.
Citizen Advocacy	Open to all individuals who need support in exercising their rights as citizens.	The development of a one-to-one relationship enables individuals to become involved in their own communities.
Peer Advocacy	Emerging as a tool to develop a sense of self-worth and empowerment, particularly for those with mental health difficulties.	Enables those with shared experiences to foster self-worth.
Collective Advocacy	Evolves from the model of self-advocacy, and is therefore open to all.	Individuals gain confidence from a group setting. Groups have a greater impact on policy reform than individuals
Family Advocacy	Is particularly associated with those with intellectual disabilities.	Their passion and intimacy has proven to be an effective body, in striving for policy change.
Professional Advocacy	A service open to all members of society who need assistance.	Such individuals possess expertise and knowledge and operate under certain standards.

Critical Review

As its word root suggests, advocacy means that voices emerge and are heard in the political domain. Governments fashion approaches to advocacy that fit the model of disability extant in a given jurisdiction: various strategies have been adopted and publicised with mixed outcomes. Some authors caution that advocacy meted out by service agencies may be tokenistic, fragmenting self-advocacy and maintaining advocates in ineffectual and marginal positions. While some advocacy and other activist groups have adopted a single-issue approach – education, or transport, for example – others have focused on the complex needs of a group with particular characteristics. Decisions on what will best meet the needs of people with disabilities in Ireland, and who should have access to advocacy supports, are political and moral. Implementing appropriate supports is also a fiscal matter. Determining the efficacy of advocacy supports over time raises important questions and should lead to programmatic, policy relevant research.

CHAPTER 3

Advocacy in Practice: International Perspectives

International Legislation

In the past two decades, 40 of the 189 United Nations member states have adopted some form of anti-discrimination legislation for people with disabilities (Degener & Quinn, 2000). Two pieces of international legislation strive to impact on the lives of those with disabilities: Articles 1 and 7 in the United Nations *Declaration of Human Rights* (1958), and the United Nations *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (1994).

Declaration of Human Rights (1958)

> *'All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.'* (Article 1)

> *'All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination'* (Article 7)

Both Article 1 and Article 7 attempt to establish an internationally recognised legal foundation for the equal treatment of people with disabilities. Under their provision, the equal rights of all people - including those with disabilities - are to be upheld by every possible means: advocacy is but one. Furthermore, these Articles entitle the individual to seek compensation in cases where they have been unable to access their rights.

The UN Standard Rules

> *'The principle of equal rights implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation' (UN, 1994: 11).*

This endorsement of using all resources to ensure equal opportunities provides the basis for the pursuit of advocacy. Rule 15 highlights the rights and needs of those with disabilities: *'States are under an obligation to enable persons with disabilities to exercise their rights, including their human, civil and political rights, on an equal basis with other citizens' (1994: 31) .*Elsewhere, it is affirmed that:

> *'States must ensure that organisations of persons with disabilities are involved in the development of national legislation concerning the rights of persons' with disabilities, as well as in the ongoing evaluation of that legislation' (1994: 31-32).*

Rule 18 specifically urges states to support and strengthen organisations of people with disabilities, recognizing that such organisations play a crucial role in the development of disability policy.

Other Instruments

While these two UN instruments have reiterated the UN's shift in disability policy to a human rights perspective, several other treaties have not had their potential utilised. These include: The International Covenant on Economic, Social and Cultural Rights; The International Covenant on Civil and Political Rights; the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment; and The Convention on the Rights of the Child. According to Quinn & Degener (2002), if such treaties were implemented, then the injustices faced by those with disabilities would be addressed more robustly and effectively.

Advocacy in Europe

In Europe, the structure of service provision for people with disabilities has undergone several changes over the last two decades, not least the development of welfare rights and advocacy provision (Moreslli, 2000). According to Quinn and Degener, elevating people with disabilities

> *'…..from objects without rights to subjects of welfare rights' has compounded exclusion. What is needed is an approach which recognises civil and human rights for people with disabilities (2002: 11).*

Since the 1990s, various European countries have adopted anti-discrimination legislation for people with disabilities (Degener & Quinn, 2000). The Council of Europe's most significant recommendation in the area of disability is *Recommendation R. (92) 6 on a Coherent Policy for People with Disabilities.* This recommends that states should enable all persons with disabilities to participate fully as citizens within their societies (Quinn and Degener, 2002). The initial focus on advocacy was to educate mainstream society while simultaneously improving the status of the individual (Moreslli, 2000). Increased involvement of patient groups in shaping service provision has emphasised the importance of the patient's input in self-determination and well being. This has resulted in a drive for advocacy in Europe. Gradually, families and individuals have realised the impact advocacy can have on service design, provision and in particular, on legislation. This awareness has encouraged a vast growth in the number of advocacy organisations, especially for those with mental health issues (Moreslli, 2000).

The development of advocacy organisations in Europe has been driven by four central goals (Moreslli 2000):

- the provision of information and training programmes
- the provision of practical help for those who seek it
- the campaign for legislative and structural change
- the encouragement of research in this area

In the United Kingdom, a parliamentary group has been set up with the specific purpose of developing advocacy for those with mental health problems. In Italy, there have been great efforts to improve the level of service provision. Elsewhere, advocacy groups have evolved with the co-operation of local authorities in the Scandinavian countries Moreslli, 2000). Sweden has introduced advocacy provision whereby guardianship and trusteeship are tools to protect those with mental health difficulties or intellectual disabilities (Brandon, 1995). In the Nordic countries and the Netherlands, there has been a long commitment to the human rights of people with disabilities and to providing equal opportunities for all citizens (Hurst, 1995). This has resulted in service providers receiving financial support in the development of services in consultation with the consumer (Hurst, 1995). In addition, the in-hospital projects in the Netherlands and Austria have received high acclaim (Forster, 1998). Both projects began in the early 1980's and 'encompass all hospital-based psychiatric facilities' (Forster, 1998: 159).

Despite such achievements, there has not been widespread advancement in the provision of advocacy for people with disabilities in Europe. For example, Spain, France, and Germany all contend that it is unlawful to discriminate against a person with a disability. Yet none of these countries have implemented legislation to counteract such discrimination (Hurst, 1995). Furthermore, the funding needed to make a real impact on advocacy provision has been scarce, and in some cases, non-existent (Moreslli, 2000: 296).

International Review

The following is a review of advocacy provision in five countries: England, Scotland, the Netherlands, the United States of America, and Australia. While it is accepted that these countries are amongst the more developed world and European economies, the following factors justify their selection:

- The international models reviewed here are relevant to Irish social policy structures. England and Scotland were deemed suitable on the basis of social, economic, and legislative similarities.
- The Netherlands has been widely acclaimed in its efforts to uphold the rights of individual with disabilities. Dutch advocacy provisions were considered to offer

an appropriate comparative yardstick for the development of an Irish model.

- The United States was chosen because of the legislative advancements it has made in the area of disability rights and its innovative approaches to funding.

- Finally, Australia was chosen also to its legislative provision for advocacy, as discussed in the Forum's document 'Advocacy- a Rights Issue'.

England

Legislative Standards

There are four key government initiatives, which attempt to establish a greater role for advocacy in England (Valios, 2002):

- *Valuing People: A New Strategy for Learning Disability for the 21st Century (*Department of Health, 2001).

- Mental health reforms

- Patient Advocacy and Liaison Services (PALS)

- *'Learning to Listen – Core Principles on the Involvement and Engagement of Children and Young People'* (Children and Young People's Unit, 2001)

Valuing People: A New Strategy for Learning Disability for the 21st Century

This policy document states that 'Effective advocacy can transform the lives of people with learning disabilities by enabling them to express their wishes and aspirations and make real choices' (2001: 46). While this *White Paper* is particularly relevant to people with intellectual disabilities, it does pave the way for advocacy provision for all citizens. The specifics of advocacy provision are *'To enable people with learning disabilities to have as much choice and control as possible over their lives through advocacy and a person-centred approach to planning the services they need' (2001: 26).* To promote the further development of advocacy, the government is implementing a 'Learning Disability Development Fund' (2001: 112). Furthermore, objectives can be achieved through:

- The promotion of the rights of people with intellectual disabilities

- Ensuring that people with intellectual disabilities can become fully and actively involved in all decisions of their lives

- Enabling advocacy to be available for people with intellectual disabilities

- Ensuring that services are based upon a person-centred approach

Mental Health Reforms

In the White Paper, *Reforming the Mental Health Act 2000,* it was proposed that service users in England and Wales should have access to specialist independent advocacy. The subsequent paper, *Independent Specialist Advocacy in England and Wales,* specified the type of advocacy to be used: professional advocacy model, implemented by trained and paid advocates (Barnes & Brandon, 2002). It was also envisaged that the current semi-independent advocacy providers would evolve into autonomous advocacy organisations (Barnes & Brandon, 2002). Furthermore, local groups would also be encouraged to gain independence through the development of their own management committees (Barnes & Brandon, 2002). Thus, local accountability would be ensured. The report also provided for the establishment of an inspectorate, which would ensure all service users, subject to the Mental Health Act, have access to specialist advocacy services These services would be 'universally available and provided in a consistent way' (Barnes & Brandon, 2002). 8).

Patient Advocacy and Liaison Service (PALS)

This provision was proposed in *National Health Service Plan 2000* (Valios, 2002). According to Barnes & Brandon (2002), this form of advocacy provision would be quite different to independent specialist advocacy recommended under the Mental Health reforms. The key difference is that PALS lacks structural independence, as it is intended to be supplied by the service provider (Barnes & Brandon, 2002). Its role would be to provide information and advice to service users and families about 'rights, services and the Mental Health system' (Barnes & Bandon, 2002:42). Directing service users to the appropriate independent specialist advocacy service would also be a key function (Barnes & Brandon, 2002).

However, *Advocacy 2000* – 'a project dedicated to supporting, defending, and promoting independent advocacy in Scotland' (*Advocacy 2000*, 1999) – has expressed concern over the establishment of PALS, in particular over the use of the term 'advocacy' (2002). It sees PALS as an advisory service rather than an advocacy service, and fear that the misuse of the term 'advocacy' will cause consumer confusion (*Advocacy 2000*, 2002). Under the National Health Service Plan 2000, PALS is due to be implemented in England and Wales, but *Advocacy 2000* fear it is only a matter of time before it is introduced to Scotland (2002).

Learning to Listen – Core Principles on the Involvement and Engagement of Children and Young People (2001)

This initiative focuses on a variety of principles, which government departments must implement for children and young people (Children and Young People's Unit, 2001). One such principle is the strengthening of advocacy services for this cohort. According to the Children Act Report 2001, the Children and Young People's Unit (CYPU) requires the strengthening of advocacy services for children in the care of local authorities (2002). Such provision must especially be made available for children wishing to lodge a complaint against their care provider (CYPU, 2002). Additionally, the Department of Health intends to draft national standards for

advocacy through local consultations (Department of Health, 2002). These initiatives encourage the development of advocacy services that are uniformly structured and monitored.

National Systems & Funding

The White Paper, '*Valuing People: A New Strategy for Learning Disability for the 21st Century' (2001),* proposes the establishment of a 'National Citizen Advocacy Network' for those with developmental disabilities, managed by a consortium of leading voluntary organisations. Through this development it is envisaged that at least one citizen advocacy organisation will develop within each local authority area (Barnes & Brandon, 2002). Previously, citizen advocacy organisations were established by professionals who recruited unpaid, independent volunteers to develop one-to-one relationships with individuals (Brandon, 1995). By 1995 there were 151 citizen advocacy schemes in the United Kingdom, nearly a third of which represented people with intellectual disabilities (Brandon, 1995). Examples of such schemes are:

- In 1985 *Survivors Speak Out* (SSO) was established as a fully national network of mental health care recipients (Brandon, 1995). The goal of SSO was to work co-operatively to promote change in the psychiatric system.

- 1991 saw the development of *The Swansea Prison Listener Scheme*, providing trained 'peer counsellors' to support those in Swansea Prison (Brandon, 1995)

- The *British Deaf Association* currently provides community advocacy services. The aim of such a service is 'to work with service providers, commissioners and deaf service users to improve access and quality of services' (British Deaf Association, undated). Through the community service, information and training is offered to encourage successful collaboration between service providers and deaf service and deaf service users (British Deaf Association, 2002).

In, '*Valuing People: A New Strategy for Learning Disability for the 21st Century'* (2001), it was proposed that the strengthening of advocacy could be achieved through 'increased funding for local self-advocacy groups' (Department of Health, 2001: 47). As part of this proposal, a *Learning Disability Fund* of up to £50 million per annum was established, with a proportion funding the development of advocacy (Dept. of Health, 2001). The government had never previously agreed to finance – £1.3m for each of the next three years – the establishment of range of independent advocacy services (Eustace, 2002). More specifically, the government affirmed its intention to set up an *Implementation Support Fund*, with £300,000 to support the recruitment of citizen advocacy volunteers (Barnes & Brandon, 2002). Accordingly, this funding would be derived from statutory resources, with special advocacy services being jointly financed, and multi-approach advocacy organisations drawing on a variety of monetary sources (Barnes & Brandon, 2002). Furthermore, *Primary Care Trusts* would be established to commission local mental health services to provide advocacy (Barnes & Brandon, 2002).

Campbell recommends that a 'coordinated approach to funding is necessary, so that reliable funding bodies are not drained of all their resources by different groups' (1990:76). Hadlow (1996) argues that consistent advocacy provision can only come about when commitment is given to overall welfare, and when advocacy is acknowledged as a right to be upheld through health and social services (Hadlow, 1996). Barnes & Brandon (2002) insist that if funding is to be provided for the development of advocacy services, then it must be realistic of a three-year minimum span. Long-term commitment is necessary if advocacy provision is to be successful. The report, *Independent Specialist Advocacy in England and Wales (*Barnes & Brandon, 2002*)*, commissioned on behalf of the British Department of Health provides valuable information on the management, provision and structure of advocacy services in England. As with '*Valuing People: A New Strategy for Learning Disability for the 21st Century'* (2001), it focuses specifically on mental health. However, it can be adapted for the general provision of specialist advocacy provision.

Management Structures

According to the Department of Health, commissioners are to be appointed to develop a planned approach to the provision of advocacy (2002). Specifically, commissioners are to ensure equity of services and adequate attendance to the diverse needs of the population (Barnes & Brandon, 2002). The Mental Health Reform Act supports the establishment of a new health care Inspectorate, which, among other duties would ensure that all individuals, under the power of the Mental Health Act have access to specialist advocacy services (Barnes & Brandon, 2002). Under the *Department of Health Report* (2002), *Primary Care Trusts* (Pacts) were given the responsibility for commissioning special advocacy services (Barnes & Brandon, 2002). However one difficulty that commissioners must face is adequately monitoring an advocacy service without compromising the service's independence (Barnes & Brandon, 2002: 3). Furthermore, within the advocacy service, it is envisaged that specialist advocates are supported and supervised by advocacy service managers (Barnes & Brandon, 2002).

Accountability

Commissioners have three core roles in the management of advocacy services (Barnes & Brandon, 2002: 30):

- To provide on-going support to advocacy services, particularly, in the initial phase, with the aim of promoting good management practices

- To arrange regular meetings with advocacy service to discuss the monitoring process. Through consultation, commissioners must ensure that the independence of the advocacy service is not compromised. However, 'quality, performance and financial monitoring are non-negotiable'

- To occasionally facilitate joint meetings between advocacy services, the service provider and the commissioners.

Under the White Paper, *Reform of the Mental Health Act,* the establishment of a new *Commission for Mental Health* was proposed (Barnes & Brandon, 2002). Among its many duties, the Commission is to ensure that the *Mental Health Act* operates within its legal framework, that it develops and implements standards for special advocacy services, and that it oversees the adoption of such standards by all relevant parties, including specialist advocates (Barnes & Brandon, 2002). Furthermore, the creation of a new health care Inspectorate has ensured that all complaints pertaining to the *Mental Health Act* will be investigated. The Inspectorate also acts an advisor on the development of standards for training specialist mental health advocates.

Service Provision

While the British Department of Health, does not specifically identify who should provide advocacy, it does advise that in order to ensure complete independence, such services should be provided by agencies that do so exclusively (Barnes & Brandon, 2002). However, it is accepted that, as several advocacy service providers currently administer services, and exclusive provision may not be possible (Barnes & Brandon, 2002). What the report, *Independent Specialist Advocacy in England and Wales: Recommendations for Good Practice* (Barnes & Brandon, 2002: 26), suggests is a 'new configuration of services, with:

- Provider agencies, which run a range of services, could develop a semi-independent stand-alone arm for advocacy management.

- The grown of numerous local or national independent agencies dedicated to the provision of advocacy, each with their own management committee to ensure local accountability

- A national or regional specialist advocacy agency would be responsible for running all specialist advocacy services, the employment, training, support and of all specialist advocacy and the monitoring and review of services.

Furthermore, when advocacy commissioners are developing the 'best' models of advocacy provision, several factors should be considered (Brandon and Barnes, 2002):

- The service should satisfy the needs of the local community. In particular, it should identify and address the differences between urban and rural provision

- Advocates should be supported and not work alone

- Frameworks should be in place, which facilitate the adoption of core standards for the delivery of advocacy

Typically, advocacy provision often develops in the community by its own members. Therefore, it is envisaged that *Primary Care Trusts* will not take

complete control of advocacy provision, but work in collaboration with local communities (Barnes & Brandon, 2002:29). The commissioners should manage tendering for advocacy provision and successful tenders should consider local circumstances and needs in creating 'service specifications' (Ibid, 2002: 30). Furthermore, once an agency has been selected, a 'service level agreement with commissioners' should be drawn up (Ibid, 2002: 26).

Scotland

In May 2001, *Advocacy 2000* conducted a study – *The Advocacy Development Programme* – that highlighted several inequalities in advocacy provision throughout Scotland (*Advocacy 2000*, May 2001). It concluded that, there were major service gaps in the provision of advocacy for people under 16 and over 65 years in Scotland, and that the majority of independent advocacy available is primarily for those who suffer from mental health difficulties. Advocacy 2000 was established to ascertain the level of advocacy provision in Scotland and to offer support and information for providers. Since 2002, Advocacy 2000 was replaced by the *Scottish Independent* A*dvocacy Alliance* (*Advocacy 2000*, March 2002). This alliance has been provided with funding for three years with the specific aim of developing *The Advocacy Safeguards Agency* (*Advocacy 2000*, March 2002). Its duties include:

- review existing work on local advocacy strategy development and develop an evaluation network and structure for the provision of advocacy

- develop government policies which ensure the provision of advocacy and conduct research on independent advocacy and act as a mediator in local disputes

Similarly, the Scottish Executive has been very active in the publication of guidelines for the development of advocacy, including *Independent Advocacy: A Guide for Commissioners.* In the *Guide,* the Scottish Executive states that 'independent advocacy is a crucial element in achieving social justice' (2001: 3). Advocacy is seen to be a necessary instrument, which ensures that all opinions are heard (Scottish Executive, 2001a). However, despite recent legislation highlighting the importance of advocacy, it can still prove difficult to access (Scottish Executive, 2001a). Advocacy 2000, published *Principles and Standards in Independent* advocacy *Organisations (2002)* which identified the following necessary elements for comprehensive advocacy provision:

- Community roots are essential for effective advocacy. Communities provide an invaluable way of achieving 'cultural change and social inclusion'. They foster independence and security through collective support and wisdom

- Advocacy organisations should develop relationships with other advocacy providers to increase their strengths, skills and knowledge

- Service users play an important role in advocacy provision as their personal experiences of disempowerment and exclusion offers 'invaluable knowledge and a unique view' (Advocacy 2000, 2002: 17)

In February 2001, the Milan Committee – a government sub-committee established to review *The Mental Health (Scotland) Act* (1984) – published a review report on the *Mental Health Act* (*Advocacy 2000*, February 2001). Several recommendations for the provision of advocacy followed:

1. The Mental Health Act should endow all mental health service users with the right to obtain access to an advocate

2. Service providers should be obliged to inform services users about the availability of advocacy services and to take steps to ensure that the user has an advocate if they wish

3. It should incumbent upon health boards and local authorities to ensure that advocacy services are availability to all who require them

4. An assurance that advocacy is of an adequate standard should be provided by the commissioning service

5. The Scottish Executive should promote advocacy

6. There should be a statutory obligation on service providers to provide support services to collective advocacy groups, as required

Funding

In *A Guide for Commissioners* (2001), the Scottish Executive envisages that local authorities and health boards should form advocacy-planning teams and work with them to create a three-year advocacy action plan, as well as providing long-term funding for advocacy projects (2001). It is essential that agencies have a reliable core grant, which lasts for at least three years with the possibility of an equivalent extension (Scottish, Executive, 2001). It is further advised that advocacy groups and statutory funders agree that both groups have a right and a duty to give feedback to each other (Scottish Executive, 2001a). Advocacy provision in Scotland is also mentioned in the *Mental Health (Scotland) Bill 1984*, which propounds an obligation on statutory authorities to ensure that a range of independent advocacy services is developed. Additionally, the Scottish Executive expects that all health boards develop high quality advocacy services and allocate sufficient funds to achieve this (Scottish Health Services Trust, 2002). *Advocacy 2000* (2002) advises that potential and current advocacy providers, where possible, should draw funding from a variety of sources. This is necessary because a reliance on one large source can cause conflicts of interest. If one has a variety of sources conflicts are shared and diluted among the funders (*Advocacy 2000,* 2002). At an Advocacy 2000 conference Kendrick highlighted the need to increase

funding sources, for, as advocacy grows, conflicts will arise over the limited availability of funding (*Advocacy 2000*, November 1999).

Service Provision

The provision of advocacy in Scotland is largely for those with mental health difficulties (*Advocacy 2000*, May 2002). However there are a number of advocacy organisation currently active in Scotland, including:

- *Edinburgh* Advocacy *and Representative Service* – This offers advocacy to older people who have been in long-term care in Edinburgh (*Advocacy 2000*, August 1999)

- The *Patients Advocacy Service* in Carstairs – a state Psychiatric Hospital (*Advocacy 2000*, May 2000).

There are also a variety of resources to assist organisations in the provision of advocacy including:

- *The Scottish Database* compiled by *Advocacy 2000*, listing all independent advocacy projects in Scotland (*Advocacy 2000*, August 1999)
- *Timebank* – this allows individuals to register their availability for voluntary activity and enables organisations to identify volunteers (*Advocacy 2000*, May 2000)

Each local council in Scotland has the responsibility for developing advocacy provision in their area. The NHS Orkney and Orkney Islands Council conducted a study of the provision of advocacy within their district, and concluded:

1. That there were as many models of advocacy as there were projects currently in existence

2. That the council could neither sustain a large generic organisation or several small client-specific advocacy groups due to difficulties experienced in recruiting volunteers

3. That citizen advocacy, specifically, is a difficult area, as volunteers tend to shy away from long-term commitment

4. A need to listen to local people, which can be successfully achieved through the appointment of an individual who will listen to the least vocal groups

The Scottish Human Services Trust (2002) has found difficulties in re-shaping current urban advocacy provision into an integrated system, particularly where there are multiple providers. Furthermore, in rural areas, services provided by lone advocates can no longer meet demands (Scottish Human Services Trust, 2002). However, the Scottish Human Services Trust (2002) believes that such issues can

be resolved through developing specialist advocacy services under the auspices of an independent advocacy umbrella organisation.

Management
Commissioners shall be the core managers of advocacy development in Scotland. Their responsibilities shall include: the clarification of accountability, and ensuring that public funding is being used well. However commissioners do not need to become involved in every minor decision made (Scottish Executive, 2001a). The Scottish Executive cites 'acceptability' as a key factor in the successful management of advocacy projects (2002: 26). Those involved in the project must trust the agency facilitating its development. Furthermore, Malcolm Chisholm MP – speaking at the *Advocacy 2000* conference in February 2001 – emphasised that Scotland requires:

> *'some form of National advocacy body….(which could) support health boards and their planning partners to develop local integrated, independent advocacy schemes and support local advocacy providers to develop'* (Advocacy 2000, May 2001: 2).

Evaluation & Assessment

The Scottish Executive (2001) maintains that assessments of advocacy projects are necessary in order that both commissioners and advocacy groups know whether their efforts have been effective. Furthermore, as the majority of advocacy organisations receive public funding, the public has a right to know if money is being used effectively (Scottish Executive, 2001a). The Scottish Executive (2001: 29) also advise, that terms should be stipulated in relation to monitoring and evaluation. Such evaluations must take into account the specific model of advocacy being used, for example citizen or peer, and be aware of its specific goals (Scottish Executive, 2001a). It must also include a jointly agreed set of outcome measures, which should be published annually and quarterly (Scottish Human Service Trust, 2002). Evaluations play a key role in the success of advocacy projects. Three factors must be considered in any evaluation:

1. The purpose of the project must be carefully scrutinised

2. A value must be placed on relationships as well as results, to provide a comprehensive evaluation of advocacy

3. There should be regular independent evaluations of all advocacy projects – but not until the initial three years has lapsed

The Scottish Human Service Trust (2002) discusses some of the research that health boards have undertaken to evaluate advocacy provision. Specific areas for examination are highlighted which are necessary for competent research – current advocacy provision; age; geography; community and institutions; specific situations; specific types of independent advocacy; and new legislation. Currently,

work is underway to devise an integrated comprehensive approach to research in a single health board area (2002). In Scotland, much has been written on the issue of advocacy provision. Comprehensive research reports have concluded that, while advocacy provisions are widespread throughout Scotland, certain minorities are excluded. When this is considered with the lack of guaranteed funding, it is clear that Scotland has a long way to go before a comprehensive advocacy service is assured.

The Netherlands

The provision of advocacy in the Netherlands is based on human and civil rights. Currently, there are shifts occurring in the provision of service for people with disabilities (van Loon & Van Hove, 2001). These shifts in provision are being shaped by the beliefs:

- That all individuals with disabilities have a right to a 'normal' quality of life.

- That inclusion is a priority and must be facilitated
- That individuals must be allowed to exercise self-determination and personal development (Van Loon and Van Hove, 2001)

In this report, discussion on the Netherlands will focus on the provision of advocacy for those with mental health difficulties, as it has been recognised as developing one of the most advanced systems in Europe.

National Systems and Funding

The Austrian and Dutch advocacy models of patient advocacy are regarded as some of 'the best developed systems of outpatient psychiatry in Europe' (Forster, 1998: 159). Such advancement has been assisted through the actions of client-controlled pressure groups, which have gradually gained support from the government (Forster, 1998). The independent *National Foundation of Patient Advocates* (Forster, 1998) was established in 1981 as a pilot project, and integrated into Dutch law in 1994. It provides all involuntary hospitalisations with access to an advocate (Forster, 1998). The funding for this service is derived from a supplemental charge on all hospital and nursing fees (Forster, 1998). The role of a patient advocate is to safeguard the patient's legal rights, inform the patient of their legal position, and help him or her to find solutions to complaints (Forster, 1998:160). As the advocate works mainly within the hospital boundaries, maintaining independence of mind is particularly emphasised. To ensure this, advocates must not assist the hospital in policy development or attend meetings without the represented individual (Forster, 1998: 161).

Service Provision

Patient advocates are employed on a full-time basis by an independent organisation, which selects, supports and supervises them (Forster, 1998). Advocacy organisations in the Netherlands are protected by legislation and receive

guaranteed state financing. However, the Dutch model of advocacy does exhibit some discrepancies. First of all, when individuals are involuntarily hospitalised, they must chose an advocate to represent them (Forster, 1998). However, what has evolved within psychiatric hospitals is the under-representation of certain groups, particularly of elderly patients (Forster, 1998). Those most in need of a 'voice' are marginalized further. The Austrian model appears to have overcome some of these difficulties through automatic allocation of an advocate for each patient (Forster, 1998). Furthermore, this approach emphasises that patients are still citizens with rights and so should be treated as such (Forster, 1998). Secondly, the Dutch model works on the 'felt needs' principle, where the individual's expressed needs are considered (Forster, 1998). The Austrian model works from a 'normative need' perspective, where individual needs are determined by social norms (Forster, 1998). The latter approach protects individuals who are unaware of their rights, and therefore unable to express them. Both Dutch and Austrian patient advocacy models are acclaimed for their ability to affirm the rights of previously disempowered people. Neither model is flawless, but both bear elements that are adaptable to Irish advocacy provision.

United States of America

The US along with Canada was the first countries to develop anti-discriminatory laws for people with disabilities (Degener & Quinn, 2000). The American Disabilities Act (ADA, 1990) is regarded as 'the most comprehensive federal law to address discrimination against [for] an estimated 50 million Americans' (Blanck, 1996). It is an extensive civil rights law, which protects those with disabilities against discriminatory practices. The ADA also shifted the focus from welfare law towards civil rights law (Degener & Quinn, 2000). Specifically the ADA has allowed for the development of a *Protections & Advocacy* (P&A) *System* (see Box) and a *Client Assistance Programme* (CAP). The evolution of disability rights in the United States and in particular the ADA has had 'an enormous impact on foreign law development' (Degener & Quinn, 2000: 12). From an Irish perspective the ADA (1990) had a marked influence on the work of the Commission on the Status of People with Disabilities (Quinn, undated). Advocacy provision in the US has been further fuelled by an alliance formed across 'a broad spectrum of political and ideological constituencies' (Kendrick, 2001: 5).

Protection and Advocacy System

As part of the ADA (1990), the P&A System was established. Under its auspices, *Disability Rights Agencies* were set up to administer four specific programmes:

- The Protection and Advocacy for Persons with Developmental Disability (PADD) Program.

- The Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program.

- The Protection and Advocacy for Individual Rights (PAIR) Program.
- The Protection and Advocacy Assistive Technology (PAAT) Program.

A number of tasks are involved in these programs:

- Providing legal representation for all persons with disabilities
- Monitoring and investigating residential services for persons with disabilities, and investigating cases of abuse and neglect.
- Ensuring that inclusive education, financial entitlements, healthcare and housing are fully accessible to persons with disabilities
- Ensuring that the rights of individuals within vocational rehabilitation services are upheld, addressing grievances, and, in some cases, providing legal representation (under CAP)

Advocacy services are provided on the basis of needs assessment. Individuals most vulnerable or with complex advocacy needs are given priority. The P&A System is guided by the principles of equity, empowerment, participation and independence (www.protectionandadvocacy.com). The National Alliance for the Mentally Ill (NAMHI) was founded in 1979 and has since been an influential player in policy provision (Foulks, 2000: 354). NAMHI has fought to change laws and policies which infringe upon the rights of people with mental health difficulties (Foulks, 2000: 354). Since its establishment, NAMHI has brought about change in funding for research and community-based programme services (Foulks, 2000: 354).

Funding

According to Kendrick, 'the USA has been remarkable in its diversity of advocacy financing sources beyond that of obtaining funds solely from public authorities' (2001: 7). As a result, both strong networks have evolved at local and national levels 'leaving few stones unturned' in the identification of viable sources of funding (Kendrick, 2001: 7). The strength of advocacy groups in the United States also comes from the solid inter-group relations (Kendrick, 2001:7). Kendrick (2001), stresses that if these advocacy organisations were more numerous, the provision of advocacy in the United States would not be as enduring. However, the sources of funding are not unlimited and Kendrick (2001) advises that *when* advocacy loses its appeal and is no longer fashionable, sources of funding will come under pressure. Whether or not the current provision of funding for advocacy is sufficient will then become apparent.

Australia

In Australia, advocacy provision is underpinned by the following legislation:

- The *Human Rights and Equal Opportunity Commission Act* (1986)

- *Australian Disability Discrimination Act* (DDA) (1992)

The *Human Rights and Equal Opportunity Commission Act 1986* established the *Human Rights and Equal Opportunity Commission* (HREOC) (Part II Section 7-11). This national independent body has responsibility for overseeing the implementation of the following: *International Covenant on Civil and Political Rights; Convention on the Rights of the Child;* and the *Declaration on the Rights of the Disabled Persons* (Part III Section 47-1).

The HREOC also ensures that violations under the *Racial Discrimination Act 1975,* the *Sex Discrimination Act 1984,* and the *Disability Discrimination Act 1992,* are addressed and investigated. The objectives of the *Australian Disability Discrimination Act* (1992) are:

- to eliminate, as far as possible, discrimination against persons on the ground of disability in the areas of:

    - work, accommodation, education, access to premises, clubs and sports
    - the provision of goods, facilities, services and land
    - existing laws

- the administration of Commonwealth laws and programs

- to ensure, as far as practicable, that persons with disabilities have the same rights to equality before the law as the rest of the community

- to promote recognition and acceptance within the community of the principle that persons with disabilities have the same fundamental rights as the rest of the community.

(DDA 1992, Part 1: 1)

In addition, the DDA 1992 aspires to promote the integration of persons with disabilities in community settings and to ensure that their rights as citizens are respected. Through the investigation of human rights complaints and the education of the public on the area of disability, the DDA strives to include all citizens with disabilities in Australian society. The DDA also admits legislative powers to the HREOC, including the development of standards for disability services [Sect. 67-1 (d) 1992] and the publication of guidelines to protect persons with disabilities from discrimination [Sect. 67-1 (k) 1992].

- Disability Services Act 1986 – This Act offers explicit definitions of self-advocacy, citizen advocacy and group advocacy. More importantly, it discusses the nature of funding for such advocacy services [Part II, Division 1, Section 7]

- Disability Advocacy Programme (see below)

Standards

In Australia, standards for the development of advocacy are discussed in the *National Disability* Advocacy *Program* (NDAP) (1999). The goal of this programme is to 'enable people with disabilities to achieve and maintain their rights as citizens and to improve their access to and participation in community life' (Department of Family & Community Services, 1999: 4). While it recognises the important role advocacy has played in improving the lives of people with disabilities. The NDAP believes that the enhancement of advocacy is possible through:

- Greater recognition of family involvement in advocacy provision

- A more focused outcome for people with disabilities

- The distribution of resources on a more equitable basis

- And the active co-ordination of service provision (Department of Family & Community Services, 1999)

The objectives of the NDAP include the prevention of abuse and discrimination against people with disabilities; the promotion and enhancement of the rights of people with disabilities; increased and social participation for people with disabilities; and the facilitation of more equal social participation for people with disabilities. The report also recommends that two categories of advocacy be adopted – individual and systemic (Department of Family & Community Services, 1999). Specifically the focus would be on individual advocacy with a small proportion of systemic advocacy at a local or regional level (Department of Family & Community Services, 1995). It is also envisaged that there would be active co-ordination with state governments, a formal mechanism being in place to represent the views of families (Department of Family & Community Services, 1999). The *National Mental Health Policy and Plan* (1992) noted several national standards for mental health services, two of which are relevant to advocacy provision:

Standard 2 Consumer and carers participation in the planning, implementation, and evaluation of the mental health service

Standard 4 The promotion of community acceptance

To fulfil these standards, advocacy needs to develop alongside active community participation for all, including those with disabilities.

National Systems & Funding

Two examples of advocacy provision in Australia relate to individuals with brain injury and those in the deaf community. The *Brain Injury Association of Queensland* (BIAQ) supports individuals with Acquired Brain Injury (ABI) who have experienced either human rights violations or social injustices (BIAQ, 2002). Where possible, BIAQ encourages individuals to become self-advocates. The duties of BIAQ include:

- The representation of individuals with ABI to Government departments and service providers
- Negotiations with the judiciary
- Offering assistance to individual funding applicants
- Mediation with landlords, health and welfare services

Headway Victoria states that its goal is 'about giving a voice to clients when they cannot' or are unable to voice their own concerns or needs (Headway Victoria, 1999). The organisation works with people with ABI, their carers and families. It aims to secure the appropriate services for the individual. This representation can take various forms, including individual or group, self or system advocacy (Headway Victoria, 1999). *The Victorian Council of Deaf People* (VCOD) aims to provide 'advocacy to deaf individuals and groups to produce systematic improvements in social justice and human rights' (undated). The VCOD has various roles. It encourages involvement in the local community through advocacy; facilitates accessibility to events and services for all deaf people; informs the state government of on-going issues; and works in partnership with deaf and hard of hearing service organisations to ensure that there is no duplication of services.

ADACAS is the *Australian Central Territory, Disability, Aged and Carer Advocacy Service.* It advocates for people who cannot represent their own interests. It also provides information and education on individual organisations, and to the general public (ADACAS, 2002). Advocacy in mental health is concerned with redressing 'the injustices dealt to people living with a mental illness', particularly around powerlessness and inequity. Advocacy aims to inspire changes, which enable consumers/carers to retain the highest possible level of control, over their lives. (Mental Health Council of Australia, undated). Government initiatives in the area of mental health have encouraged the development of advocacy further. The *Community Development Project (*CDP), seeks to:

> *'……..enhance the capacity of the community sector, to undertake advocacy work through increased knowledge and strengthening skills within the mental health community sector' (Mental Health Council of Australia).*

The CDP is linked to a community awareness programme, which attempts to reduce discrimination against people with mental health difficulties. What has emerged from this project is the 'The Kit'. This is a 'resource to support consumers and carers to undertake activities which promote sustainable change' (Mental Health Council of Australia, undated). It contains information on systems, attitudes and strategies, which can be utilised to achieve various goals. The Australian government also produced a *Mental Health Statement of Rights and Responsibilities*. This discussed consumer rights and responsibilities, provisions of mental health problems, and proposed standards. However it has met with severe criticism from carers who feel it is inadequate in allowing consumer rights to be shaped around mental health service provision (Mental Health Council of Australia).

Funding

There have been recent developments in the funding of mental health services in Australia. Several sources of funding have been utilised – state and territorial governments, commonwealth government, and private health insurance funds. A 'Medicare Agreement' has evolved which states that:

- The current level of expenditure on specialist mental health services should be maintained

- Any resources released from the rationalisation of the mental health service should be re-invested in the mental health programme.

The NDAP recommends the investigation and development of 'suitable funding systems with links to performance indicators, output and outcome measures (Department of Family & Community Services, 1999). Currently, seventy-six advocacy services receive $10 million from the Australian government, with the NDAP monitoring its allocation (Department of Family & Community Services, 1999). The Commonwealth Department of Health and Family Services fund by the Australian Central Territory Department of Health and Community Care, and independent advocacy organisations, such as ADACAS. Despite the improvements in advocacy provision throughout Australia, certain barriers still exist to total advocacy provision:

- Advocacy still lacks credibility among the wider community

- A lack of co-ordination between organisation result is inequalities of support for consumers

- Prejudices regarding people with disabilities still exist in society, particularly for those with mental health issues.

Canada

In 1992, the *Ontario Advocacy Act* allowed for the provision of advocacy for all citizens with disabilities in Canada. However, in the same year, the bill was revoked. In 1996 an *Amended Substitute Decisions Act* was passed, for the following purposes:

- To make the law more accessible to persons with disabilities
- To broaden the criteria for application for the role of advocate, thereby strengthening the position of families and service providers of persons with disabilities
- To achieve the correct balance of protection and empowerment toward independent living for persons with disabilities.

It was envisaged that through the amended act, the issue of guardianship would be simplified and clarity would be obtained for those seeking to become advocates for persons with disabilities.

Psychiatric Patient Advocacy Office
In 1983, the first nation-wide advocacy programme was established in Canada – the *Psychiatric Patient Advocacy Office* (PPAO). Its remit: is to advance the legal and civil rights of patients in psychiatric care. The PPAO's advocacy endeavours can be regarded as essential to the reform of the mental health sector. The work of the PPAO is supported by the Mental Health Act and Regulation, 741, Section 9 (1):*'The Minister of Health and Long-term Care must designate a rights adviser for each psychiatric facility designated as an institution under the Mental Hospital Act'* Section 9 (1) also clarifies the necessary qualifications of such advisers and the form of delivery that advisory services should take *(www.ppao.gov.on.ca).*

Guyana

Looking further afield, it can be observed that advocacy is not only limited to the more prosperous countries. According to McConkey & O'Toole (2000), a community based rehabilitation programme in Guyana, South America, has proven most effective thorough the use of self-advocacy. Experts from both Africa and Europe have educated the citizens in Guyana on self-advocacy and helped them to establish effective advocacy collectives (McConkey & O'Toole, 2000). By encouraging media coverage of disability issues and the promotion of the rights of persons with disability within political circles, an increased sense of solidarity for those with disability in Guyana is emerging. As a result, persons with disabilities are becoming influential players in the development of disability policies in Guyana.

Uganda

Over the last few years much recognition has been given to the development of the National Union of Disabled Persons of Uganda (NUDIPU) (Ssekabira, 2000). The development of the NUDIPU has meant that persons with disabilities in Uganda can finally make their voices heard, notably, with regard to the formulation of disability policy (Ssekabira, 2000) Decades of lobbying by the NUDIPU has resulted in greater consideration of the needs of persons with disabilities in drawing up national programmes and policies, and greater room for individuals with disabilities to direct the course of their own lives. The NUDIPU has expanded to every district in Uganda and now includes representatives within local government. The involvement of the NUDIPU in lobbying for persons with disabilities has had a wider affect on policy makers – the rights and views of those with disabilities are now being considered in all sectors. What is to be learnt from Uganda is that in order for effective and appropriate legislation for persons with disabilities to develop, these persons must be directly involved in policy design.

Critical Summary

The *Declaration of Human Rights* and the *United Nations Standard Rules* pave the way for the development of advocacy. However, such documents are not legally binding and merely provide advice to UN member countries on the potential ways of improving the quality of life for persons with disabilities. Countries such as the UK and the US have developed policies which not only emphasise advocacy as necessary instrument in disability services, but which discuss and source the funding of advocacy services. However, not all vulnerable groups are considered under such policies. In many countries the human rights of children and the elderly are ignored. Furthermore, advocacy provisions vary for different sections of the disability sector. Where developed advocacy services exist for those with mental health difficulties equivalent provisions for those with developmental disabilities are missing, and vice versa. The level of influence of a specific group is often crucial to policy development. By reviewing intentional legislation, Ireland can learn from the mistakes and accomplishments of other countries. However, specific cultural factors must be considered and our own marginalized groups included.

Chapter 4

ADVOCACY IN IRELAND

In Ireland, there is virtually no statutory provision of advocacy for citizens with disabilities. However there are several non-statutory bodies involved in advocacy provision. This chapter reviews some advocacy programmes currently supported by several umbrella bodies in Ireland.

Irish Advocacy Network

In January 2002, the Minister for Health and Children stated that:

> *'there is a need to generate greater public awareness, an understanding of mental health issues and to change attitudes to mental illness among the general public and health professional…advocacy services [are] a priority'* (Department of Health, 2002).

He was speaking at the launch of *Regional Advocates* by the *Irish Advocacy Network* (IAN). The IAN received ¤250,000 in funding from the government to develop a national mental health advocacy service, specifically a National Peer Advocacy framework (Department of Health, 2002). The Minister maintained that *'the development of the IAN and the appointment of regional advocacy is a major step forward in the development of advocacy services'* (Department of Health and Children, 2002). Furthermore, the Minister outlined that advocacy provides those who have mental health difficulties with valuable practical assistance in their rehabilitation (Department of Health and Children, 2002).

Interview with Irish Advocacy Network (IAN) Representatives

A discussion took place with representatives from the Irish Advocacy Network, on 23rd October 2002. The most important points raised in the interview appear in this section. The IAN is the first peer advocacy organisation in Europe to have an accredited training course, and is currently in negotiations to upgrade its status to that of a recognised diploma.

Goals of Advocacy

> *'Civilisation is measured by its treatment of its most vulnerable citizens. Citizens in care are no less citizens. Their voices should be heard, views respected and interests defended' (Quote relayed by IAN: Edna Conlon, 1990).*

However, it does see the role of advocacy for those with mental health difficulties distinct from other groups. Not only is advocacy regarded as a tool to redress injustices, but also 'as a road to recovery'. The IAN perceives advocacy as a means for achieving the following key goals:

- To grant basic human rights, which those with mental health difficulties have been refused

- To afford those with mental health difficulties the same respect as other citizens

- To secure freedom and liberty for those with mental health difficulties

- To enable those with mental health difficulties to become equal citizens.

Since receiving funding from the Department of Health in January 2002, the IAN has placed a peer advocate in five of the eight health board areas. Negotiations regarding the remaining three are ongoing. It is intended that volunteer peer advocates will be recruited in each of the health board regions.

Peer Advocacy

As peer advocacy involves individuals who have shared similar experiences, there are no power-sharing issues. It is person-centred to the individual's needs. Furthermore, 'the person is the director of what happens'. Peer advocacy for those with mental health difficulties has existed since 1630 – and the *House of Bedlam.* IAN believes that if advocacy is to develop in Ireland exploration of the development of provision since 1620 must be carried out. IAN sees current advocacy provisions in Ireland as totally unacceptable. The principal problem is, in its view, a lack of legislation protecting advocacy as a right. According to the IAN the provision of advocacy included in the Disability Bill 2001 (rescinded in 2002), was misguided. If *Comhairle,* or a large statutory commission, were to oversee advocacy development in Ireland, this would compound existing problems. The organisations, which have oppressed and ignored those with mental health difficulties in Ireland would be the very ones shaping advocacy. Should this framework develop, vulnerable individuals will become even more marginalized.

The establishment of the IAN was inspired by its members' feelings of exclusion from the processes designed to develop advocacy in Ireland. This exclusion continues to the present. Nonetheless, the IAN does want to be part of a process, which provides advocacy for all those who require it, but not one which will compound the oppression of marginalized groups. The IAN also caution against comparative studies of international advocacy systems. While it is accepted that lessons can be learnt from 'successful' provisions in other countries, the flaws of provision can often be overlooked by such comparisons.

Members of the IAN have experience of working with advocacy groups in the United Kingdom. Fifteen years ago, these advocacy groups became involved in consultations with statutory bodies. In this period there has been little progress in the provision of peer advocacy. IAN believes that if Ireland continues on its current path, a similar fate will be suffered.

IAN also has direct contact with peer advocacy groups in Scotland. It is regularly requested to provide peer advocates for state hospitals in Scotland. From their experiences they suggest that Scotland may not be a suitable model to follow. Closer examination of advocacy services in Scotland may reveal an increased marginalisation of advocacy groups — in particular, those groups which pre-date advocacy legislation. Therefore, IAN suggests that the exploration of advocacy should begin with an examination of what is in existence in Ireland. Specifically, those models which have, in the short term at least, proved successful. The study currently being conducted by *Comhairle* will hopefully highlight such models.

The Disability Federation of Ireland (DFI)

The Disability Federation of Ireland (DFI) is 'a national umbrella organisation for voluntary non-statutory agencies who provide support services to people with disabilities and disabling conditions' (DFI, www.disability-federation.ie). The DFI provides supports and services to voluntary organisations providing services to those with disabilities. It also assists member organisations to strive for the rights of people with disabilities to full and equal citizenship (www.disability-federation.ie).

Interview with DFI Representatives

A discussion with a representative from the Disability Federation of Ireland took place on the 8th of October 2002. The most important points raised in the interview appear in this section.

Advocacy in Ireland

According to the Disability Federation of Ireland (DFI), advocacy is accorded very little recognition in Ireland. There is confusion over the role of advocacy stemming from a lack of understanding of disability. A definition of advocacy that is applied consistently from service provider to user is needed. Public perceptions of advocacy are unlikely to change as long as disability is treated from a health perspective. Despite these problems, there are very active and vocal groups involved in advocacy in Ireland. The members of these have acquired a 'half-decent lifestyle' through advocacy. However, there is a perception that all groups operate to the same success is without foundation. In particular, there is a very obvious rural/urban discrepancy.

Delivery of Advocacy

The DFI believes that *Comhairle* is in the best position to deliver advocacy in Ireland. However, if *Comhairle* assumes this role, certain structural reviews need to precede its involvement. Secure funding is necessary if advocacy is to succeed. Without this, individuals will not be able to take control of their lives. Advocacy is part of a 'cutting edge' of disability rights development and 'we should look beyond the usual areas to find enlightened ideas'. ***'Advocacy will only work if we believe a lot of things have to change'.***

The Forum of People with Disabilities

The *Forum of People with Disabilities* produced a report '*Advocacy - a Rights Issue'* in 2001. This explores advocacy provision in Ireland and reviews some of the main service providers. It also outlines current international legislation and directives, which facilitate the development of advocacy in Ireland. The *Forum* stipulates that the government needs to:

> *'address advocacy as a human and civil rights issue, enshrined within a package of pro-active and anti-discriminatory legislation, which all disabled people within closed environments can claim.' (2001: 97)*

The *Forum* (2001) makes several recommendations based on its research, including:

- Advocacy must be framed in human and civil rights language, as a rights issue
- Advocacy must be named and detailed with a pro-active anti-discrimination legislative package, similar to that of Australia
- There should be a charter of rights and accessible information in relation to advocacy.
- An advocacy system should include comprehensive monitoring and complaints procedures
- Advocacy services should be independent of other service providers

Interview with Forum Representatives

A discussion took place with a representative from the Forum of People with Disabilities on the 9th of October 2002. The most important points raised in the interview appear in this section.

Advocacy as a Right

In order for advocacy to be effective, it needs a legislative base – essential, to enshrine it as a right. At present individuals with disabilities in Ireland are not protected by state law. Mechanisms are in place to protect those in prisons, however this does not extend to those in residential care. In its neglect of citizens, the *Forum of People with Disabilities* believes that the state is in violation of international laws.

Provision of Advocacy

Currently, there is no organisation, which could deliver independent advocacy in Ireland. Existing statutory bodies would have to concentrate solely on the provision of advocacy, to the detriment of their other duties. A position similar to that of the Ombudsman may prove successful for advocacy provision. An amalgamation of appropriate bodies, for example, the Human Rights Commission, the Equality Authority, could form part of a Commission on Advocacy. Such a Commission should aim to establish standards for all in 'closed spaces' or residential settings.

Furthermore, though specific disability must be recognised, all representative bodies can be held to account in a universal advocacy system. Adequate independent funding is vital to the provision of advocacy. This could be monitored by a national advocacy entity. In order to preserve independence, the regional health boards should not be part of this process.

The Future of Advocacy

The future of statutory advocacy in Ireland is dependent upon the knowledge of those managing its development. Statutory bodies involved in advocacy provision should be thoroughly competent with regard to current provision in Ireland. Furthermore, both service providers and the government need to be open to change. Advocacy needs to be embraced and accepted as a necessary element of an equitable society.

Brí

Brí is a recently formed advocacy group for those with Acquired Brain Injury (ABI). It was formed from *Headway Ireland* and is based on the eastern coast of Ireland.

Interview with Brí representative

A discussion took place with a representative from *Brí* on the 28th of August. The most important points raised in the interview appear in this section.

Advocacy Provision

Brí sees advocacy as part of an overall package to facilitate the rehabilitation of those with ABI. It regards advocacy as a way to ensure that all those with ABI receive an Individual Care Plan on their release from hospital care. *Brí* approaches the provision of advocacy in Ireland in a cautious manner. It believes that smaller organisations, like *Brí,* will be swamped by larger organisations with 'louder voices'. By involving existing local organisations in advocacy provisions, local needs would be addressed by 'local application'. *Brí* aims to generate discussions with health boards so that current focus includes those with ABI.

Critical Summary

In summary, interviews took place with representatives of four umbrella organisations in Ireland. The outcomes of these interviews indicated an emerging consensus that independent and responsive advocacy support services should be available to all individuals who seek them. However, the representatives offered diverse views on the policy and legislative strategies to pursue in Ireland.

Chapter 5

CONCLUSIONS & RECOMMENDATIONS

In Ireland, diverse voices have emerged calling for the statutory provision of advocacy for those with disabilities. Based on evidence from the published literature, from other countries and from interviews with representatives of the disability sector in Ireland, this chapter, first, presents a brief review of current provision in Ireland. Next, it proposes four recommendations:

- advocacy should be developed within a rights framework
- advocacy services should be independent
- long-term funding for advocacy agencies should be secured
- the structure and implementation of advocacy services should be based on consultations and period reviews of their efficacy

Current Provision

Current services in Ireland takes many forms: self-advocacy, parent advocacy, peer advocacy and citizen advocacy. No services are mandated, however. Overall, provision in Ireland has developed on an ad-hoc basis. Advocacy organisations have emerged with few resources, born out of their commitment to support the most vulnerable sections of Irish society. *Comhairle* are currently exploring the extent of advocacy in Ireland: questionnaires were distributed to various health boards and organisation across the country. This project aims to collect data regarding the level of advocacy provision nationwide. Many have originated from service provider agencies, which, despite giving advocacy a 'rung on the ladder', calls into question the independence of such advocacy groups.

Expanding advocacy provision in Ireland will involve similar difficulties to those encountered in other international models. Based on evidence from other countries, it is likely that he primary problems will arise from a failure to regard advocacy as a human and civil right, and the lack of guaranteed funding. In February 2002, the *Regional Advocacy Network* became the first independent advocacy organisation to receive funding from the government. However, questions regarding funding commitments remain with the initial funding only guaranteed for three years.

A Word of Caution

Caution is advised in this task. Advocacy at the moment is a very 'fashionable' term, with many organisations evaluating their current provisions of advocacy. However, what is emerging is the attenuation of the concept of advocacy. For example, residential services for those with intellectual disabilities may stretch

advocacy to mean their weekly house meeting. The induction of self-advocacy sessions into weekly agendas is a welcome step. However, the weight of advocacy is reduced if it comes to constitute discussion on menus and weekend activities. Clarity is needed on the meaning of advocacy, and on how the individual is best enabled to exercise his or her rights. If this is done within the confines of the residential setting and with support from staff, independence is most definitely compromised. As noted, many service providers today place greater emphasis on the issue of advocacy. Alongside this, the meaning of advocacy must be clarified and upheld, and the independence of advocacy groups assured. A study assessing the level of advocacy provision in Ireland must address advocacy in its true sense. There must be no room for confusion. While it is accepted that professionals in the area of health care regularly advocate on behalf of individuals, frontline staff must be aware that such representation is often blighted by bias arising from conflict between employers and consumers. Such conflict can be avoided through educating staff and family members on advocacy and its inherent imperatives.

Furthermore, confusion arises regarding the legal jurisdiction of advocacy. Frontline staff and families often feel threatened by advocacy, with parents anxious that their opinions can be over-ruled, and, at worst, their child removed from their care. Frontline staff, too, may be apprehensive toward the introduction of advocates, fearing assessment of their ability to deal with consumers. Again, these issues can be overcome through the education of staff, families and the wider society. If advocacy is to become part of everyday life and a tool for the disempowered, each citizen must be made aware of its importance.

Recommendations

This Report makes the following recommendation*s*:

- **The recognition of Advocacy as a right**

- **The development of an Independent Advocacy Commission, to explore further the practical measures necessary for the development of advocacy in Ireland by consulting with current providers of advocacy**

- **A review of the availability of funding for Advocacy from non-statutory agencies, drawing on successful strategies in other countries**

- **Meaningful consultation with existing, local Advocacy groups in expanding Advocacy provision in Ireland**

Advocacy as a Right

First and foremost, advocacy needs to be enshrined in Irish legislation as a basic constitutional right (Forum of People with Disabilities, 2002). As the *Forum* recommends, advocacy must be imbedded in a human and civil rights framework (2001: 94). Advocacy enables the individual to access civil and human rights, therefore advocacy should be a right in itself – a necessary tool in participating in society as a full and equal citizen. Advocacy is the way forward if freedom and liberty is to be made available to *all* citizens (IAN, 2002). By ignoring the rights of individuals with disabilities, the Irish government could lend itself to international prosecution (Forum of People with Disabilities, 2002). This study suggests further exploration of working models of advocacy, in particular, the Dutch model where advocacy provision is developed from a human and civil rights perspective. However, in the interest of both cohesiveness and cost, it would be preferable if the right to advocacy were part of the right to services. Rights to services and a right to advocacy are not exclusive – one cannot exist without the other. An individual may have a right to services but be unable to utilise them. Similarly, an individual may have a right to advocacy without being able to access services. The provision of services must be based on a right to such services and this must be accompanied by a right to advocacy, as a means of taking full advantage of rights to services.

Independent Advocacy Commission

Previous research and current international practice highlights the necessity of the provision of Independent advocacy services. The Disability Bill 2001, rescinded in 2002, included a provision for advocacy, which was to be developed by Comhairle. As previously discussed, the most appropriate model of advocacy demonstrates independence of mind, structure and funding. Comhairle is funded by and answerable to the government. Using the above criteria, it clearly cannot be regarded as independent. This view is supported by some of the organisations contacted for this paper. However, if Comhairle were to play a part in the development of advocacy provision in Ireland, perhaps a commissioning role – similar to that of the Scottish Executive – would be most suitable. The prospective development of a commission on advocacy emerged from discussions with umbrella bodies involved in disability in Ireland. It is envisaged that such an agency would incorporate representatives from the Human Rights Commission, the Equality Authority, the Law Reform Commission, as well as statutory and voluntary bodies involved in the field of disability. The principles of such a commission should be based on those of the Commission of People with Disabilities (1996), but with the specific remit of advocacy provision in Ireland. A Commission on advocacy should include the following in its terms of reference:

- To examine *in detail* current advocacy provision for disabled people Ireland

- To explore the most equitable means for the provision of advocacy in Ireland and develop codes of practice

- To estimate the costs of advocacy provision and to identify sources of funding – notably, the Commission on the Status of People with Disabilities proposed that funding for advocacy should be covered by the Department of Health (now the Department of Health and Children). However, such a system of funding could prove problematic as it could foster acceptance of a narrow medical or welfare model of disability. Encouraging funding from a variety of sources would be more likely to facilitate financial independence, because the demands of a single investor would not have to be pandered to.

Funding

To be effective over time, advocacy requires long-term, secure funding. Government funding for the IAN is a positive step, but one which could easily be negated if its longevity is not guaranteed. If an advocacy commission were established, its first role would be to source funding from the statutory, private, and public domains. If secure funding is to be guaranteed, it must be part of an overall commitment to the provision of advocacy. This can only evolve if the right to advocacy is given a legislative foundation. A closer review of funding structures in Scotland would enable the Irish government to ascertain the best funding strategy for advocacy provision on the basis of a working model.

Structure & Implementation

Existing models of advocacy successfully operating in Ireland can offer valuable knowledge and experience in the development of statutory advocacy. Rather than replacing existing organisations it would be advisable to nurture expansion and growth. These groups have established relationships with their communities and are aware of the pit-falls of advocacy provision. Such awareness is evident in organisations like IAN, currently receiving financial support to develop peer advocacy networks throughout Ireland. IAN urges the government to look at current Irish models, which are successfully providing advocacy to a wide range of individuals (IAN, 2002). While international comparisons are valuable already existing models in Ireland would provide domestic practical experience.

The most important aspect of existing advocacy structures in Ireland are the connections to local communities. Much has been documented about the importance of community links to advocacy provision. Dispersing community-based groups as part of the establishment of statutory advocacy may have repercussions for community involvement. Models such as citizen advocacy rely on community members to volunteer support for vulnerable individuals. It would be advisable to support communal advocacy provision rather than attempting to assert any kind of external control over it. Rather than specifically identifying one particular model for advocacy delivery in Ireland, closer consultation with current providers needs to be carried out. Existing advocacy groups will possess the knowledge necessary for the wider application of advocacy for their specific users.

Critical Summary

This report proposes the following recommendations for the development of advocacy provision in Ireland:

- the recognition of advocacy as a right
- the establishment of an Independent Advocacy Service
- the securement of long-term funding for advocacy organisations
- that the structure and implementation of advocacy provision be subject to consultation and periodic reviews of effectiveness.

In addition, it is necessary that evaluative tools, for ascertaining the cost-efficiency and efficacy of advocacy supports, be developed – that is, to ensure that advocacy supports have a measurable impact on the independence, social inclusion and quality of life of people with disabilities. Therefore, agreed outcomes need to be specified in order to monitor the effectiveness of advocacy and its role in improving the quality of life for persons with disabilities. Further research has been identified as necessary in the following areas:

- Identifying advocacy outcomes, which will illustrate the effectiveness of advocacy
- Individual application for advocacy services
- The development and monitoring of universal standards for advocacy provision should it be mandated to the local voluntary agencies

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http://www.c-c-d.org

http://www.ncd.gov/index.html

http://www.familyvillage.wisc.edu/education/panda.html

Physical/Intellectual Disabilities

www.partners.dabsol.co.uk

www.dpi.org/index.html

www.nami.org

www.bcdp.org.uk

http://cil.gcal.ac.uk/home.html

www.nrh.ie

www.headwayireland.ie

www.biaq.com.au

www.enableireland.ie

Human Rights and Civil Liberties

www.equality.ie

www.iccl.ie

www.interights.org/

www.actionaidireland.org

Sensory Disabilities

www.britishdeafassociation.org.uk

www.irishdeafsociety.com

www.ncbi.ie

www.vcod.com.au

Mental Health

www.iol.ie/lucia

www.mensana.org

www.nmha.org

www.wfmh.com

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Children

www.firstcallbc.org

www.ncb.org.uk