

Developing an Advocacy Service for People with Disabilities

Volume 1

July, 2004

Goodbody Economic Consultants
Ballsbridge Park, Ballsbridge, Dublin 4 • Tel: 353-1-6410482 • Fax: 353-1-6682388
Website: www.goodbody.ie/consultants/ • Email: econsultants@goodbody.ie

Foreward

In preparation for the new Disability Bill, Comhairle commissioned this study to identify and examine the components of an advocacy service that would meet the needs of people with a disability in Ireland. The brief for the study was to set out the strategic framework and estimate the costs of developing the service over a five-year period. Goodbody Economic Consultants were commissioned to undertake the study, which commenced mid-year 2003.

Comhairle had previously undertaken a number of initiatives on advocacy including a report *The Jigsaw of Advocacy* published in 2003. That report examined advocacy models and current services in Ireland and set out possible future options for Comhairle in the context of its statutory mainstream responsibilities. It did not attempt to address advocacy in the context of the particular needs of people with a disability.

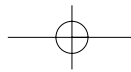
This study focuses on people with a disability. The provisions in the 2001 Disability Bill for the establishment by Comhairle of advocacy services including a Personal Advocacy Service, and discussions with representatives of the Department of Social and Family Affairs established the context for this study. In addition to consulting with a range of stakeholders in Ireland, substantial research was undertaken on the international experience of advocacy services. Research papers were prepared on seven countries and these are reproduced in Volume 2 of this report.

This is a comprehensive study and includes, in addition to the views of Irish stakeholders and the international research a review of the concept of advocacy, an overview of the policy context in which services are to be developed and outlines the current institutional environment. It sets out options and proposals for developing advocacy services for people with a disability and the implications for Comhairle.

I believe that the report will facilitate further discussion on advocacy services and their role in the overall development of services for people with a disability. Advocacy is a complex area and initially there may be unduly high expectations of what can be achieved by this service. The issue of independence must be addressed but care must also be taken to ensure high standards and good practice in developing the services. The report charts a route for Comhairle in anticipation of forthcoming legislation. This is a combination of promoting and supporting the development of advocacy services in the voluntary sector, developing a new initiative in respect of services for people in residential care and directly providing a personal advocacy service. This strategy appears to offer the best approach to meeting the varying needs of people with a disability while building on existing expertise in the voluntary sector.

The development of advocacy services will ultimately depend on the availability of resources to Comhairle. I welcome this report and I consider that it offers valuable information and advice on the establishment of advocacy services in Ireland.

Tom Daly
Chairman



Acknowledgements

This report has benefited from the advice and insights of many individuals. The authors would particularly like to acknowledge the cooperation afforded to them on their study tour of Australia and Scotland by the following organisations.

Australia:

The Office of the Public Advocate, Victoria
 The Department of Human Services, Victoria
 The Commonwealth Department of Family and Community Affairs
 Action for Community Living, Victoria
 VALID, Victoria
 Koomarri Community Services, Canberra
 People First, Canberra
 ADACAS, Canberra

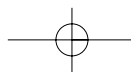
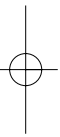
Scotland:

Scottish Executive
 Scottish Human Services Trust
 Advocacy Safeguards Agency
 Partners in Advocacy

The Authors also wish to acknowledge the assistance of the management and staff of Comhairle, in particular Leonie Lunny, Chief Executive, Tony McQuinn, Senior Manager, Development and Support and Eileen Fitzgerald, Senior Manager, Regional Services.

Table of Contents

| | |
|---|-----------|
| 1. Introduction | 8 |
| 1.1 Background | 8 |
| 1.2 Approach to the Study | 8 |
| 1.3 Outline of the Report | 11 |
| 2. Advocacy: Definitions and Concepts | 12 |
| 2.1 Introduction | 12 |
| 2.2 Defining Advocacy | 12 |
| 2.3 The Principles of Advocacy | 13 |
| 2.4 Forms of Advocacy | 14 |
| 2.5 Advocacy and Service Delivery | 16 |
| 3. Government Policy and Comhairle's Disability Advocacy Remit | 17 |
| 3.1 The Commission on the Status of People with Disabilities | 17 |
| 3.2 The Report of the Establishment Group "Building a Future Together" | 17 |
| 3.3 Disability Bill and Comhairle | 17 |
| 3.4 Comhairle's Remit | 18 |
| 3.5 Current Position | 19 |
| 4. Profiling People with Disability | 20 |
| 4.1 Introduction | 20 |
| 4.2 Profile of the Population of People with Disability | 20 |
| 4.3 Estimates of Numbers of People with Disabilities | 20 |
| 4.4 People with Disabilities Using Disability Services | 23 |
| 5. The Institutional Setting and Consultation on the Role of Comhairle | 26 |
| 5.1 Introduction | 26 |
| 5.2 Overview of Institutional Setting | 26 |
| 5.3 Institutions and Services with a Disability Focus | 27 |
| 5.4 Other Relevant Institutions and Services | 31 |
| 5.5 Views on the Role of Comhairle and Advocacy Priorities | 33 |
| 5.6 Conclusions | 35 |



| | | |
|-----------|--|-----------|
| 6. | The International Experience of Advocacy for People with Disability | 36 |
| 6.1 | Introduction | 36 |
| 6.2 | Advocacy in England and Wales | 37 |
| 6.3 | Advocacy in Scotland | 41 |
| 6.4 | Advocacy in Australia | 45 |
| 6.5 | Advocacy in Victoria | 48 |
| 6.6 | Advocacy in New Zealand | 50 |
| 6.7 | Advocacy in Sweden | 52 |
| 6.8 | Advocacy in United States | 55 |
| 6.9 | Advocacy in Canada | 58 |
| 6.10 | Overview | 62 |
| 7. | Advocacy Services in Ireland: Background and Principles | 64 |
| 7.1 | Introduction | 64 |
| 7.2 | Overview of Principles for Policy Option Appraisal | 64 |
| 7.3 | Accessibility | 65 |
| 7.4 | Independence | 65 |
| 7.5 | Promotion of Self-Reliance and Empowerment | 66 |
| 7.6 | A Focus on the Most Vulnerable | 66 |
| 7.7 | Well-founded and Safe | 66 |
| 7.8 | Client-centred and Promoting the Best Interests of the Client | 67 |
| 7.9 | Addressing Issues at the Most Appropriate Level | 67 |
| 7.10 | Integrating Individual and system Advocacy | 68 |
| 7.11 | A Partnership Approach with the Community and Service Providers | 68 |
| 7.12 | A Commitment to Quality | 68 |
| 8. | Overall Strategic Approach | 69 |
| 8.1 | Constraints | 69 |
| 8.2 | The Broad Options | 69 |
| 8.3 | Evaluation of Options | 69 |
| 8.4 | Meeting the Needs of the Institutionalised Population | 71 |
| 8.5 | Summary of the Strategic Approach | 72 |
| 9. | Key Features of the Proposed Advocacy Service | 73 |
| 9.1 | Introduction | 73 |
| 9.2 | Strategic Issues: The Personal Advocacy Service (PAS) | 73 |
| 9.3 | Strategic Issues: The Community and Voluntary | 77 |
| 9.4 | The Community Visitors Programme | 79 |

| | | |
|------------|---|-----------|
| 10. | Implications for Comhairle | 80 |
| 10.1 | Introduction | 80 |
| 10.2 | Comhairle's Role | 80 |
| 10.3 | Institutional and Organisational Implications for Comhairle | 82 |
| 10.4 | Budgets and Phasing | 83 |
| 11. | Recommendations | 86 |
| | Appendix 1: Bibliography | 88 |
| | Appendix 2: List of Persons Consulted | 95 |

List of Tables

| | | |
|------|--|----|
| 4.1 | Percentage of the Irish Population with a Long Term Illness or Disability by Age Group | 21 |
| 4.2 | Distribution of People by Degree of Disability | 22 |
| 4.3 | Estimated Distribution of Adults by Type of Disability | 22 |
| 4.4 | Main Residential Circumstance of People with Intellectual Disability | 23 |
| 6.1 | Breakdown of Statutory Funding of Advocacy by Specific Groups of People (2003-2004) | 44 |
| 6.2 | Breakdown of Statutory Funding of Advocacy by Types of Advocacy Organisations and Groups (2003-2004) | 44 |
| 10.1 | Phasing of Activity and Budgets | 85 |

List of Figures

| | | |
|-----|--|----|
| 6.1 | The Scottish Model for Advocacy Services | 43 |
|-----|--|----|

Introduction

1.1 Background

Current Government policy envisages that advocacy for people with disabilities will have two key components. The first is supporting and developing appropriate advocacy services and initiatives, working with and on behalf of people with disabilities. The second is the provision of a dedicated Personal Advocacy Service.

One of the principal functions of Comhairle is to support the provision of independent information, advice and advocacy services to assist and support individuals, particularly those with disabilities, in identifying and understanding their needs and options and in accessing their entitlements to social services. The Disability Bill, 2001 included provision for the establishment by Comhairle of advocacy services for people with disabilities, including, specifically, a Personal Advocacy Service.

In this context, Comhairle commissioned this study to:

- Identify and examine the components of an Advocacy Service for and on behalf of people with disabilities that would best fit and could be applied in Ireland taking into account existing functional responsibilities and administrative systems;
- Set out a strategic framework for establishing and developing such a service;
- Estimate the cost of developing the service;
- Identify funding and accountability structures which would guarantee the independence of the service; and
- Set out a five-year programme to implement the strategic framework identified.

Goodbody Economic Consultants were commissioned to undertake the study. In undertaking the study, they were supported by Michael Kendrick and Sue Leigh Doyle.

1.2 Approach to the Study

The approach to the study comprised the following elements:

- Review of International Experience of Advocacy Services;
- Review of the Current Institutional Framework within Ireland;
- Consultation with the Major Stakeholders; and
- Development and Elaboration of Strategic Options.

1.2.1 Review of International Experience of Advocacy Services

This embraced:

- A review of the literature relating to advocacy services abroad;
- Commissioning of expert papers on advocacy services in four countries; and
- Two study visits to relevant jurisdictions.

An initial literature review and web-based search was undertaken to analyse the role, structure and historic development of advocacy services in other countries. This resulted in the identification of seven jurisdictions, which were considered to merit further research. These were:

- Australia;
- New Zealand;
- United States;
- Canada;
- England and Wales;
- Scotland; and
- Sweden.

The first four of these countries were considered to embrace a range of models in terms of the delivery of advocacy services. For these, experts resident in each country were identified and short papers were elicited from them in relation to their systems, on foot of common terms of reference. For the remaining three countries, Goodbody Economic Consultants undertook detailed research. The result was a set of seven papers detailing the systems and experience in these countries. These papers are reproduced in Volume 2 of this report.

Arising from these papers, it was considered that two countries merited further investigation – Scotland and Australia. These countries are notable in that in both cases, Government has planned and put in place a coherent set of policies with respect to advocacy for people with disability. Initial research indicated that the State of Victoria in Australia had in place an advocacy service delivered directly by a Government body. As this had a particular resonance for the proposed approach in Ireland, the study visit to Australia concentrated on Victoria.

A bibliography of the documentation, which was amassed during this and other elements of the study is presented in Appendix 1.



1.2.2 Review of the Current Institutional Framework within Ireland

The design of the Advocacy Service must take account of the existing institutional arrangements that impinge on advocacy. There was a need, in the context of the report, to set out the roles played by agencies, such as Comhairle (in its existing role), the Health Boards, the Equality Authority, the National Disability Authority, the Office of the Ombudsman, the Legal Aid Board, the Inspector of Mental Hospitals, and the Mental Health Commission. As well as mapping the institutional framework, it was also necessary to profile the population of people with disability and establish the current resources devoted to advocacy services for them.

1.2.3 Consultation with the Major Stakeholders

It was essential that all the stakeholders in advocacy services be consulted. Consultation took place with:

- The voluntary and community organisations that represent and provide services to people with disability;
- The statutory agencies, including relevant Government departments; and
- Key influencers in relation to policy on disability.

Consultations focused on:

- Needs of people with different categories of disability;
- Needs of people in different institutional settings;
- Current provision;
- Views on how the service should be developed;
- Priorities in service development;
- Barriers to the development of the service;
- Conflicts of interest for and independence of service providers; and
- Capacity of the voluntary and community sector to participate in the new service;

A full list of persons and organisations consulted is given in Appendix 2.

1.2.4 Development and Elaboration of Strategic Options

Based on the international and domestic research and the consultation process, a number of options for the organisation and delivery of advocacy services were devised.

Following consideration of these options against a range of criteria, a preferred approach was outlined. Consideration was then given to the appropriate budget levels and phasing of service introduction.



1.3 Outline of the Report

The report is presented in two volumes. Volume 2 presents the research papers on the seven countries identified in Section 1.2. This volume is set out as follows. Section 2 briefly reviews the concept of advocacy. Section 3 provides an overview of the policy context within which advocacy services are to be developed. In Section 4, the population of people with disabilities is profiled. Section 5 outlines the current institutional environment in Ireland and the results of the consultation exercise. Section 6 reviews the international experience of advocacy.

Sections 7 to 10 set out proposals for the developing of advocacy services in Ireland. Section 7 establishes some principles that should underlie the delivery of advocacy services. The options for the development of an advocacy service are discussed in Section 8. Section 9 profiles the proposed advocacy service while Section 10 sets out the implications for Comhairle. Section 11 presents the report's recommendations.

Advocacy: Definition and Concepts

2.1 Introduction

People with disability often need support in standing up for themselves, putting forward their views, and gaining control over their lives. Advocacy is a means of supporting or speaking up for someone, their needs and rights. It can involve pleading their case on behalf of the person with disability, or supporting them to speak up for themselves. The empowerment that advocacy can bring to the lives of disadvantaged and vulnerable people is considerable. In particular, advocacy services can support people with disabilities in gaining access to quality social services and ensuring fair and dignified treatment by service providers.

This Section explores the various aspects of advocacy and the concepts and principles that it embraces.

2.2 Defining Advocacy

Advocacy is something that many people do for others on a daily basis. Parents speak up for their children everyday. Relatives and friends speak on the behalf of vulnerable persons when necessary, and defend their basic rights and entitlements as human beings. While advocacy is thus a widespread activity, which is often delivered in an informal manner, the emphasis in this report is on development of a formal advocacy service.

There are many different definitions of advocacy. Perhaps the most encompassing and oft-quoted definition is that of Professor Wolf Wolfensberger, who is seen by many as having a key role in the development of the original concept of citizen advocacy, in the 1960s. He defines social advocacy as being:

“...the functioning (speaking, acting, writing) with minimum conflict of interest on behalf of the sincerely perceived interests of a person or group, in order to promote, protect and defend the welfare of, and justice for, either individuals¹ or groups, in a fashion which strives to be emphatic and vigorous.”²

Advocacy should not be confused with the giving of information, the offering of advice or social work. While the purpose of social work is to resolve issues and find solutions, advocacy strives to make a case for someone or support them in making a case. Although advocacy cannot be simply described as the giving of information or the offering of advice, both of these are aspects of the advocate's role.

Advocacy is often seen as embodying a number of basic principles, as outlined below.

¹ See section 5.5 for a full definition of citizen advocacy.

² Quoted in *Safeguarding Advocacy for People with Disabilities in Australia*, Judith Cross and Lorraine Zeni. Disability Advisory Council of Australia, 1993. For a further discussion of the nature of advocacy, see: *The Jigsaw of Advocacy*. Comhairle, September 2003.

2.3. The Principles of Advocacy

Advocacy embraces four main principles:³

- Empowerment;
- Autonomy;
- Inclusion; and
- Citizenship

2.3.1 Empowerment

People with learning disabilities, disabled people, and those with mental health problems are among the least powerful in our society. They are often not given the opportunity to voice their concerns or issues, and in some cases may be incapable of doing so themselves. Advocacy can provide these people with the support necessary to make their own decisions and choices. It can enable them to have more control over their lives. Even the provision of information and education on the options available, and the advantages and disadvantages of them, is hugely empowering for the individual in the sense that it may give them the self-confidence to act on their own. The empowerment that advocacy brings supports the other three principles of autonomy, inclusion and citizenship.

2.3.2 Autonomy

An autonomous individual is considered to be someone who directs their own life in accordance with their own conception of what they want to do with their life.⁴ Autonomy should not be confused with independence. Where people with learning disabilities may have to depend on others for some level of support in their everyday living, it is still possible that they can determine their own lives by being autonomous. Advocacy supports a person's right to voice their views, opinions and preferences in fora where others are making decisions which impact directly on that person's life. It plays a key role in enabling people to make informed choices about, and to remain in control of, their own lives.

2.3.3 Inclusion

The most vulnerable people in society are often isolated from social groupings and communities because of inequalities in access and opportunity. These inequalities can occur at many levels from the physical, where actual access to public transport and other public facilities may not be user-friendly, to the emotional, where people with learning disabilities are not treated as independent-thinking individuals in their own right. Having an advocate to communicate with, and work alongside can help to increase all levels of access thus offering greater opportunities within the community to all.

³ *Advocacy: A Review*. Dorothy Atkinson, 1999. Joseph Rowntree Foundation.

⁴ *Towards a model of disability advocacy practise*. Dr. David Sykes, 2001. Office of the Public Advocate, Australia.

2

2.3.4 Citizenship

Advocacy can also serve to protect the rights and privileges that should be available to all citizens within a society, but which are often blocked from those more susceptible to exclusion and isolation. It fundamentally identifies, promotes and defends a person's basic human rights.

2.4 Forms of Advocacy

2.4.1 Introduction

A taxonomy of advocacy must first distinguish between legal and social advocacy and also between advocacy that focuses on individual or systemic issues. Within this broad context, the delivery of advocacy can take many forms, from self-advocacy, peer advocacy and family advocacy to group advocacy, citizen advocacy and professional advocacy.

2.4.2 Legal versus Social Advocacy

Legal advocacy, as the name suggests, involves members of the legal profession helping individuals to exercise their rights through the courts and legal system. Legal advocacy has a significant role to play in the area of mental health, specifically with issues such as involuntary detention. Social advocacy on the other hand, involves supporting an individual's wishes and way of life, pleading on their behalf or supporting them to speak for themselves, but without the use of any legal resources. While the broad distinction between legal and social advocacy is clear, there is in practice a continuum of advocacy activity that embraces the two concepts. Thus, for example, advocates with no legal background may become involved in advocacy in legal or quasi-legal settings.

2.4.3 Individual versus Systemic Advocacy

The next distinction is between individual (or personal) advocacy and systemic advocacy. While individual advocacy supports individual persons, systemic advocacy aims to influence the policies and procedures of agencies, institutions, governments and societies that affect people. In the context of this study, most forms of advocacy discussed are of a social nature⁶, and may exist at both individual and systemic levels.

2.4.4 Self-Advocacy

Self-advocacy is the act of speaking up for oneself. With the right support in terms of advice, information and encouragement, self-advocacy is something that many individuals can achieve. The term "advocacy" literally means standing with or speaking for someone, so self-advocacy is sometimes interpreted as being a contradiction in terms. In reality, self-advocacy is the process by which people are empowered to speak for themselves. Although self-advocacy is often seen as the ultimate goal of advocacy, it may not be feasible for some people. People with severe mental disability, for example, may be unable to speak for themselves and will need the support of other forms of advocacy.

⁵ Legal advocacy does fall under the category of professional advocacy as discussed in section 5.6.

2.4.5 Peer Advocacy

Peer advocacy occurs when someone in a similar situation, or with similar experiences to the individual concerned, acts as their advocate. The knowledge of the relevant systems and organisations and their own experience makes them informed and powerful advocates. They also tend to have considerable empathy for the individual, and the relationship between them is often of a very equal nature. This adds to the empowerment of the individual.

2.4.6 Family Advocacy

This form of advocacy is fairly self-explanatory. A family member acts as advocate for the individual. The most simple example of this happens everyday, when parents speak up for their children. It is often the case that an individual with a disability, particularly those who live with their families, will receive the informal advocacy services of their parents or siblings. It should be noted, however, that this form of advocacy has the potential for conflicts of interest, particularly in terms of dependency and in terms of the differing levels of power that family members can exercise.⁶ Families may engage in collective advocacy through community-based organisations or associations.

2.4.7 Group Advocacy

Group advocacy is a form of self-advocacy. It occurs when a group of people, with a common cause, acts collectively to reach their shared goal. Group advocacy also has some overlap with peer advocacy as members of the group may have similar circumstances and some may have prior experience of advocating. Like self-advocacy, it is seen as enabling people to have a voice, enhancing personal identity and raising self-esteem.⁷ For less confident individuals, being part of a common group can be more empowering than acting on an individual basis, which may cause undue stress. The resources of a group of advocates are stronger than an individual and thus can provide invaluable support systems for individual advocates.⁸ This form of advocacy is only appropriate where there is a common cause.

2.4.8 Citizen Advocacy

Citizen advocates are unpaid volunteers who work in partnership with disadvantaged or vulnerable individuals. The partnership is usually ongoing and strong friendships are often formed, although this is not a purpose of the service. Citizen advocates are particularly valued as they are seen as being impartial, thus adding a sense of independence to advocacy. Citizen advocates can operate in two capacities. On one hand, they can act as supportive enabler, encouraging their partners to advocate for themselves. On the other, they can speak up for those who do not have a voice of their own.

2.4.9 Professional Advocacy

Professional advocacy usually refers to advocates who are paid to provide a particular advocacy service. They are usually engaged on a short-term basis,

⁶ *Advocacy: A Rights Issue*. The Forum of People with Disabilities, 2001.

⁷ *Advocacy: A Review*. Dorothy Atkinson, 1999. Joseph Rowntree Foundation.

⁸ *Advocacy: A Rights Issue*.

2

working with the client until a specific problem is resolved, or can be taken no further. Professional advocates are often engaged in dealing with crisis or very complex issues that require the expertise and resources that a paid advocate can offer. Professional advocacy can also refer to highly trained advocates who work in very specialised areas, such as the law surrounding mental health care.

2.5 Advocacy and Service Delivery

Advocacy is often concerned with access to, and adequate delivery of, services for people with disability. In this context, it should not be regarded as a substitute for pro-active policies on the part of service deliverers to provide services in a fair manner to transparent standards, and to have in place systems of feedback and redress for the consumer of those services.

Service providers that are effective often have customer service action plans that form the basis for their interaction with the customer. These encompass the setting of standards and performance targets, service agreements, formal complaints systems and ways of achieving feedback from customers, e.g., through consumer panels.

Service agreements or individual service plans for the clients of service delivery agencies can be designed to include monitoring and quality issues, as well as systems for feedback, thereby challenging agencies to become more person centred. Both positive and negative feedback play a part in enabling an organisation to shape their operations appropriately.

Service delivery within the context of explicit standards and feedback mechanisms serves both to reduce the need for advocacy and to render advocacy services more effective.

3

Government Policy and Comhairle's Disability Advocacy Remit

3.1 The Commission on the Status of People with Disabilities

The Commission on the Status of People with Disabilities published their report, *"A Strategy for Equality"* in 1996.⁹ This Strategy provided a blueprint aimed at removing the barriers facing people with disabilities in living full and fulfilled lives. The report contained a number of recommendations with regard to advocacy for people with disability, including mandatory advocacy services for people in residential care settings and support for self and citizen advocacy.

3.2 The report of the Establishment Group "Building a Future Together"

In November 1998 the Government approved the formation of an Establishment Group. The Establishment Group was asked to prepare detailed proposals for the establishment of the National Disability Authority and the future location of Departmental responsibility for the functions of the National Rehabilitation Board (NRB). The Establishment Group was also tasked with the setting up of a Disability Support Service. The group recommended that the requirements of the proposed Disability Support Service as set out in the report of the Commission on the Status of People with Disabilities should be met by merging the appropriate services of the National Rehabilitation Board and the National Social Service Board into a new organisation. This organisation, Comhairle, was established on 12th June 2000.

3.3 Disability Bill and Comhairle

The Disability Bill, 2001 included provision for the establishment by Comhairle of advocacy services for people with disabilities, including, specifically, a Personal Advocacy Service. In the Disability Bill, advocacy in relation to people with disabilities, was defined as including:

⁹ *A Strategy for Equality*. Report of the Commission on the Status of People with Disabilities. 1996.

- Representing, supporting or training people with disabilities for the purpose of self helping them to promote their best interests in relation to matters affecting their welfare and quality of life;
- For that purpose, supporting or training their families, carers or other persons, or members of organisations or groups representing their interests; and
- Representing, helping or supporting "qualifying people" to get access to a service provided by a statutory body or voluntary body, but not representation in legal proceedings.

The Personal Advocacy Service was envisaged as representing "qualifying people" and helping or supporting them in relation to:

- Applying for an assessment of need;
- Getting a health service;
- Getting any other service to which he/she is entitled;
- Making a complaint;

An Advocacy Service for and on behalf of people with disabilities is thus envisaged as having two key components:

- Supporting and developing appropriate advocacy services and initiatives working with and on behalf of people with disabilities; and
- Provision of a dedicated Personal Advocacy Service.

The provisions of the Draft Disability Bill (2001) would appear to envisage both individual and systemic advocacy services. However, the clear emphasis of the Bill is on individual services through a Personal Advocacy Service. The scope of activity envisaged is wide in that advocacy services are seen as supporting an application for an assessment of need, a health service, and "any other service... from a statutory body or voluntary body..." Thus, a pro-active individual service is envisaged. It is also clear that substantial State involvement in the provision of the service is foreseen. For example, the Director of Advocacy Services has the function of assigning personal advocates.

Government policy, as enunciated in the Disability Bill, is that Comhairle shall have a specific responsibility for the provision of advocacy services for people with disability. While it is clear that Comhairle is to provide a Personal Advocacy Service (PAS), the other activities by which Comhairle are to support the provision of advocacy services are not precisely specified.

3.4 Comhairle's Remit

In determining the scope of Comhairle's disability advocacy activities, regard must also be had to the Comhairle Act, 2000. The Comhairle Act establishes that Comhairle shall "support the provision of, or... provide directly, independent information, advice and advocacy services, so as to ensure that individuals have access to accurate, comprehensive and clear information relating to social services and are referred to relevant services".

The Act also particularly identifies people with disabilities as being in need of support and indicates that it is a function of Comhairle "to assist and support individuals, in particular those with disabilities, in identifying and understanding their needs and options and in accessing their entitlements to social services".

Reference is also made in the Act to the role of Comhairle in promoting and supporting the development of voluntary bodies that provide social services.

3.5 Current Position

At the time of writing, Government is reconsidering legislation with regard to both people with disability and Comhairle. In particular, a new Bill to replace the Comhairle Act (2000) is being prepared. This will set out the role of Comhairle in relation to *inter alia* advocacy for people with disability. It is our understanding that this Bill will have similar provisions to that of the Disability Bill (2001), in so far as it relates to advocacy for people with disability.

Thus, it is clear that Comhairle has a specific responsibility in relation to the development of a Personal Advocacy Service and an, as yet undefined, responsibility in relation to advocacy services for people with disability generally.

However, the Comhairle Act (2000) and its successor will provide the legislative backing within which the wider responsibilities can be exercised. This study is aimed at identifying the options for Comhairle both in relation to the Personal Advocacy Service and the provision of that wider range of services.

Profiling People with Disability

4.1 Introduction

This section presents data on people with a disability in Ireland, identifying the numbers involved, and the nature and severity of their disability, and the extent to which they are resident at home or in institutions.

4.2 Profile of the Population of People with Disability

4.2.1 Introduction

It is difficult to characterise the population of people with a disability, largely because disability varies in the degree of severity and there is no objective measure of disability. Most attempts to profile the population of people with disability in Ireland involve surveys where respondents declare their disability status themselves. There are four principal sources of data on people with disability. These are:

- Census of Population, 2002;
- European Community Household Panel (ECHP) Survey;
- The Quarterly National Household Survey (QNHS); and
- The National Disability Databases.

The Census of Population is the most comprehensive source of data on the numbers of people with disabilities in Ireland. However, it provides little information on the nature of such disabilities. For this type of information we must rely on the ECHP and the QNHS which are surveys of adults living in private households only, while the Disability Databases are essentially surveys of people with disability that are regarded as being in need of services from the State.

4.3 Estimates of Numbers of People with Disabilities

4.3.1 Numbers of Persons with Disabilities

The Census of Population 2002 provides for the first time an estimate of the total number of people with a disability in Ireland – in both household and institutional settings (unfortunately, at the time of writing, no information is available on the breakdown between these two groups).

The Census indicates that 323,707 or 8.3 per cent of the Irish population have a long-term illness or disability as defined. Table 4.1 gives a further indication of the occurrence of long term illness or disability by age and gender.

Table 4.1: Percentage of the Irish Population with a Long Term Illness or Disability by Age Group

| Age Group | Males (%) | Females (%) | Persons (%) |
|-------------------|-----------|-------------|-------------|
| Under 15 years | 2.6 | 1.6 | 2.1 |
| 15-19 years | 3.1 | 2.5 | 2.8 |
| 20-24 years | 3.6 | 3.0 | 3.3 |
| 25-34 years | 4.1 | 4.0 | 4.1 |
| 35-44 years | 5.8 | 6.0 | 5.9 |
| 45-54 years | 9.1 | 8.8 | 8.9 |
| 55-64 years | 15.3 | 13.0 | 14.2 |
| 65 years and over | 27.4 | 34.0 | 31.1 |
| All | 7.8 | 8.7 | 8.3 |

Source: Census of Population 2002

This shows that, as expected, the prevalence of disability increases significantly by age from 2.1 per cent of the under 15 years age group to 31.1 per cent of the 65 years and over age group.

The Census of Population also reveals that, of those aged 15 plus with a disability, 45,025 persons classified themselves as at work. This indicates that 30 per cent of males with a disability in their age group were at work, compared with 20 per cent of females.

The Census of Population also provides data on the number of unpaid carers in the State. Almost 150,000 people aged 15 plus indicated that they provide regular, unpaid, personal help for a family or friend with a long-term illness, health problem or disability.

4.3.2 Incidence and Degree of Disability

The 1998 ECHP comprised in-depth interviews of all adult persons in 2,729 households throughout Ireland, resulting in 6,324 individual records.¹⁰ Over 1,000 people with a disability responded to the survey. This analysis provides estimates of the degree of severity of disability.

The proportion of people falling into each of the three categories of disability identified in the 1998 survey are shown in Table 4.2.

Table 4.2: Distribution of People by Degree of Disability

The ECHP indicates that 16 per cent of the disabled population are severely disabled, while 60 percent have a chronic or mental health problem, illness or disability by which this person is at least to some extent hampered in their daily activities. A further 24 per cent have a disability without being hampered in their daily activities.

¹⁰ The data presented here are taken from analyses undertaken by Goodbody for the Equality Authority.

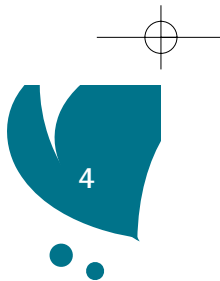


Table 4.2: Distribution of People by Degree of Disability

| Degree of Disability | Proportion (%) |
|--------------------------------------|----------------|
| Disabled and severely hampered | 16 |
| Disabled and to some extent hampered | 60 |
| Disabled and not hampered | 24 |
| Total | 100.0 |

Source: ECHP 98

4.3.3 Type of Disability

The Quarterly National Household Survey (QNHS) undertook a special analysis of disability among the population of working age in the second quarter of 2002. Table 4.3 provides a breakdown by type of disability.

This indicated that the vast majority of adults with disabilities (70 per cent), have a physical disability. The next highest category is mental or emotional with 10.5 per cent of the total. In interpreting these statistics, it should be noted that only those suffering from illnesses of more than six months duration were included, and that no indication of the severity of the disability is given.

Table 4.3: Estimated Distribution of Adults by Type of Disability

| Type of Disability | Proportion of Total (%) |
|---------------------|-------------------------|
| Physical | 69.6 |
| Sight | 1.7 |
| Speech | 0.5 |
| Hearing | 2.1 |
| Mental or Emotional | 10.5 |
| Other | 5.6 |
| Total | 100.0 |

Source: QHNS

4.3.4 Summary

The data presented above indicate that approximately 324,000 people in Ireland have a long-term health problem or a disability. Available data suggest that three quarters of adults in this group are, to some extent at least, hampered by their disability. The data also indicate that most adults with disability (70 per cent) have a physical disability, followed by 10 per cent with a mental or emotional difficulty.¹¹ There are no data on the level and type of disability among those under 15 years of age.

It should also be noted that the figures are influenced by the definition of disability used and that the ECHP and the QNHS indicate higher overall levels of disability than that suggested by the Census of Population.

¹¹ Breakdowns of type and severity of disability are only available for those living in private households. Inclusion of those living in institutions would most likely have the effect of increasing the proportion with severe disabilities.



4.4 People with Disabilities Using Disability Services

4.4.1 Intellectual Disability

Data on people with an intellectual disability is compiled annually by the National Intellectual Database Committee. Only those in need of intellectual disability services are included in the database. In April 2001, there were 26,688 people registered on the National Intellectual Disability Database. Of these, 39.6 per cent have a mild disability, 36.1 per cent moderate, 15.1 per cent severe, and 4.1 per cent profound.

Of the 26,688 persons, 34.6 per cent are aged 19 and under, 29.2 per cent are aged between 20 and 34 years, 26.6 per cent between 35 and 45 years, and 9.6 per cent are 55 years or over. A high proportion of the 19 years and under group is categorised as having a mild disability. The profile of the older groups is more severe. This reflects the fact that many children who are in receipt of services do not transfer to adult services when they leave school.

Over the last three decades, the number of adults has increased and the number of children has declined. This reflects in part the high birth rates at the beginning of the period, and the subsequent decline. The longevity of people with intellectual disability is also increasing. These trends have implications for the development of advocacy services, in that as their carers age and die, people with disability will require greater supports from third persons.

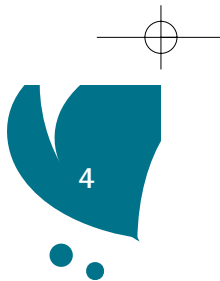
The main residential circumstances of people with intellectual disability are set out in Table 4.4. There are 16,341 people living in a home setting, representing 61.3 per cent of the total. 707 people (2.7 per cent) are living independently, while 8,296 (41.1 per cent) are in full-time or virtually full-time care.

Residential circumstances vary with age. The majority of those in a home setting are children, while the majority of those in group homes or residential centres are over the age of 35 years.

Table 4.4: Main Residential Circumstance of People with Intellectual Disability

| Residential Circumstance | Numbers | Proportion (%) |
|-----------------------------|---------------|----------------|
| In Home Setting | 16,341 | 61.3 |
| In Independent Living | 707 | 2.7 |
| In Community Group Home | 3,097 | 11.6 |
| In Residential Centres | 3,444 | 12.9 |
| In Psychiatric Hospitals | 677 | 2.5 |
| In Other Full Time Services | 1,078 | 4.1 |
| Unclassified | 1,624 | 4.9 |
| Total | 26,688 | 100.0 |

Source: National Intellectual Disability Database



4.4.2 Physical and Sensory Disability

The National Physical and Sensory Disability Database is a database established to facilitate service planning. As such, it does not provide information on the total population experiencing physical and sensory disability. Rather it provides information on the numbers who:

- Have a persistent physical or sensory disability arising from disease, disorder or trauma;
- In the case of dual disability, where the predominant disability is physical or sensory;
- Are less than 66 years of age;
- Are receiving or require a specialised health or personal social service which is related to their disability; and
- Have consented to being included on the database.

Comprehensive data are not available from the database as yet, as its introduction is being phased. Based on one area for which there is good data coverage (South Tipperary), it is estimated that as many as 38,000 persons or 1.1 per cent of the total population may be included on the database, when it is completed.

4.4.3 People with Mental Health Problems

There are 54 psychiatric hospitals and general hospital psychiatric units in Ireland. In 2001, there were 24,446 admissions to psychiatric hospitals and units.¹² Of the total admissions, 2,667 were non-voluntary and 21,779 were voluntary. At any time in the year 2001, there were 4,321 patients in psychiatric hospitals and units. Numbers are tending to decrease year by year.

A very high proportion of admissions (55 per cent) are single people. Admission rates are highest among the age group 35 to 54 years, and are lower for younger and older people. There is a high incidence of repeat admissions.

There are 254 out-patient clinics operating in hospitals with 237,667 attendances.

There has been a very significant increase in community psychiatric facilities over the last decade. This increase in community residences and other facilities has given rise to a large increase in the number of people being treated in the community. This has reduced both the number and duration of stay of people being treated in psychiatric hospitals. There are now 404 community residences with 3,077 places (2001). Community residences cater for patients who cannot live on their own. There are low, medium and high support facilities. High support facilities are staffed on a 24-hour basis, medium support are visited by nursing staff twice daily, while low support are unstaffed. There are 1,345 places in high support facilities, 623 in medium and 1,109 in low.

The emphasis of community-based services is on out-patient treatment and day care, so that patients can remain in their own home. There are 179 day facilities available for the mentally ill, with 5,231 persons attending (2000). These day

¹² This is the latest year for which data are available. The data include repeat admissions.



centres provide social activities for patients. There are a further 17,516 persons attending day hospitals, where they receive treatment and therapeutic activities.

4.4.4 Summary

The key conclusions are:

- There are 26,600 people with intellectual disability who are in need of or in receipt of services, of which 9,200 are children;
- A tentative estimate is that there are some 38,000 persons with physical or sensory deprivation who are in need of or in receipt of services;
- Some 24,500 persons with mental health problems are hospitalised every year.
- There are 14,800 persons with mental or intellectual disability in hospitals or full time in residential and community facilities, at any one point in time;
- Of these, 7,300 have mental health problems, while 7,500 have intellectual disability;
- There are 54 psychiatric hospitals or units and 404 community psychiatric residences;
- Of particular relevance for the delivery of advocacy services is the fact that, unlike in many other jurisdictions, a significant proportion of people with disability continue to be resident in institutions.





The Institutional Setting and Consultation on the Role of Comhairle

5.1 Introduction

This section of the report is divided into two parts. The first profiles the main organisations – service providers and voluntary bodies – that provide services to people with disabilities and highlights emerging trends in relation to the provision of advocacy services by these organisations. The second part presents the views of these and other organisations on the key issues involved in developing advocacy services for people with disability.

5.2 Overview of the Institutional Setting

The State engages in and promotes a number of activities that impinge on the provision of advocacy services in Ireland. These include the activities of both State agencies and services, and voluntary organisations. These organisations and services provide either advocacy services, systems of complaint and redress, or advice on policy and standards. While most of these organisations and services are not focussed on people with disability in particular, there is a concern that the development of advocacy services for people with disability should complement existing and planned services, both State-inspired and voluntary.

The institutions and services that have been identified as relevant are as follows:

Institutions and services with a disability focus

- Comhairle
- The National Disability Authority
- The Equality Authority
- Office of Director of Equality Investigations
- The Mental Health Commission
- The Office of Inspector of Mental Health Services



- The Health Boards
 - Voluntary bodies with a disability focus
- Other relevant institutions and services
- Office of the Ombudsman
 - The Irish Social Services Inspectorate
 - The Wards of Court system
 - The Guardian Ad Litem Service

5.3 Institutions and Services with a Disability Focus

5.3.1 Comhairle

Comhairle is the national agency responsible for supporting the provision of information, advice and advocacy on social services. As a statutory agency, Comhairle comes within the remit of the Department of Social and Family Affairs. The agency has a statutory commitment to assist and support people, particularly those with disabilities, in identifying and understanding their needs and options and in accessing their entitlements to social and civil services. Its remit in relation to advocacy has been outlined in Section 3 above.

Comhairle supports the provision of information to the public through a nationwide network of Citizens Information Centres, the Citizens Information Phone Service and through the OASIS and Citizens Information Databases. There are about 100 Citizens Information Centres (CICs) that are registered with and supported by Comhairle. These provide free, impartial and confidential information across the full range of state services and entitlements as well as local services and supports. A full time service is available in county towns and urban areas, while local CICs provide a part time service.

Through the CICs, Comhairle currently provides a limited amount of advocacy services for its clients, some of whom have disabilities. These services are focused at present on issues around access to State benefits and appeals in this area. CICs would require specialist training and expertise, as well as additional resources, if they were to provide a more in-depth advocacy service for people with disabilities. Comhairle carried out pilot advocacy projects in 2002, based in Sligo and Clondalkin CICs.

5.3.2 National Disability Authority

The National Disability Authority (NDA) is an independent statutory agency established under the aegis of the Department of Justice, Equality & Law Reform by the National Disability Authority Act 1999. On behalf of the State, it promotes and helps secure the rights of people with disabilities.

Its role requires it to:

- Act as a national body to assist in the co-ordination and development of disability policy, undertake research and develop statistical information for



the planning, delivery and monitoring of programmes and services for people with disabilities;

- Advise the Minister on standards for programmes and services and prepare codes of practice;
- Monitor the implementation of standards and codes of practice; and
- Take the lead in both encouraging and recognising the promotion of equality of people with disabilities.

5.3.3 The Equality Authority

The Equality Authority is an independent body set up under the Employment Equality Act 1998. The Authority replaced the Employment Equality Agency, and has a greatly expanded role and functions. The Employment Equality Act, 1998 and the Equal Status Act, 2000 outlaw discrimination in employment, vocational training, advertising, collective agreements, the provision of goods and services and other opportunities to which the public generally have access on nine distinct grounds, including disability.

The Authority helps individual complainants in a number of ways, e.g., by:

- Explaining the current legal position on an issue;
- Advising on the facts as presented;
- Communication with the employer on behalf of the complainant;
- Preparing written submissions for the Director of Equality Investigations and for the Labour Court; and
- Representing and/or providing free legal representation for the complainant during the investigation.

The Equality Authority has an in-house Legal Service that may, at its discretion, where the case has strategic importance, provide free legal assistance to those making complaints of discrimination under the Employment Equality Act 1998 and the Equal Status Act 2000. Given the limits on available resources, it is not possible to provide legal assistance for all those who request it. Only a minority of cases are referred to the legal section and only a minority of these are represented to the Equality Tribunal.

In 2002, the Authority dealt with 93 cases from people with disability relating to discrimination under the Employment Equality Act. This represents 19 per cent of the total of 489 cases on hands. It was exceeded by the number of cases on gender grounds (162) and race (107).

Disability accounted for 87, or 10.9 per cent, of the 795 cases under the Equal status Act in the same year. This was exceeded only by cases relating to the Traveller community (429).

The Authority is also supporting the development of community advocacy, where local community groups are enabled to provide alternative sources of support to complainants. The focus is initially on the Traveller community.



5.3.4 Office of the Director of Equality Investigations

The Office was established in 1999 under the Employment Equality Act, 1998. It is an integral part of the equality infrastructure, which is designed to promote equality and eliminate discrimination.

The role of the Office was extended by the Equal Status Act, 2000, to include the investigation and mediation of complaints of discrimination in relation to access to goods and services, disposal of property and certain aspects of education. This protection against discrimination applies to all nine grounds on which discrimination is prohibited by the legislation.

The Office offers a simple, straightforward mechanism to remedy discrimination. Customers include people who feel they have experienced unlawful discrimination and people or businesses against whom a complaint is made. Equality Officers appointed by the Director have wide powers to investigate a complaint and, where it is upheld, to order compensation and/or a specified course of action. Decisions are binding unless appealed. They also offer mediation where appropriate. Customers are not required to be formally represented. The role of the Office includes the investigation and mediation of complaints of discrimination in relation to access to goods and services, disposal of property and certain aspects of education.

5.3.5 The Mental Health Commission

The Mental Health Commission is an independent statutory body, whose primary function is to promote and foster high standards and good practices in the delivery of mental health services and to ensure that the interests of detained persons are protected. It was established in April 2002 and is currently resourcing itself to carry out its functions.

Under the Mental Health Act, 2001, each decision by a consultant psychiatrist to detain a patient for psychiatric care and treatment on an involuntary basis and each decision to extend the duration of such detention will have to be referred to the Commission. The Commission will arrange for an independent review of all such decisions by Mental Health Tribunals that will operate under its aegis. The tribunals will comprise a consultant psychiatrist, a lawyer and a lay person. The Mental Health Tribunal will arrange, on behalf of the detained person, for an independent assessment by a consultant psychiatrist. A tribunal will be empowered to order the release of a patient, if it considers that he/she does not require to be detained involuntarily. A free legal aid scheme for all detained patients will be operated by the Commission. All patients detained in psychiatric hospitals will have their cases reviewed by a Mental Health Tribunal.

A further function of the tribunals, under the direction of the Mental Health Commission, is to consider any request for authorisation from a consultant psychiatrist to perform psychosurgery on a patient where the patient gives their consent in writing to such treatment. Surgery will be authorised only where the tribunal is satisfied that it is in the best interest of the person.



The Commission will be the registration authority for all hospitals and in-patient facilities providing psychiatric care and treatment. The existing Office of the Inspector of Mental Hospitals will be replaced with the Office of the Inspector of Mental Health Services. The Inspector will be required to visit and inspect all approved centres at least once a year. The Minister will be empowered to make regulations specifying the standards to be maintained in all approved centres and these will be enforced by the Inspector. The Inspector will receive and assess complaints from patients and their relatives and seek action from service providers. The Inspector's annual report and review of the mental health services will be published along with the Commission's annual report. In the past, very few complaints have been made to the Inspector. Whether this is the result of ignorance of this procedure or lack of problems is unclear.

5.3.6 Health Boards

One of the aims of the Health Boards is to move towards greater independence for individual users of their disability services. They are committed to developing peer advocacy services and are gradually incorporating these into service agreements. Individual service plans are becoming more sophisticated. They are including monitoring and quality issues, support systems and advocacy. They are challenging agencies to become more person centred. These service agreements are based around confidentiality, empowerment and feedback.

The Midland Health Board provides an example of the development of a new model of engagement involving the Health Boards, service providers and parents and customers. The Board has Regional Consultative Committees covering the main areas of disability. Under these Committees are sectoral teams working on specific sub-sectors. Each of these is involved in advocacy at an individual and group level. However, this has been relatively unstructured up to now. The only specialist Advocacy Service funded by the Health Board is the Irish Advocacy Network (IAN).

5.3.7 Service Providers in the Voluntary Sector

The main service providers in the area are increasingly involved in the development of advocacy related services, including the Brothers of Charity, St John of Gods, St Michael's House, and Sunbeam House. All are at the initial stages in the development of these services, although some are more advanced than others. For example, the Brothers of Charity set up structures in 1998 to support the development of advocacy services across their different regional organisations. There is strong institutional support for the development of advocacy services as part of a wider cultural change within this organisation, aimed at ensuring greater client involvement in decisions that affect their lives.

Within the Brothers of Charity, self-advocacy groups are being established at local level. They then elect representatives to a regional council that discusses and decides on regional issues. They, in turn, elect representatives to sit on the National Council where national issues raised through the advocacy process are debated and acted upon. The National Council also has a number of subgroups that deal with the issues that have arisen in the National Council. These subgroups include clients and staff members.



At regional level, a range of advocacy supports are being developed. For instance, in Waterford an advocacy officer has been appointed, who provides training to both staff and service users to act as advocates and self-advocates. These staff carry out these functions on a voluntary basis. They provide advice, get opinions on issues and assist service users to make informed choices. The Advocacy Officer here has developed her own training material suitable for the client group involved. There are now 8-9 self-advocacy groups in the Waterford/south Tipperary region. While the issues they dealt with initially were fairly simple and straightforward, they are now becoming more complex.

5.3.8 The Community and Voluntary Sector Generally

A wide range of community and voluntary organisations provide services for people with disabilities. These organisations operate at a range of different levels.

National Umbrella Bodies cover:

- All Disabilities: People with Disabilities in Ireland, Disability Federation of Ireland, Forum for People with Disabilities
- Major Disability Groups: Irish Wheelchair Association, National Association of Mental Health in Ireland
- Specific Disability Groups: Schizophrenia Ireland, Irish Deaf Society
- Specialist Advocacy Services: Irish Advocacy Network (in the Mental Health Area)

All of these organisations are involved in systemic advocacy on behalf of their members, often working with local membership networks in campaigning and lobbying for political and social change. They also provide some level of support for peer and self advocacy to their members and local networks. Usually this is in the form of either nationally or regionally based advocacy workers providing local support in the form of awareness raising, training, etc to their local networks. Such activities are currently on a reasonably small scale and little data are available on numbers involved.

As far as can be ascertained, the only organisation providing specialist advocacy service for people with disabilities in Ireland at the present time is the Irish Advocacy Network (IAN). The IAN provides peer advocacy for clients with mental health issues. The IAN is funded by the Department of Health and the Health Boards. They provide advocacy services for people in mental health institutions and those reintegrating into the community.

5.4 Other Relevant Institutions and Services

5.4.1 Office of the Ombudsman

The Ombudsman deals with complaints against Government Departments, Local Authorities, Health Boards, and An Post. Its mission is to help achieve a public service, which is open, fair and accountable. The Ombudsman can investigate an action where a complaint has been made to her or on her own initiative. The Ombudsman does not make representations on behalf of individuals.



The Ombudsman is empowered to make recommendations only; her findings are not binding. When the Ombudsman carries out an investigation she must inform the complainant of the result of the investigation. She must also indicate how the body complained against has responded to any recommendations she may have made. Where it appears to the Ombudsman that the response to a recommendation, which she has made, is not satisfactory she may make a special report on the matter to the Oireachtas. The Ombudsman must make an annual report on the performance of her functions to the Houses of the Oireachtas.

The Ombudsman does not differentiate between complainants who have a disability and those who do not. However, her work does impinge on people with disability as on other groups in society. The Office of the Ombudsman has carried out a number of investigations in relation to disability.

5.4.2 The Social Services Inspectorate

The Department of Health and Children established the Social Services Inspectorate (SSI) in 1999 as an independent body to inspect social services provided by health boards. In the first phase of its existence, the SSI has been focusing on residential childcare services. It also monitors the implementation of the child protection guidelines and seeks to ensure safe care practices.

To date, the SSI has been conducting inspections under the statutory powers contained in Section 69 of the Childcare Act 1991, which states that, "The Minister may cause to be inspected any service provided or premises maintained by a health board under this Act". The Act excluded institutions for children with disabilities, but Section 267 of the Children Act, 2001 (enacted in April 2002), brought the inspection of residential centres for children with a disability within the remit of inspection. The SSI has yet to be resourced to include these institutions in their remit.

The Health Strategy¹³ states that the remit of the Social Services Inspectorate will be extended to include residential care for people with disabilities. It also states that national standards for residential care for people with disabilities will be prepared. The National Disability Authority is working in partnership with the Department of Health and Children to develop these standards.

5.4.3 Wards of Court System

The Wards of Court system is the main legal mechanism for substitute decision-making. It provides protection for persons who do not have legal capacity. This includes minors and adults, particularly older people, who may be made wards of court as circumstances dictate. The criteria for wardship are that the person in question must be of unsound mind and incapable managing their person and or property. Petitions for wardship are usually brought by family members. The system is administered by the Registrar and staff of the Office of Wards of Court.

The Law Reform Commission has issued a Consultation Paper on Law and the Elderly, which sets out a new system for the protection of vulnerable adults.¹⁴ This envisages the replacement of the Wards of Court system by the establishment

¹³ *Quality and Fairness: A Health System for You*. Department of Health and Children, 2001.

¹⁴ Law Reform Commission.



of a new independent Office of the Public Guardian. This office would oversee the making of Guardianship orders in the case of people who do not have legal capacity and are in need of guardianship. Personal Guardians would be appointed to make substitute decisions for such persons. The Office would have greater flexibility in dealing with guardianship than the Wards of Court system so as to ensure retention of as much autonomy as possible for vulnerable adults.

While the Commission envisages that the Office would be concerned with vulnerable older people in the first instance, it acknowledges that it could embrace other vulnerable adults, including people with disability. It would also appear that the Commission envisages that the Office of the Public Guardian would have a role in relation to the provision of information and advice to vulnerable adults.

It is clear that, in the context of the creation of the Office of the Public Guardian, the role of an advocacy service would need further consideration. In particular, the existence of the Office might serve to enhance the need for an independent advocacy service to be available for people, when the appointment of a Personal Guardian is being considered.

5.4.4 Guardian Ad Litem Service

Under the Childcare Act 1991, The Guardian ad Litem (Guardian at Law) Service provides children who might become the subject of a care or supervision order with an independent voice in court. A Guardian ad Litem is appointed by the Court and ensures that the voice of the child is heard and advises on what is in the best interest of the child concerned. The Guardian ad Litem consults with the child, the child's family, Health Board and any other statutory or non-statutory organisations who know the child and the family. These consultations are crucial to ensure that the child's best interests are presented independently to the Court. The Service specialises in representing the best interests of children, adolescents and young adults who have a disability

5.5. Views on the Role of Comhairle and Advocacy Priorities

5.5.1 Introduction

The consultation process was focussed on obtaining views on:

- The role which Comhairle should play in the provision of advocacy services; and
- The priority groups, to whom advocacy services should be delivered.

5.5.2 Role of Comhairle

Given the range of persons consulted, it was inevitable that there would not be unanimity concerning the appropriate role for Comhairle. Having said that, there was a high level of agreement that Comhairle should:

- Provide a central advocacy support service; and
- Be responsible for a programme of financial support to the community and voluntary sector in respect of advocacy services.



There were conflicting views as to whether Comhairle should be responsible for the provision of a Personal Advocacy Service, although this was envisaged by the Disability Bill (2001).

A central advocacy support service was envisaged as covering research, promotion, awareness raising, referral, information collection and monitoring, training and certification as well as operational guidelines for disability organisations, service providers and individual clients and their families engaged in advocacy work.

Where consultees considered that Comhairle should be involved in the delivery of personal advocacy services, it was generally the view that this would be best effected via a highly professional service with specialised knowledge and expertise. The Personal Advocacy Service was not seen as a substitute for community and voluntary services, which would still be required to play a major role.

There was uncertainty about the role of the CICs. Some respondents envisaged that the CICs would be engaged only in the referral of individuals to advocacy services. Others considered that the CICs would directly provide advocacy services, with, perhaps, the referral of more complex cases to a central personal advocacy service.

There was a widespread view that the institutional arrangements for the delivery of advocacy services should ensure maximum independence. In particular, respondents were often strongly of the view that advocates should not be attached to the institutions delivering services.

There was a strongly held view among respondents in the mental health sector that peer advocacy is the most appropriate model for people with mental health problems. In this regard, it was considered that the focus of advocacy services for this group should be community-based rather than through a central personal service operated by Comhairle.

5.5.3 Priority Groups for Advocacy Service

There was a large degree of unanimity regarding the priority groups for advocacy services. In essence, respondents felt that those most at risk or most vulnerable should be prioritised. These were seen to include the following:

- Adults with learning disabilities;
- People with mental health issues, especially the long term ill;
- People with dementia; and
- People with brain damage.

It was recognised that the degree of vulnerability of individuals in the above categories would vary considerably. In particular, some persons would have the support of carers, such as parents or siblings, who would act in their best interests and reduce their advocacy needs.

Similarly, it was recognised that persons in institutions are especially vulnerable and dis-empowered, and should be a priority for advocacy services.



5.6 Conclusions

It is clear that formal advocacy services for people with disability are very undeveloped in Ireland at present. Comhairle provides limited advocacy services through its Citizen Information Centres and has initiated a number of pilot projects in the area. The Equality Authority provides support for people with disability in matters of discrimination and people with disability are increasingly making use of this service. Reform is underway with regard to the detention of people with mental health problems for psychiatric care and treatment on an involuntary basis. This includes an independent review of all such decisions by Mental Health Tribunals and a free legal aid scheme for all detained patients. The existing Office of the Inspector of Mental Hospitals will be replaced with the Office of the Inspector of Mental Health Services. The Inspector will be required to visit and inspect all approved centres at least once a year.

Service providers, including the Health Boards and the voluntary bodies providing residential care and respite are placing increasing emphasis on advocacy within their work. This reflects a cultural change currently taking place in the disability area, involving a move towards a more partnership, client-based approach which strives for greater involvement and empowerment of service users. Such a cultural change will take time to work its way through the system. At present, very limited funding and other resources are available for the development of advocacy services at this level.

With regard to voluntary and community bodies representative of people with disability, the main emphasis to date has been on systemic advocacy. However, some initiatives focussed on individual advocacy are underway: for example, the individual advocacy services provided by the Irish Advocacy Network in respect of people with mental health problems.

With regard to the role of Comhairle, there was a high level of agreement that Comhairle should provide a central advocacy support service and be responsible for a programme of financial support to the community and voluntary sector in respect of advocacy services. There were conflicting views as to whether Comhairle should be responsible for the provision of a personal advocacy service, although this was envisaged by the Disability Bill (2001). Respondents felt that those most at risk or most vulnerable should be prioritised for advocacy service. These include people with cognitive disability and mental health problems, especially those resident in institutions.

The International Experience of Advocacy for People with Disability

6.1 Introduction

This section reviews the policies and the institutional frameworks that underlie the delivery of advocacy services in a number of countries. The countries studied were:

- England and Wales
- Scotland
- Australia
- New Zealand
- Sweden
- United States
- Canada

The emphasis of the section is on gaining an understanding of the policy approach adopted, the institutional mechanisms employed, and, where possible, the scale of advocacy activity or budgets. During the course of this international review, a significant body of knowledge was obtained in relation to the principles and practice behind the delivery of advocacy services. This section does not report on these aspects. However, the information obtained was used to inform the establishment of both a set of objectives for Irish policy in relation to advocacy for people with disability and the principles that should inform the delivery of such a service (see Sections 7 and 8).

This section proceeds to discuss the experience of each of the above countries in turn before drawing some conclusions of relevance to the design of an Irish advocacy system.

6.2 Advocacy in England and Wales

6.2.1 Policy Background

In recent years, the British Government has increased its focus on the development of advocacy services. The strategy adopted by the British Government for the development of advocacy services has its main focus on patients and users of the National Health Service (NHS), people with mental health problems and people with learning disabilities.

Reform of the NHS was initiated through the NHS Plan, which was published in July 2000. This pledged sustained increases in funding and a full reform of public health services. The plan was essentially aimed at redesigning the NHS around the needs of the patient.

A feature of the plan was that the NHS and social services would come together with new agreements to pool resources, and new Primary Care Trusts (PCT) would be established to commission social and health care in a single organisation. This would reduce the potential for some patients to fall between the two services.

6.2.2 Patient and Advocacy Liaison Service (PALS)

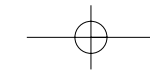
One of the proposed outcomes of the plan was the establishment by 2002 of a NHS-wide Patient and Advocacy Liaison Service (PALS) in every trust, beginning with every major hospital. The NHS Plan pledged funding of £10 million per annum to the service. This included all those trusts offering specialist learning disabilities services and other health services to people with learning disabilities.

The idea behind PALS is that advocacy teams, usually located in the main reception area of hospitals, act as a welcoming point for patients and carers, and as a clearly identifiable point for information. Patient advocates also act as independent facilitators to handle patient and family concerns, with direct access to the chief executive and the power to negotiate immediate solutions. In mental health and learning disability services, the Patient Advocate and Liaison Service team will build on and support current specialist advocacy services. PALS does not replace external advocacy services for learning disabled people, but where necessary, it would be able to provide signposting to independent advocacy services. An estimated 600 Trusts now have a PALS in place.

6.2.3 Independent Patients' Forums

The National Health Service Reform and Health Care Professions Act 2002 made it a requirement of every NHS trust and PCT to have independent Patients' Forums in place. This Act also made it the responsibility of these Forums to commission and provide the independent advocacy services required under the Health and Social Care Act.

The legislation establishing Patients' Forums for every trust and PCT became effective commenced in September 2003. In the latter half of 2003, the Commission for Patient and Public Involvement in Health recruited and appointed members to each forum. Each Forum must have a minimum of seven members before it can be fully operational, and begin its work developing advocacy services.



6.2.4 Mental Health Advocacy

This White Paper – *Reforming the Mental Health Act* – which was published in December 2000, sets out the British Government's plans for new mental health legislation for England and Wales

In this paper, the Government stated its intention to establish a Commission for Mental Health to look after the interests of all people who are subject to care and treatment under powers in the new Act. The new Commission replaces the existing Mental Health Act Commission.

Among their responsibilities,¹⁵ the Commission is required to assure the quality of local specialist advocacy services, and to provide support and advice to specialist advocates. This includes assuring the quality of training for key practitioners and people who provide specialist independent advocacy services.

Following the White Paper, the Department of Health commissioned the University of Durham to produce a report that set out what these specialist services might look like. The report also made recommendations for a service model and standards of good practice. No legislation has yet been passed in relation to this, so these recommendations have yet to be put into practice.

In terms of current provision of advocacy services for people with mental disorder, the United Kingdom Advocacy Network (UKAN) is a network of voluntary and charitable advocacy groups, working for people with mental disorder. With over 350 affiliated groups, the UKAN provides information and support for these groups, as well as campaigning for improvements to mental health services.

A draft Mental Health Bill, was published in June 2002. Whereas current legislation allows for compulsory treatment in hospitals only, the draft Bill proposes that new legislation would enable doctors to enforce patients to adhere to treatment plans in the community. With this in mind, the draft Bill also proposes a number of necessary safeguards for patients receiving care under the proposed Act. The safeguards include the provision of an independent mental health advocacy service for patients who are subject to the compulsory powers of the Bill and to patients with long-term incapacity. Advocates will help patients with information about their medical treatment, the legal authority under which the treatment is provided, and their right to challenge the use of these powers. They will also support patients to exercise their right to challenge. At the time of writing, a final draft of the Bill has not been published and the Act has not yet been passed.

6.2.5 Advocacy and Learning Disability

This White Paper- *Valuing People: a New Strategy for Learning Disability for the Twenty First Century* – was published in March 2001. One of the objectives established in the White Paper was "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"¹⁶. Among other

¹⁵ Other responsibilities of the Mental Health Commission will be to monitor the use of formal powers under the Act, to provide guidance on the operation of these powers and to ensure quality of training for practitioners with key responsibility under the legislation. Inspection and monitoring of facilities will rest with the Commission for Health Improvement and the National Care Standards Commission.

¹⁶ Ibid.



things, this would involve developing and expanding advocacy services, particularly citizen advocacy and self-advocacy. When *Valuing People* was written, citizen and self-advocacy were unevenly developed across the country. Barriers to their development included insecure funding, limited support for local groups, and potential for conflicts of interest with statutory agencies who provide funding. The Government pledged a minimum investment of £1.3 million per annum for three years to develop and expand these advocacy services in partnership with the voluntary sector.

This investment was to be used in two ways. Firstly it would be used to establish a National Citizen Advocacy Network for Learning Disability. Led by a consortium of leading voluntary organisations, this network would be charged with distributing funds to local groups in an equitable and open manner. It would operate within criteria agreed by the Department of Health. Their aim would be to work towards at least one citizen advocacy group in each local authority area. This funding would be in addition to, and not as a replacement of, existing funding sources for citizen advocacy. The second aspect of the £1.3m (£1.9m) investment was to focus on increasing funding for self-advocacy groups and on strengthening the national infrastructure for self-advocacy.

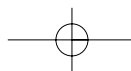
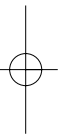
In addition to this specific funding, the White Paper made the development and support of advocacy services a priority area for the Learning Disability Development Fund. This fund, to be introduced in April 2002, would be used to support the implementation of the Government's proposals and could be up to £50m (£72m) per annum.¹⁷

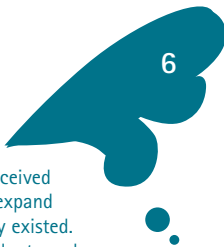
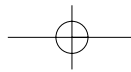
6.2.6 Citizen Advocacy

One of the proposals made in *Valuing People* was for the establishment of a National Citizen Advocacy Network for Learning Disability to work towards at least one citizen advocacy group in each local authority area. The National Coalition of Citizen Advocacy Schemes was formed in September 2001. Membership of the coalition is open to organisations that seek to create citizen advocacy partnerships as either their sole purpose or as part of a range of activities. The main aim of the Coalition is to develop and strengthen citizen advocacy at a national level.

Valuing People also proposed funding to support the development of citizen advocacy. The Department of Health has allocated £650,000 per annum for an initial period of three years. This funding is for distribution to local groups who will use the grants to develop citizen advocacy specifically for people with learning disabilities. The British Institute of Learning Disabilities (BILD), which is a not-for-profit organisation, is responsible for managing and distributing these funds, which are designed to be additional to existing funding. This is to increase independence and give groups a basis for long term planning. The Advisory Group for the programme includes people with learning disabilities, citizen advocates and representatives of national bodies involved in advocacy.

¹⁷ £30 million will be revenue funding and £20 million capital.





In the first year of operation, thirty-four projects throughout England received support. Funding has been given to both established groups wishing to expand their projects, and groups setting up new projects where none previously existed. Since the beginning of this programme, nearly 250 more people have volunteered as citizen advocates.¹⁸

6.2.7 Self-Advocacy

Funding has also been made available to further develop and support self-advocacy. The Department of Health has given the responsibility of managing and distributing these funds to Values into Action (VIA). VIA is an UK-wide campaigning organisation that promotes the rights of people with learning disabilities.

VIA has built this funding programme into an overall advocacy project that also provides guidance and support both to existing self-advocacy groups, and to people with learning disabilities wishing to set up new groups. The Government initially pledged £540,000 (€782,000) per annum for three years, but this was increased by £140,000 (€202,000) to nearly £700,000 (€1m) per annum following recommendations by the Learning Disability Task Force.¹⁹ In the first few months of the project, 41 groups received financial support under the programme. The project is due to run until March 2004.

With self-advocacy being about empowerment and control, the project has people with learning disabilities at its heart: as paid staff, as VIA Trustees managing the project, as members of the project's advisory group and as members of the Grants Board.

6.2.8 Conclusions

In the development of advocacy services in England and Wales, attention has been given to three specific user groups, and different approaches have been taken for each group. Both independent and 'non-independent' models have been employed and supported.

- For all users of the NHS, including people with learning disabilities and people with mental health problems, advocacy is becoming a mainstream service;
- For mental health patients, the approach is for specialist advocacy services to be delivered specifically in relation to the care and treatment that the patient receives under mental health legislation;
- For people with learning disabilities, the focus has been on the development of community and voluntary sector activity, including citizen and self-advocacy services.

Advocacy services in England and Wales are undergoing a process of change and development that is not yet complete. Generally speaking, funding levels for advocacy, both existing and proposed, are relatively modest.

¹⁸ *Making Change Happen*, The Government's Annual Report on Learning Disability, 2003.

¹⁹ The Learning Disability Task Force was established to monitor and support the implementation of the proposals made in *Valuing People*.



6.3 Advocacy in Scotland

6.3.1 Policy Background

Over the last four years, the Scottish Executive has been developing a policy in relation advocacy that emphasises independent advocacy provided by the community and voluntary sector. The first Scottish Executive committed itself to a number of different actions relating to social and economic development. It promised to protect the most vulnerable members of society by the introduction of legislation in 1999 to reform the law on managing the welfare and finances of adults who are incapable of making their own decisions about these matters.²⁰ The programme also promised to deliver person-centred health and community care, pledging to publish proposals for services for people with learning disabilities in 2000.²¹

The Scottish Executive's pledge, mentioned above, to publish proposals for services for people with learning disabilities came to fruition in May 2000 with the launch of *"The Same as You?"*. This report reviewed the services already available to people with learning disabilities and made recommendations based on the results of the review.

The report offered a framework for the following 10 years by making twenty-nine recommendations. One of these recommendations was that local authorities, Health Boards and Primary Care Trusts should form Partnership in Practice (PIP) agreements. The agreements should include "advocacy and other measures which place people who use services and carers at the centre of the decision making process".²² The PIP would also have a "local area co-ordinator" who would work with a small number of people using services in one area, to help them and their families through the maze of systems. One of the tasks of the local area co-ordinator would be to provide information and to help people gain access to advocacy services.

The final report emphasised that advocacy was as important to improving the lives of people with learning disabilities as other care services. It also stated the need to build towards a position where everyone who has complex needs or who is particularly vulnerable would have ready access to an advocate. It also recommended the creation of a "change fund" to support certain services including advocacy.

6.3.2 Developing Advocacy

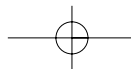
The Scottish Health Plan published in 2000, highlighted mental health as being one of its three clinical priorities identified for special action.²³ The Health Plan began by creating 15 new unified NHS Boards, each responsible for all services in their area. The plan also aimed to strengthen links between the NHS and local authorities to make community services more efficient and easier to access. As a result of the Health Plan, in December 2001, it became a requirement of all NHS Boards to work in partnership with local authorities to ensure that integrated

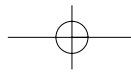
²⁰ The Adults with Incapacity (Scotland) Act was passed in 2000.

²¹ *The Same as You?* was published in May 2000.

²² *The Same as You?*, P. 17.

²³ The three priority areas stated in the Health Plan are heart disease, cancer and mental health.





advocacy services were available to those who most needed them. All Health Boards and local authorities were required to produce three-year plans for developing independent advocacy. These plans were to be reviewed on an annual basis and updated on a three-year cycle. The Health Plan also pledged improvements in mental health through a speedier implementation of the *Framework for Mental Health*²⁴. In relation to advocacy services, the *Framework for Mental Health* had stressed the importance of involving those who receive mental health services in their own care and in the planning of services. It emphasised that advocacy has a key role in enabling people to make informed choices about, and to remain in control of their own care. To achieve the aims of the Health Plan, the Scottish Executive pledged a three-year investment of Stg£14m (€20.2m) to "help the NHS communicate with, listen to and work with individuals and communities".²⁵

Responsibility for the development of independent advocacy services is vested with the Health Boards and local authorities. These bodies collaborate to commission advocacy services from independent providers. The Scottish Executive published *Independent Advocacy, A Guide for Commissioners* in September 2000. This was a follow-up to the Health Plan's requirement for all Health Boards to have three-year plans for developing independent advocacy services in place by December 2001. This document aimed to provide commissioners with a basic framework of principles and practical steps, around which the planning, funding and implementation of independent advocacy could be structured. The document emphasised a number of principles of good independent advocacy including the view that advocacy groups should be constitutionally and psychologically independent of local and national government and should not be both providers of a service and advocates for users of that service.

6.3.3 Institutional Supports for Advocacy

Advocacy 2000 was a project committed to safeguarding independent advocacy in Scotland. With funding for three years from the Community Fund (National Lottery), Advocacy 2000 operated between 1999-2002. The aims and objectives of the project were to support existing and new advocacy developments through networking, training, promotion and support. The report *Principles and Standards in Independent Advocacy Organisations and Groups* was produced by Advocacy 2000 in January 2002 to highlight the core values around independent advocacy.

Following Advocacy 2000, the Scottish Executive established the Scottish Independent Advocacy Alliance (SIAA), which has an extensive membership of independent advocacy organisations and groups. The SIAA provides support for independent advocacy projects by improving the flow of information to local health networks and the wider community about independent advocacy. It also undertakes training on advocacy and related issues for agencies in the statutory and voluntary sectors, and ensures that the voice of the advocacy movement is heard at a national level to influence current and future practice and policy.

²⁴ *The Framework for Mental Health* was the Scottish Office's response to the Scottish Affairs Committee's 1995 report, *The Closure of Psychiatric Hospitals in hospital*. The framework was a statement of aims and points to be covered in local strategies.

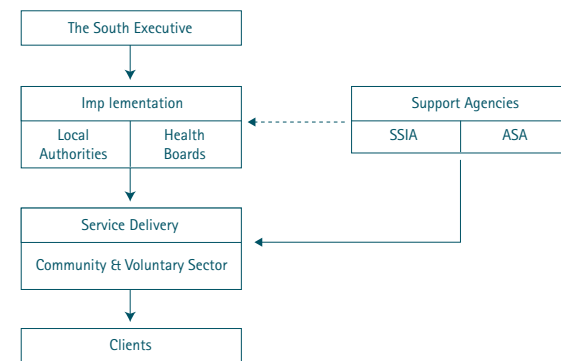
²⁵ Scottish Executive Press Release, 23rd February, 2001.



The Scottish Executive has also funded the Advocacy Safeguards Agency (ASA) to ensure the quality and availability of these organisations and groups. The main tasks of the ASA, which is still in its infancy, include policy development and implementation, giving support to Health Boards and local authorities to develop and implement their advocacy plans, research, evaluations of advocacy projects, and complaints and dispute mediation.

Figure 6.1 below illustrates the Scottish model in simple terms.

Figure 6.1 The Scottish Model for Advocacy Services

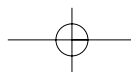
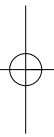


6.3.4 The Community and Voluntary Sector

Each of the 15 NHS Health Boards of Scotland have now produced and started to implement their three-year independent advocacy development plans in conjunction with the relevant local authorities in each area.

Total funding for advocacy now amounts to some £7.7m per annum (€11 million). During the period 2003-2004, statutory funding accounts for roughly 83 per cent of total advocacy funding, the balance coming from charitable donations.²⁶

To date, the majority of advocacy services have been provided for people with mental health problems and people with learning disabilities. This is reflected in Table 6.1, which gives a breakdown of advocacy funding in percentage terms, by specific groups of service users. With the focus of recent legislation being on people with mental health problems and people with learning disabilities, it is unclear whether this apparent imbalance is driven more by a greater provision of funding for these two groups or by a lesser demand from the other groups. If the former is true, it would imply a need for greater provision of services to other groups such as people with physical or sensory disabilities, vulnerable children and ethnic minorities.



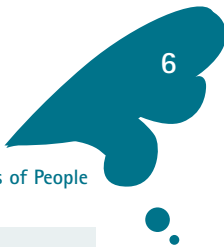
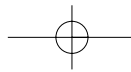


Table 6.1: Breakdown of Statutory Funding of Advocacy by Specific Groups of People (2003–2004)

| | 2003–2004 (%) |
|---------------------------------|------------------|
| Mental Health | 29 |
| Learning Disabilities | 22 |
| Older People | 11 |
| Ethnic Minorities | 2 |
| Carers | 3 |
| Physical Disability and Illness | 1 |
| Children and Young People | 5 |
| Homeless | 0.7 |
| Generic | 27 |
| Total | 100.0 |

Source: *A Map of Independent Advocacy across Scotland, Edition 2003–2004*. Advocacy Safeguards Agency.

Advocacy services in Scotland are provided by both professional or voluntary organisations. Table 6.2 shows a breakdown of how funding has been split across the different types of advocacy for the year 2003–2004. Professional or voluntary advocacy organisations that offer a more specialist form of advocacy received over 70 per cent of statutory funding. However, these figures may not be an exact indication of the types of advocacy services available. The very nature of collective or group advocacy means that often, such groups will come together and operate without funding, out of people's homes.²⁷ It is likely that there are more collective advocacy groups in existence in Scotland, but general awareness about them is low.

Table 6.2: Breakdown of Statutory Funding of Advocacy by Types of Advocacy Organisations and Groups (2003–2004)

| | 2003/2004 (%) |
|---|------------------|
| Independent Professional/Voluntary Advocacy | 78 |
| Collective/Group Advocacy | 13 |
| Citizen Advocacy | 9 |
| Total | 100.0 |

Source: *A Map of Independent Advocacy across Scotland, 2003–2004*. Advocacy Safeguards Agency.

While independence is now the main principle behind advocacy in Scotland, some 30 per cent of organisations and groups cannot be considered as having an independent status.²⁸ In other words, advocacy is just one of a number of services that some organisations supply and so there could be potential for conflict. As advocacy services are further developed, it is expected that these "non-independent" organisations will fall in number.

²⁶ *A Map of Independent Advocacy Across Scotland, Edition 2003 – 2004*. Advocacy Safeguards Agency.

²⁷ *Ibid.*

²⁸ *A Map of Independent Advocacy Across Scotland*. Updated edition 2002–2003.



6.3.5 Conclusion

Since the establishment of the Scottish Executive, Scotland has been very proactive in the development of advocacy services. The focus is on independent advocacy delivered through voluntary and community organisations. People with mental health problems and learning disability are prioritised.

The approach taken has been very strategic. The country was firstly reorganised into 15 NHS Board areas, each responsible for the delivery of all services within their area. It was made a requirement that each NHS Board had plans for the development of independent advocacy services in place by the end of 2001. Guidelines and development recommendations were made available, and the provision of these services was backed up with new legislation.

6.4 Advocacy in Australia

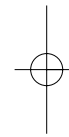
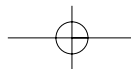
6.4.1 Policy Background

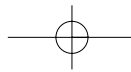
During the 1980s, the Australian Government undertook a comprehensive review of services for people with disability, which involved extensive consultation. Out of this process, the New Directions Report was published which established the basis for disability policy. On foot of this report, the Disability Services Act (1986) provided the legislative basis under which advocacy services are promoted and funded in Australia. In this context, it is important to note that services for people with disabilities are not solely in the domain of the Commonwealth (federal) government and it was necessary that each State create legislation consistent with the Commonwealth (federal) mandate.²⁹ The Commonwealth–State Disability Service Agreement was signed in 1991, identifying the role of both branches of government in the delivery of services including advocacy. This Agreement established standards and codes of conduct, which provided a framework for funding agreements between the Commonwealth and State governments.

6.4.2 Role of Government

The 1991 Agreement indicated that the Commonwealth and States should have a shared responsibility for advocacy services. It was considered inappropriate that one level of Government should have sole responsibility. This was because responsibility for service delivery was also shared between the two levels of Government, with the Commonwealth having responsibility for employment policies relating to people with disability, with the States being charged with delivery of services in relation to health and accommodation, for example. The Agreement established the National Disability Advocacy Programme, which provided funding to voluntary bodies to carry out both systemic and individual advocacy. Under this Programme specialist voluntary advocacy organisations are funded by both the Commonwealth and States. This funding of voluntary organisations is the principal and, in some States, the exclusive mechanism by which advocacy services are delivered. In a minority of States, however, it is supplemented by direct State provision of advocacy services. The most notable

²⁹ The term "States" is understood to include "Territories".





example of this is the State of Victoria, which has established an Office of the Public Advocate. As this institutional arrangement has a particular resonance for the Irish situation, it is considered further below.

6.4.3 The Role of the Voluntary Sector

There are currently 75 advocacy organisations funded in Australia under the Disability Advocacy Programme. Annual funding amounts to Aus\$11.6m (€7.1m) from the Commonwealth and Aus\$4m (€2.4m) from the States. It is estimated that between 130 and 160 full time equivalent advocates throughout Australia are supported under the Programme. These bodies are virtually totally reliant on the Government for support, as Australia does not have a philanthropic tradition.

A feature of the Australian approach is that different types of voluntary body are distinguished. These are peak, State-wide, and local bodies. Currently, there are eleven peak bodies, and some 30 and 40 State-wide and local bodies respectively. At State-wide and local level, these are specialist advocacy bodies that do not engage in general service delivery to people with disability. This separation of advocacy from service delivery is aimed at ensuring that advocacy is undertaken in an independent fashion.

The 11 peak or national bodies have a mandate to undertake advocacy for their specific disability type. The peak bodies are:

- Australian Association for the Deaf
- Carers Association of Australia
- Deafness Forum of Australia
- Head Injury Council of Australia
- National Association of People Living with HIV/AIDS
- National Caucus of Disability Consumer Organisations
- National Council on Intellectual Disability
- National Ethnic Disability Alliance
- Blind Citizens Australia
- Physical Disability Council of Australia
- Women with Disabilities (Australia)

These peak bodies are focused particularly on systemic issues and are viewed as a means by which the voluntary sector can achieve a better co-ordination of advocacy services. State-wide and local organisations are concerned with both systemic and individual advocacy, and are distinguished by their reach and size.

Initially funding was directed towards organisations dealing with intellectual disability. Currently, however, funding extends both to organisations that focus on a type of disability (for example, physical disability or brain injury) and those that adopt a particular form of advocacy (for example, family based or citizen advocacy). The bulk of advocacy organisations operate on a case basis. Citizen



advocacy is on the decline, due to the difficulties in recruiting and maintaining long-term advocates.

A review of the Disability Advocacy Programme was undertaken in 1999 (Department of Family and Community Services, 1999). This review established inter alia that:

- Significant areas of Australia do not have access to an advocacy service;
- Conflicts are arising between different forms of advocacy, for example group and parent advocacy, and between different philosophical approaches to advocacy;
- There was a need to involve people with disabilities more directly in the provision of advocacy services and decisions that affect them; and
- Greater accountability of advocacy services was required;

Arising from this review, it was recommended that the distinction between individual and systemic advocacy be more clearly drawn. Individual advocacy was to be the primary focus of the Programme, with only a small element of systemic advocacy being carried out at State-wide or local level.

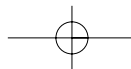
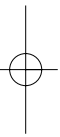
The Commonwealth Government subsequently imposed accountability frameworks by introducing Quality Assurance Standards and Key Performance Indicators. Although staffing levels and caseloads are not prescribed, each advocacy organisation negotiates with Government regarding the targets and outcomes for the year.

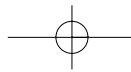
As may be seen, the Commonwealth and State Governments established a coherent policy framework for advocacy in the early 1990s. As a result, a significant advocacy effort developed in the voluntary sector. However, it would be fair to say that progress in developing advocacy services has been slow. The Commonwealth Government is no longer as directly involved as heretofore in driving the system forward. At the level of the States, there has been some retrenchment in support for the voluntary sector. In Victoria, for example, there has been reduced political support for advocacy and the number of State-funded advocacy services has been reduced considerably. At €9.5m annually, the level of funding for voluntary organisations is not large, given that 75 organisations are funded. In addition, there is an increasing tendency not to provide core funding for organisations, but rather to fund advocacy projects.

6.4.4 Community Visitor Programmes

A number of States operate a Community Visitors Programme. These programmes are aimed at monitoring the quality of services for people who are vulnerable and living in institutions. The focus is on people in mental health institutions and those for the intellectually disabled.

The visitors are independent of service providers and visit institutions on a regular basis. They assess and report on the extent to which the service is respecting the rights of residents and meeting appropriate quality standards. Written reports are provided on the institutions and these are usually submitted to the State





parliament. Community visitors are often unpaid volunteers, although paid visitors are also used. These programmes complement community and voluntary advocacy services by reaching people in institutions that the community and voluntary sector find difficult to reach.

6.4.5 Conclusions

In the early 1990s, Australia established a structured and coherent approach to the development of advocacy services. The focus of the approach was on the development of specialist advocacy services in the voluntary sector. While considerable progress has been made, it is clear that there are significant gaps in advocacy services and that the delivery of individual advocacy services in particular need to be enhanced. The level of funding per organisation remains low and, in some States, there has been a reduction in the number of organisations funded.

6.5 Advocacy in Victoria

6.5.1 Introduction

The State of Victoria makes provision for advocacy in two ways:

- Funding and supporting advocacy services in the community and voluntary sector; and
- The Office of the Public Advocate

This section of the report provides an overview of these activities.

6.5.2 Funding and Supporting Community Advocacy Services

In 2003–2004, the State of Victoria budgeted for an expenditure of Aus\$1m (€0.6m) on these services. This expenditure supported the following:

- Funding of three peak community and a small number of locally-based advocacy services;
- A disability advocacy resource unit;
- A self advocacy resource unit; and
- Disability advocacy training development

In recent years, the number of funded community organisations has fallen. The level of support for individual organisations is low, so that these organisations typically have no more than one full time advocate. State funding for advocacy is less than one quarter of that provided by the Commonwealth in the State of Victoria.

6.5.3 The Office of the Public Advocate

The Office provides services in relation to advice, advocacy, and guardianship. The Office is not focused exclusively on people with disability, although the latter form a large part of the client group.

The advice service provides information and assistance about the rights and services relevant to people with disability. An emergency after-hours service is also available.



The advocacy service provides individual advocacy for people with disabilities who are being abused or neglected, and where no other advocacy is available. It also provides strategic advocacy to address systemic issues arising from individual advocacy work.

The guardianship service provides an independent guardian for people with disability when guardianship orders are made by the Victorian Civil and Administrative Tribunal.

As well as direct provision of services, the Office also provides training and support for volunteers in for three programmes that it operates:

- The Community Visitors Programme;
- The Independent Third Person Programme; and
- The Community Guardian Programme.

The Community Visitors Programme independently monitors residential services provided to people with a disability and mental health facilities, to ensure high quality services by focusing attention on issues of concern.

Community Visitors have powers to visit eligible services, which include residential institutions and community residential units for people with disabilities, mental health inpatient services, extended care facilities, community care units and supported residential services. Community Visitors enquire about standards of care, treatment and opportunities at these services and have access to relevant records and documents when it is required. They also have access to service managers, supervisors and staff to discuss, negotiate and resolve issues

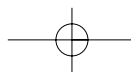
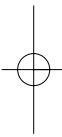
The Independent Third Person's Programme assists a person who has a cognitive disability or a mental illness during an interview or when making a formal statement to Victoria Police. The person may be a victim, witness or suspect. The role of the ITP is to facilitate communication and support the person throughout the process.

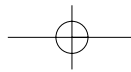
The Community Guardianship Programme helps people in the community become involved in the lives of people with disabilities. A Community Guardian makes lifestyle decisions, e.g. about health care and accommodation, for a person whose disability prevents them from making reasonable decisions for themselves.

The total annual budget of the Office is Aus\$4.1 (€2.5m)

6.5.4 Advocacy Services

Twenty-four full time paid professional advocates are employed and these allocate some 30 per cent of their time to providing advocacy services, with the bulk of the rest being concerned with guardianship. The focus of the advocacy service is very much on individual advocacy, particularly in crisis situations. Advocacy in relation to issues of exploitation, abuse, and neglect form the bulk of the casework. Individual cases arise through referrals from the advice service, service providers, and the community and voluntary sector. These are divided into short-term and long-term cases, with the long-term giving rise to formal case files. In 2002, 355 case files were active, with 178 cases finalised. Some 700 short-term cases were also handled.





Advocates are informed by the wishes of the client, but ultimately act in the client's best interests. Advocates extend their activities to mediating between clients and service providers.

Systemic advocacy often arises in relation to particular institutions, especially when they are being closed down and clients are transferred to community based facilities.

The Community Visitors Programme had 327 volunteer visitors in 2002 who made 5,200 visits during the year, in respect of 1,282 facilities.

6.6 Advocacy in New Zealand

6.6.1 Policy Background

In 1994, the Health and Disability Commissioner Act was passed which provided "a consumer-focused and consumer-accountable health and disability service and has become the primary vehicle for dealing with complaints about any health or disability services provider in New Zealand."

The way in which the rights of consumers are upheld is through the implementation of the Code of Rights, which has an accompanying complaints procedure. A major responsibility of the Office of the Health and Disability Commissioner is to provide advocacy services in ensuring the resolution of complaints for consumers of health and disability services in New Zealand.

The Health and Disability Commissioner Act makes statutory provision for the appointment of a Director of Advocacy. The functions of the Director of Advocacy are to:

- Administer advocacy service agreements;
- Promote advocacy services through education and publicity;
- Oversee the training of advocates; and
- Monitor the operation of advocacy services.

The Director of Advocacy within New Zealand currently contracts three organisations to deliver advocacy services. These are:

- Health Advocates Trust (HAT) that covers Northland and Auckland;
- Advocacy Network Services (ADNET) located in both central and lower North Island; and
- Advocacy Services South Island Trust (ASSIT).

These advocacy services respond to complaints. In 2001–2003, 3,712 complaints were considered. Some 49 per cent (1802) were partly or fully resolved through the support of the advocacy services; 27 per cent (1,016) closed through consumers taking their own action and 24 per cent (894) being dropped or referred to the Health and Disability Commissioner or to another agency. In this time period, consumers rated all three advocacy agencies highly, with satisfaction ratings of over 80 per cent. Thirty advocates were employed to undertake the work. In the



year ending June 2003, the annual budget for the three advocacy service contracts combined was just under \$2m (€1.1m).

As a result of a review of advocacy services in 2002 (Health and Disability Commissioner, 2002), the following objectives have been built into the three advocacy contracts with a view to strengthen such services:

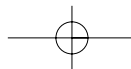
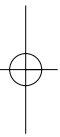
- Increase the number of complaints resolved at a low level;
- Increase the number of consumers who feel empowered to take their own actions to resolve their complaint;
- Resolve simple and standard complaints more quickly;
- Increase user-friendliness of advocacy services and access to communities who traditionally do not use the service;
- Increase the number of providers willing to participate in training to improve their ability to comply with the code;
- Increase the number of providers willing to meet with consumers directly to listen to and resolve complaints.

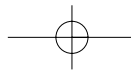
Within the Health and Disability Commission, the advocacy service works in conjunction with the Enquiries and Complaints Resolution Service, which is based centrally in Auckland and Wellington. A major plank of complaints resolution policy is that complaints should be resolved at the lowest level. This means that as well as receiving requests for advocacy support locally, the advocacy services also receive requests to provide advocacy services from the Enquiries and Complaints Resolution Service.

6.6.2 Community and Voluntary Organisations

Within New Zealand, unlike Australia, there are very few dedicated advocacy organisations. Instead, voluntary agencies, that are usually disability service specific, undertake parent and consumer advocacy as part of their activities. Traditional organisations such as IHC (focus on intellectual disability); Royal New Zealand Foundation of the Blind (focus upon blindness and vision impairment); and New Zealand CCS (focus upon physical disabilities) provide government subsidised services as well as promoting advocacy both at an individual and systemic level. For example, NZCCS promotes public advocacy that has incorporated lobbying for accessible environment, inclusive education, collaboration with the Human Rights Commission in the establishment of a Human Rights Training programme, and lobbying for disability policy that is in line with human rights legislation and the Disability Strategy (New Zealand CCS, 2003).

Apart from traditional organisations operating in New Zealand, there is also a growing number of groups that are premised on the concept that people who have the lived experience of disability are in the best position to advocate on their own behalf. The DPA, Disabled Person's Assembly, promotes itself as a national umbrella organisation and the national voice of people with disabilities. The DPA advocates on a broad range of issues including health, education, employment, accommodation and transport.





Although the Government has strengthened its commitment to consumer advocacy through the work of the Health and Disability Commissioner Office, there is the lack of significant funding for voluntary agencies and interest groups to advocate at both a systemic and, particularly, individual level. There are no recurrent subsidies, for example, for family and parent advocacy, citizen advocacy, and legal advocacy. Where such schemes exist, their co-ordination is usually funded annually on a recurrent basis through government grants and philanthropic trust monies.

Throughout the late 1980s and 1990s within New Zealand, there was a move to establish Citizen Advocacy. The first programme began in Auckland and continues until the present time. Three other programmes were operational in the early to late 1990s but, owing to lack of funding, have not survived. The demise of three other citizen advocacy programmes in regions outside of Auckland occurred in the late 1990s when the Government decided to fund advocacy within the Health and Disability Commissioner's Office only. However, as has been noted, this latter type of advocacy is premised upon the lodging of complaints and not on supportive advocacy relationships.

6.6.3 Conclusions

There has been a number of positive developments in New Zealand. The Health and Disability Services Consumer Advocacy Service has been established and is beginning to take a much more educative, preventative and proactive approach to ensuring that health and disability services comprehend the implications for compliance with the Code of Rights. This is essential if the service is to be seen as more than just a complaints service.

The role of the consumer advocate has been strengthened by having a legislated Code of Rights, which enables advocates to work collaboratively with agencies in ensuring that the rights of people are not only upheld but also proactively implemented.

The introduction of the Health and Disability Standards with their emphasis on consumer rights and compliance requirements is raising awareness of the role that consumer advocates can play in agencies working to meet the audited standards.

However, there is the lack of significant funding for voluntary agencies and interest groups to advocate at both a systemic and, particularly, individual level.

6.7 Advocacy in Sweden

6.7.1 Policy Background

The focus of Swedish Disability Policy is on the following three dimensions:

- Ensuring that a disability perspective permeates all sectors of society;
- Creating a more accessible society; and
- Improving the way the disabled are treated.

In order to realise these goals, the National Action Plan for Disability Policy was developed. A feature of the plan is mainstreaming of actions in that each area of



society must take responsibility for implementing disability policy in respect of their own area of interest.

In Sweden, local authorities have the basic responsibilities for health care. The State is dominant in the provision of health services and voluntary and charitable organisations do not play a significant role.

There are two main strands to the provision of advocacy services for people with disabilities in the Swedish system. These are the Disability Ombudsman (HO), and the support by the Government for organisations representing people with disabilities.

6.7.2 The Disability Ombudsman

The Disability Ombudsman (HO) is one of five Ombudsmen set up to safeguard people's rights in society. The other offices of "rights Ombudsmen" are as follows: Equal Opportunities Ombudsman (JämO), Ombudsman against Ethnic Discrimination (DO), Ombudsman against Discrimination on grounds of sexual orientation (HomO), and the Children's Ombudsman (BO).

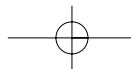
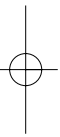
The Disability Ombudsman was established in 1994, under the Law on the Disability Ombudsman. It is an independent examining body, which monitors the entire Swedish society, including the Riksdag (Swedish Parliament) and Government, as to its performance in relation to disability issues. It would seem that the work of the HO mirrors that of the Equality Authority and the Office of the Director of Equality Investigations in Ireland, in so far as it relates to disability.

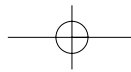
The HO carries out investigations and studies into how society actually functions in practice for people with disabilities. When deficiencies within society, including legislative issues, are uncovered, these inadequacies are pointed out to the relevant authorities. Thus, the HO contributes to the amendment of laws, by detecting problems in the current legislation and by submitting proposals.

The HO investigates reports and complaints on behalf of individuals who feel they have been discriminated against because of their disability. This can result in improvements for the individual as well as systemic effects. Throughout the course of the investigation, an opportunity is given to the individual against whom the complaint is being made, to present their version of events. In relation to discrimination in the workplace, the HO can play an important role and become a legal representative for the individual if the relevant work union will not.

The HO's lawyers can provide legal advice on rights, laws and rules. These lawyers are experts in issues relating to disability. If a person is unhappy with a decision made by an authority, the HO can give advice as to how they can appeal against it. They provide their legal advice through correspondence, telephone and they provide information on disability rights through their website.

The Ombudsman promotes public awareness by making statements to the media, issuing press releases, issuing a regular newsletter, presenting reports on the outcomes of its studies, and by providing information on their website.





The HO has set up a National Accessibility Centre, to provide support and information on compliance for the national authorities to make facilities and information accessible to all people with functional impairments. The Centre also provides information to construction companies, and to the local and national authorities on best solutions to adapt their activities to meet the needs of those people with disabilities.

Following on from the work of the Centre, the HO works in conjunction with other sectoral authorities, such as the National Board of Health and Welfare, the National board of Housing, Building and Planning and the National Road Administration, which all work within the disability sector.

Finally the HO collaborates with the disability organisations in the areas of investigations, conferences and campaigns.

6.7.3 The Community and Voluntary Sector

The Swedish Disability Movement is a well-established and structured movement which is highly regarded by the State. Nationally, there are more than 70 organisations representing different disability groups which have grouped together to form the Swedish Disability Federation, an umbrella organisation comprising of approximately 39 member associations.

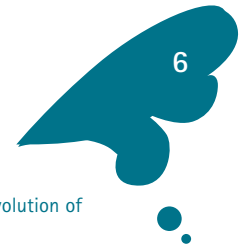
Of the 70 organisations, about 40 of them receive State funding or funding from county councils or the local authorities for their activities as political interest groups, i.e. their work involving publicity, opinion formation and studies in policy important disability issues. One of the key characteristics of these organisations is the fact that they are usually run by people with functional impairments.

These organisations provide a wide range of disability services in their specialist areas. For example the Swedish Association for Persons with difficulties in Reading and Writing/Dyslexia (FMLS) provides advice to those with reading difficulties, specifically in the areas of reading and writing. The objective of this particular organisation is to actively support those with learning disabilities in these areas as well as to safeguard and monitor their interests.

The Swedish Disability Federation represents a unified voice for the Disability Movement. Ultimately, each organisation makes its own decision but when there is an issue on which all member organisations agree, common action is taken. The federation is a member of the Government's disability council. It is understood that every political issue has a disability aspect and the main task of the federation is to inform about this and to influence decision makers and the general public. One such way of employing such influence has been the development of Agenda 22.

From an examination of the range of services provided by the disability organisations, individual advocacy is not well developed. However the National Action Plan raises the possibility of an increased involvement of the organisations in individual advocacy. It states "personal support to users with disabilities and to user support centres based on the active involvement of disabled people's organisations is an interesting option, not least bearing in mind the independent status these organisations enjoy *vis-à-vis* responsible public organisations".³⁰

³⁰ From *Patient to Citizen – A National Action Plan for Disability Policy*, Ministry of Health and Social Affairs, Sweden.



6.7.4 Conclusions

Swedish disability policy is based on mainstreaming of actions and devolution of responsibility to the local level.

The principal body ensuring the proper delivery of service at the local level is the Disability Ombudsman. The Ombudsman has responsibility for both systematic and individual advocacy in relation to issues of discrimination. Sweden has a long established tradition of supporting representative bodies for people with disabilities. These bodies provide a range of services including systematic advocacy. At present, their involvement in individual advocacy would appear to be low, although the Government is considering an enhancement of their role in this regard.

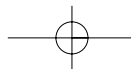
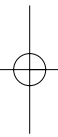
6.8 Advocacy in the United States

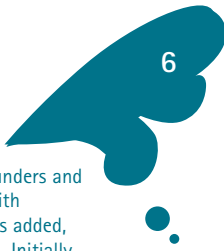
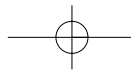
6.8.1 Role of Government

In the US, the Federal Government has put in place policies and programmes to support advocacy. This is known as the Protection and Advocacy (P and A) system. Legal advocacy is also strong in the US, where class action lawsuits are common. However, as in other countries, the bulk of advocacy is community based.

The origins of the P and A system were in the Developmental Disabilities Bill Of Rights and Assistance Act of 1975. This Act authorised a nation-wide system of legal and other advocacy services directed at vulnerable persons with disabilities, to pursue legal, administrative and other appropriate remedies "to protect and advocate for the rights of individuals with developmental disabilities under all applicable Federal and State laws".

This Act helped create a protection and advocacy agency in each State that was designated by that State as the being the responsible authority under that law. In the vast majority of cases, this agency is an independent non-profit organisation with its own independent governance, but in the case of a small number of States, the agency is itself a part of State government, albeit with varying forms of independence related firewalls or the equivalent. States had the option of exceeding the minimal federal requirements for funding such advocacy, and many states have done so. Consequently, the size of the programmes undertaken by the various P and A organisations varies widely, as does the level of State government participation.





The P and A system has been “assembled” over time as new elements, funders and target groups were added. The “system” began as a system for people with developmental disabilities. Then the Client Assistance Program (CAP) was added, which had as its focus people using the vocational rehabilitation system. Initially, this programme was located within such vocational rehabilitation systems, almost as a facilitator of client access, and was later configured more strictly as an independently constituted advocacy program.

In 1986, the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program was established with the intent to offer advocacy to persons with mental illness located in restrictive settings such as institutions. In time, this focus has shifted to include people with mental illness needing advocacy in the community. This is distinct from the “service for 90 days after discharge from such facilities” provisions that were the original scope of the PAIMI program.

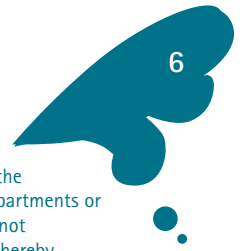
In 1993, the PAIR Program (i.e. The Protection and Advocacy for Individual Rights) was established as a national programme to assist people with disabilities with their rights. However, only modest monies were made available to carry out this intent. In 1994, The Protection & Advocacy for Assistive Technology (PAAT) Program was created when Congress expanded the Technology-Related Assistance for Individuals with Disabilities Act (Tech Act) to include funding for P & A's to “assist individuals with disabilities and their family members, guardians, advocates and authorised representatives in accessing technology devices and assistive technology services, through case management, legal representation and self advocacy training. This built on a national effort since 1985 to facilitate access to needed assistive technology for persons with disabilities.

In 1999, the PABSS programme was established under the auspices of the Ticket to Work and Work Incentive Improvement Act (TWWIIA). This is an employment related national advocacy programme. In 2002, a start was made on strengthening advocacy for persons with traumatic brain injuries through an advocacy grants arrangement offered at a national level. This is more a funding stream since there is no specific legislation to which it is anchored. Nonetheless, it does create a precedent for funding advocacy for people with traumatic brain injuries. In reality, each programme of the Protection and Advocacy “system” is quite distinct, and were it not that they were housed in the same State level mechanism, the programmes might appear even more disparate.

The Federal Government has been the key player in establishing the advocacy programmes that are now components of the national P and A system.

The installation of the P and A system was accomplished with a mix of nominating existing State level non-governmental advocacy organisations to be the designated state P and A agency, and the creation of equivalents to these where these were absent, or were judged unsuitable. This strategy was supplemented by a quite extensive use of “contracting out” with existing community advocacy organisations.

The American P and A system has managed to ensure a modicum of independence for the advocacy effort it supports, due to three distinct factors. First, the sources of advocacy funding are substantially removed from the likely targets of the



advocacy. This is in contrast to Scotland, England and Australia where the advocacy funding comes from mainline service delivery government departments or local authorities. Secondly, the P and A system also has to a large, but not complete degree, the advantage of a legislative base for its existence, thereby insulating it to a substantial degree from the vagaries of Government spending. Lastly, the P and A system has set for itself a kind of working standard both in legislation and in its practice of adopting the principle that its advocacy ought to be independent and free from compromising conflicts of interest.

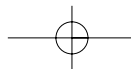
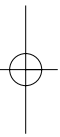
6.8.2 Legal Advocacy

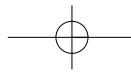
The next element of advocacy services that deserves mention are the advocates and advocacy organisations whose identity and mission is largely legal in nature, but that attract much broader constituencies depending on whom they partner. Their most prominent actions are public interest class action lawsuits principally directed against governments, but also occasionally against some corporate interests. These actions can originate from individual lawyers, but often involve legal advocacy organisations, and may attract other participating parties on either side of the case. The most notable objective of these cases has been the elimination of residential institutions as well as other attempts to gain community service benefits, rights and freedoms for people with disabilities. In many cases, such systemic legal actions have caused to be created various forms of entitlements by class members to individual paid or unpaid advocacy and representation.

The vast majority of legal advocacy takes place without direct government subsidy or involvement, as it is carried either by independent legal practitioners, special disability-focused law firms, (often non-profit in nature), or through collaborations with both prominent and modest community-based voluntary organisations. In some instances, the Federal government has joined in on lawsuits, through its US Justice Department, that are directed at practices and responsibilities carried by State governments.

6.8.3 The Role of the Community and Voluntary Sector

Most, but not all, advocacy for people with disabilities in the US has originated from within the community and voluntary sector as opposed to arising principally from a State sponsored platform. Generally, the control of community and voluntary effort rests in the hands of private citizens and its resources and policies are not controlled by, or regulated by the State. In some instances, the organisations or individuals may receive funds for non-advocacy related work or services from the State, but essentially they are not dependent on the State for the viability of their advocacy. In the US, charitable or “non-profit” organisations are quite restricted in their ability to lobby governments. At the same time, governments at the State or Federal level do not normally directly sponsor or fund advocacy that is controlled by non-governmental groups except in a few instances. These are either where legislation authorises this, lawsuits have created exceptions, or where the aid from the State is indirect, such as funding training for advocacy, but not funding advocacy itself.





In reality, the greatest burden in terms of advocacy in the US rests not with Government at all, but rather with the community and voluntary sector. Nevertheless, both the Federal and State governments are rarely entirely dismissive of advocacy claims, as they often concede to the merit of these in their agreements to settlements reached as part of litigation, and in their support for at least some of the policies advanced by community based advocates. In this respect, much of what are considered advances in the sector, have their origins in some manner of de facto agreement between governments and advocates on both what the issues are, and what constitutes a fair and equitable remedy.

6.9 Advocacy in Canada

6.9.1 Federal Government

In Canada, the Federal government has a limited direct relationship to people with disabilities. The Federal government is responsible for national anti-discrimination legislation and federal tax legislation, which includes provisions for disability tax credits. The Federal government also carries out and funds disability related research and provides time-limited project grants and contracts to successful national and local disability applicant organisations across Canada.

However, the Federal Government does support services for people with disability indirectly through transfer payments to the provinces, which in turn are used by the provincial, territorial and aboriginal governments to provide services to people with disabilities. In recent years, Federal transfers have been reducing so that the provinces are funding services to a greater degree. This is resulting in greater variation in the both the services provided and the institutional arrangements across the provinces.

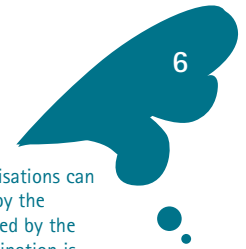
6.9.2 Provincial Government

Historically, provincial Government funding principally supported the provision of Government and institutionally based services. However, in recent decades, there has been progressive closure of these institutions, and the increased presence of people with disability in their communities, provincial Governments have turned to the community sector to deliver services. These community services may operate on a commercial or not-for-profit basis.

In the prevailing view, Governments, either federal or provincial are not seen as having a major role in supporting advocacy. The belief is that Government funded advocacy is always at risk of being compromised. As a result, Provincial Government provision of advocacy services is largely but not exclusively associated with protection against discrimination, public guardianship for children and adults (e.g., child welfare, adult protection), trusteeship, and advocacy for people in mental health institutions.

6.9.3 Protection against Discrimination

Human rights commissions exist at the federal and provincial levels, each relating to corresponding federal and provincial human rights legislation. These laws



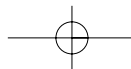
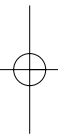
prohibit discrimination on the basis of disability. Individuals and organisations can file complaints under these laws and the complaints will be reviewed by the respective commissions. Complaints found to have merit are investigated by the commissions, who have the power to effect certain remedies if discrimination is found to have occurred. Disability-related complaints while still at a low level are increasing with the largest number relating to employment.

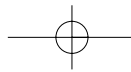
6.9.4 Guardianship

Provincial legislation provides for the appointment of guardians for children and adults under specific circumstances. Child welfare authorities may apprehend children at risk of neglect or abuse, with the province then becoming the child's temporary or permanent guardian (this is a legal process involving the courts). While child welfare is not disability specific some studies have found that 60 per cent or more of the children taken "into care" are children with special needs. Parents with intellectual and other mental disabilities are particularly vulnerable to child welfare apprehensions, while lacking the legal and other resources needed to either contest the apprehension, be fairly considered, or access the resources needed to successfully raise their children at home.

An example of the limits of Government advocacy under the offices of children's advocates which exist in a number of provinces. Without fail, these government appointed and funded advocates file annual reports that are highly critical of child welfare practices, often identifying system practices that jeopardise vulnerable children. Consistently these reports are ignored and/or the views of the advocate are dismissed. When changes are implemented they seem to have little affect on child welfare practices. Suggestions for improvement have primarily focused on having the children's advocate report to the legislature rather than a specific ministry and having the advocacy carried out by community organisations.

Also, legislation exists at the provincial level for the appointment of guardians for adults who are deemed by the courts as unable to make decisions for themselves (this legislation applies primarily to persons with intellectual disabilities, people with a mental illness and senior citizens). Guardians may be private (e.g., family members) or public (e.g., government). Depending on the jurisdiction, guardianship may be limited to only certain spheres of life in contrast to all spheres while in other jurisdictions guardianships can be all or none, rather than partial. Some jurisdictions have endorsed and support the concept of supported decision-making, which enables an individual who needs support to have assistance in making decisions without having to lose their rights. Guardianship is not automatically required and many individuals with intellectual and other disabilities are supported by families and friends, without resorting to guardianship. Similarly, each provincial jurisdiction has the capacity to legally appoint government trustees for individuals deemed by the courts to be unable to manage their finances. Another example of inherent conflict is evident when any unexpended funds upon the death of an individual are returned to the state. Private, in contrast to public government trustees, may also be appointed.





6.9.5 Mental Health Advocacy

The province of Ontario established a Psychiatric Patient Advocate Office (PPAO) in 1983 to protect the civil and legal rights of in-patients in psychiatric hospitals. The PPAO provides individual and systemic advocacy, rights advice, and education.

From the beginning, the intention was that the Office would operate at arm's length from the Ontario Government with only administrative accountability to the Ministry of Health. Initially the programme was introduced on a project basis but was established on an ongoing basis in 1986.

Currently, the Office undertakes instructed and non-instructed individual advocacy, investigation of incidents within institutions and the institutional response, resolution of complaints, and referral to external advocacy agencies as appropriate.

Advocacy services in relation to mental health are currently under review in Ontario

6.9.6 The Ontario Advocacy Act, 1995

The Ontario Advocacy Act (1995) was perhaps the most ambitious advocacy initiative undertaken in Canada and is often quoted as a model which should be adopted in the Irish context.

The Ontario Advocacy Act (1995) was targeted at people having intellectual and physical disability or mental health problems. The Act provided for three types of advocacy service:

- Individual advocacy, primarily client instructed;
- Advice on rights; and
- Systemic advocacy

An Advocacy Commission was set up to administer the act. It was envisaged that the advocacy services would be delivered by either contract workers or employees of non-Governmental bodies. However, it was anticipated that community-based volunteers would also be involved.

The policies behind the Act emphasised the need for advocates to be independent of service delivery, recognised that the interests of vulnerable adults and their families did not always coincide, and generally adopted a rights based rather than needs based approach.

Both families and service providers were wary of the approach adopted. There were concerns on the part of families, given the lack of clarity in the Act, that the advocacy services put in place would be intrusive of family life. Service providers believed that their exclusion from provision of advocacy services would deprive the service of the skills required. Additionally, the Government did not prioritise the groups that would avail of the service, so that concerns arose regarding the potentially high costs of the initiatives under the Act.

Soon after the Act became law, there was a change in Government. Because of the concerns outlined above and fiscal problems, the new Government repealed the Act. At this stage, many of the original supporters of the Act had withdrawn their support, and the repeal of the Act did not give rise to strong political opposition.



The Act has been characterised as being "too much, too late"³¹, in that it was over ambitious, not specific in content, did not build on existing services and resources, and took too long to implement.³¹

6.9.7 Advocacy Organisations

In Canada, advocacy within the disability community evolved from the grassroots, without much Government assistance or support. It began approximately 50 years ago with families coming together to discuss common concerns and aspirations. Self-advocacy organisations are a more recent phenomenon. Over time these informal groups coalesced into formal community organisations, then provincial and national organisations. Government funding was directed at the provision of community living supports and not advocacy. Organisations that received Government funding for the provision of community living supports typically abandoned advocacy, other than advocating continued or increased funding for services.

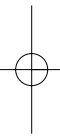
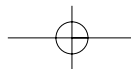
Most advocacy organisations that provide assistance to individuals and families or advocate for systemic change, rely on fund development activities and receive little direct Government funding for advocacy at the local and provincial levels. Federal sustaining grants to national advocacy organisations existed for some time but these were reduced substantially during recent periods of economic restraint. These grants were subsequently replaced with project funding that was contractually based and not perceived as directly funding advocacy. Many organisations use this Government funding to support the agency infrastructure to enable advocacy but are careful to separate their advocacy from this funding when reporting to Government.

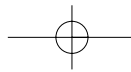
Most national and provincial advocacy organisations have charitable status under Canadian law. This standing enables them to raise funds and provide donors with tax receipts. Non-profit organisations may still raise funds without being a registered charity but they cannot provide donors with tax receipts – this typically limits their fund development capacities. Some national, provincial and local advocacy organisations also operate their own businesses, which may be non-profit and a registered charity as well. The funds generated from these businesses over and above the operational expenses of the business go to support the advocacy organisations.

A major restriction exists under Canadian law with respect to a registered charity's capacity to engage in advocacy. Technically, this law severely limits a registered charity's ability to engage in political and social advocacy. The voluntary sector has been working for many years, as yet unsuccessfully, to change this law, which rests on an archaic court interpretation of the nature of charity work.

This was true for advocacy-based organisations, many of whom abandoned their initial advocacy mandate and evolved into formal support services. The strength of advocacy within Canada today is very much a reflection of those early organisations who did not lose or abandon their primary focus and remained advocacy-based, often sacrificing sustained Government funding in order to do so.

³¹ E.S. Lightman and U. Aviram. 'Too Much, Too Late: the Advocacy Act in Ontario'. *Law and Policy*. Vol. 22, No. 1, January 2000.





While the lack of assured funding for advocacy creates substantive weaknesses it paradoxically contributes to a strong and independent advocacy movement; not as a service but as a voice and a social grassroots movement. Advocacy organisations have to be resilient and creative in securing funding and often lean years and good years.

6.10 Overview

In most countries, Governments have put in place policies and legislation to forbid discrimination against people with disability and other minorities. This usually involves a form of legal advocacy on behalf of these groups, although it would appear to be a widespread experience that people with disability are slow to avail of this form of legal advocacy and complaint resolution. Governments also make provision for guardianship of minors and adults under certain circumstances. Again, this can result in a form of legal advocacy that impacts on some people with disability as well as on other vulnerable groups.

However, the primary concern of this study is to inform the development of a broad-based advocacy service that embraces social advocacy. In this context, it is noted that in most of the countries surveyed, Government takes a lead role in the development of such advocacy services. The exception is Canada, where advocacy is largely seen as the responsibility of private entities, and, with a few exceptions, Government does not intervene to animate or support this activity.

It is also clear that Governments rarely provide advocacy services directly. The dominant model is one in which Government funds other agencies to provide the services. Again the dominant approach is that the Government grant aids voluntary bodies. This is the approach in Australia, Scotland, England and Sweden. In the US, both voluntary bodies and commercial entities are contracted to deliver services, while in New Zealand long term advocacy contracts are given to commercial entities.

In some States of Australia, notably Victoria, support for the voluntary sector is combined with direct delivery of advocacy services by State entities.

In Victoria, the Office of the Public Advocate (OPA) provides advocacy services directly to a range of vulnerable persons including people with disability. As this is the model that will be employed in part for delivering services in Ireland, the following aspects of the OPA's operations are relevant:

- The OPA adopts a casework approach, rather than one of continuing support to clients;
- The focus is on the most vulnerable people, which in effect are people with cognitive problems;
- Cases are prioritised and only a proportion of cases that come to the attention of the OPA are taken on;
- The annual budget of the OPA is relatively modest. Annual expenditure in 2002 was Aus\$4.1 (€2.5m), and this included expenditure on guardianship and the Community Visitors and other programmes, as well as on advocacy; and
- The OPA employs the equivalent of nine full-time persons on advocacy alone, in the context of a State population of almost five million people.



The extent to which disability advocacy is mainstreamed varies from country to country. In the US, there are particular advocacy programmes aimed only at people with disability. The same is true of Australia in respect of supporting the role of the voluntary sector, but not in respect of the Offices of the Public Advocate, which generally take a wider perspective. In a number of countries, advocacy for people with disability is bundled with advocacy for the sick and other vulnerable groups. This is true of England, Scotland, and New Zealand.

In most countries, Governments grant aid voluntary bodies that are engaged in the delivery of other services to people with disability. The engagement of the voluntary sector is seen as vital to the success of advocacy service policies, not least because many advocacy needs can be met in the community and do not require intervention at a more formal level.

In Australia, grant aid is provided to organisations that are engaged only in advocacy. In Scotland too, there is an aspiration that eventually only specialised advocacy organisations will be grant aided, although in order to develop services non-specialised organisations are currently supported. The desire to maintain the independence of advocacy organisations is the motivation for this approach.

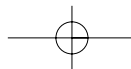
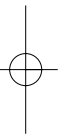
Government support for the voluntary sector usually takes the form of grant aid for core activities. However, in Australia, there is increasing focus on project funding.

In delivering advocacy services, the voluntary sector largely adopts a casework approach. Voluntary organisations that adopt the citizen advocacy model are an exception in this regard. However, there is evidence from a number of countries, including Australia and Scotland that the citizen advocacy model is in decline.

The scale of support for the delivery of advocacy services varies from country to country, but can hardly be regarded as substantial. For example, in Australia, New Zealand and Scotland the annual Government provision for advocacy services is €9.5m, €1.1m and €8.7m respectively. From a number of countries there is evidence that demand for advocacy services exceeds supply by a considerable margin, and this is also most probably the case for other countries for which this assessment is unavailable.

Countries are not prescriptive in terms of the types of disability or the advocacy models that are supported. With regard to the types of disability, prioritisation by voluntary or contract bodies usually results in a focus on people with intellectual disability or mental health problems. With regard to advocacy models, diversity is seen as valuable in that people with disability need to have a choice and different models are appropriate for different issues and settings.

A review of policies and practice abroad, such as this one, normally provides a perspective on the approaches that have worked and those that have been found to be wanting. In the countries surveyed, however, there was an absence of monitoring and evaluation activities that would contribute to such a critical analysis. This is undoubtedly due in part to the fact that advocacy services for people with disability are generally at an early stage of development.





Advocacy Services in Ireland: Background and Principles

7.1 Introduction

It is clear that advocacy services for people with disabilities are very undeveloped in Ireland, but that both service providers and the community and voluntary sector are increasingly aware of the need for advocacy services.

The population of people with disability is large, and the potential demand for advocacy services is likely to exceed the resources available. While other countries are more advanced than Ireland in the provision of advocacy services, it must also be recognised that the resources made available for advocacy services in other countries are generally modest relative to the demands for such services.

As in other countries, the priorities for advocacy services in an Irish context need to be established. Based on experience abroad, the priority is those that are most vulnerable, and these will often comprise people with intellectual disability and those with mental health problems.

Unlike many other countries, Ireland still has a significant population of people with disability that are resident in institutions. As these people are particularly vulnerable, it is essential that advocacy services are designed to reach out to this group.

One of the advantages that Ireland possesses is a vibrant community and voluntary sector. International experience supports the view that involvement of this sector is a vital element in the provision of advocacy services.

7.2 Overview of Principles for Policy Option Appraisal

At the outset there is a need to set down some principles that would inform a consideration of appropriate institutional structures for advocacy services and the way in which those services are delivered. It is taken as a given that the expenditure of public monies on advocacy, as with all such expenditure, must be effective and efficient. "Effective" means delivering a service that provides a basis for meeting the expectations of people with disabilities and other stakeholders. "Efficient" means providing value for money for the taxpayer. However, it is necessary to look behind these general principles to identify a number of other criteria or principles that are specifically relevant to the development of advocacy services for people with disability.

Based on the consultation process and the research conducted, a number of such principles are set out below. Many of these principles have been adopted by advocacy agencies abroad, and have proved useful in shaping both institutional structures and advocacy service delivery. The principles that are considered to promote an effective and efficient advocacy system are:

- Accessibility;
- Independence;
- Promotion of self-reliance and empowerment;
- A focus on the most vulnerable;
- Well-founded and safe services;
- Client-centred and promoting of the best interests of the client;
- Addressing issues at the most appropriate level;
- Integrating individual and systemic advocacy;
- An approach of partnership with the community and service providers; and
- A commitment to quality

In putting forward these criteria, it is recognised that some of these principles are in conflict, and that resolving the tensions between them will be an ongoing theme in the delivery of advocacy services.

7.3 Accessibility

It is obvious that advocacy services need effective means of communication with people with disability, including assistive technology where appropriate. However, in terms of designing advocacy services, two major accessibility issues arise that will have a bearing on the success of advocacy structures and services. The first relates to the fact, unlike many other countries, Ireland still has a significant population of people with disability that are living in institutions. People in institutions often have special need of advocacy services, as institutionalisation itself may lead to disempowerment. Also, people in institutions may have a degree of cognitive disability that hinders the articulation of their needs. It is important, therefore, that advocacy services in Ireland reach out to those in institutions, and address the individual and systemic issues that arise.

A second accessibility issue arises from the fact that Ireland is a country in which large numbers of people still live in rural communities, and that some of these people, including people with disability, are less than fully mobile. This suggests *inter alia* that advocacy services must in part be locally based.

7.4 Independence

Some people who work in bodies providing social services are often under resource pressures and find it difficult to be critical of the services they provide. For advocacy to be at its most effective, it has to be independent of the service



provider. Independence can be promoted at both the personal and institutional level. At the personal level, for example, service providers that wish to set up advocacy structures within their institutions need to have personnel dedicated to this task who are not involved in service delivery. A more preferable approach is institutional separation, whereby an independent body is charged with providing advocacy services.

In delivering advocacy services, Comhairle will have a strong measure of independence by virtue of the fact that although it is a State organisation it is not involved in service delivery. However, there is a need to ensure that the structures put in place further enhance the independence of the advocacy system.

7.5 Promotion of Self-Reliance and Empowerment

It is important that the advocacy system promotes the capacity of and provides the space for people to speak up for themselves. At the structural level, advocacy systems that incorporate community effort are more likely to be empowering. Similarly, the self-advocacy model is important as it assumes that people with disabilities are essentially able to conduct their own affairs. While for some the self-advocacy model will not always be appropriate, there will be a range of less complex issues that could be dealt with on a self-advocacy basis. The process of self advocacy often yields benefits that are in excess of the benefits arising from the issues tackled. Group advocacy models are similarly supportive of self-reliance and empowerment and an advocacy system must encompass both these models. At the level of service delivery, it is important that advocates try to facilitate their clients in speaking up for themselves and do not impose their own views on their clients.

7.6 A Focus on the Most Vulnerable

Advocacy services need to be responsive to the needs of people with disability. Demands for advocacy services are also likely to exceed the capacity to provide these services. In this context, there is a clear need to focus services on the most vulnerable. This will require guidelines as to who is most vulnerable. It is important to note in this regard that vulnerability will need to be assessed in terms of the issues on which people with disability require advocacy services. This approach needs to recognise that a person cannot necessarily be categorised as vulnerable, but rather as vulnerable in certain circumstances.

7.7 Well-founded and Safe

Individuals in all walks of life provide advocacy support to disabled relatives and friends, without any particular form of training or to any standards. However, it is clear that once the State becomes involved, the more formal relationship that ensues necessitates that advocates be trained, properly resourced and operate to clear guidelines. This is not least because advocacy services provided by the State are likely to focus on "hard cases", which may involve the health and life

expectancy of clients. Institutional structures must deliver the appropriate training and research and promulgate the appropriate standards.

7.8 Client-centred and Promoting the Best Interests of the Client

Advocacy services must be client centred and address the concerns and wishes of the person with disability. In the majority of cases, the wishes of the client will coincide with an increase in their welfare. On occasions, however, the advocate may be faced with a situation where the client's wishes are at variance with their best interests.

In the field of disability, the best-interest approach has particularly negative connotations. This is because, in the past, the rights of people with disability to make decisions affecting their own lives have often not been recognised. On occasion, coercive actions have been taken by service providers or others because it was considered in the best interests of the person with disability. The unnecessary institutionalisation of people is an obvious example. Best interest actions are therefore seen as paternalistic in nature and destructive of the autonomy of the individual.

In this context, the stance of any advocacy service should be to view the client instructed approach as the basic or default option in delivering an advocacy service. That is, that there is a presumption of competence on the part of the person with disability. However, occasions arise where the client may wish to take a course of action, which is potentially injurious to their health or have other very serious negative consequences. In such circumstances, advocates may have to act in the client's best interest and not on their wishes. This in turn will require a clear set of operating principles that informs any decision to depart from the client's wishes and act in the client's best interests.

A principle that is of value with regard to advocacy is the principle of the least restrictive option. This suggests that *ceteris paribus* both the advocacy approach adopted and the solutions advocated for should be as least restrictive of the person's freedom of decision and action as is possible.

7.9 Addressing Issues at the Most Appropriate Level

From the point of view of the client, it is important that advocacy be delivered in as informal a setting as possible. In addition, many advocacy issues may not require significant casework, are not complex, and could be addressed before they escalate into more significant issues. This suggests that community-based advocacy has a strong role to play in local resolution of issues. The scarce resources available to advocates working within the State sector could then be devoted to the more complex cases.



7

7.10 Integrating Individual and Systemic Advocacy

The effectiveness of social and other public services in Ireland will be enhanced if these services are made more responsive to the needs of people with disability. Responsive and well-designed public services will also reduce the need for individual advocacy services. It is important, therefore, that advocacy services in Ireland be designed to ensure that the issues that arise at the individual level inform systemic changes in both the policy and delivery of public services.

7.11 A Partnership Approach with the Community and Service Providers

It has already been remarked that ordinary members of the community frequently engage in informal advocacy. Other members of the community are actively working on behalf of people with disability through membership of voluntary bodies. By working in partnership with the community, the State can deliver a more effective and efficient service.

While advocates must be clearly on the side of their clients, there are benefits, where possible, in adopting a cooperative approach to service providers in order to effect the changes necessary to address the client's needs. This is especially the case as advocacy services are just one element, along with the setting of standards, appeals and complaints mechanisms, and monitoring and evaluation procedures, of the changes required to ensure more equitable services of higher quality.

Recognising that advocacy is in part a response to a failure of the social service system to adequately meet the needs and respect the rights of people with disability, there is a need for advocacy services to support the establishment of client-oriented quality assurance systems within service providers.

7.12 A Commitment to Quality

A commitment to quality advocacy services will require not only appropriate training and standards setting but also that monitoring and evaluation of the advocacy services are in place. Monitoring and evaluation needs to take place within the context of a set of clear and agreed objectives for the advocacy service in question. Independent monitoring and evaluation has advantages, especially where services are being provided in a partnership between the State and the community and voluntary sector.

Having considered the principles that should underlie the strategic and operational approach to advocacy services in Ireland, the next section considers the broad strategic options.



8

Overall Strategic Approach

8.1 Constraints

Government policy, as enunciated in the Disability Bill 2001, is that Comhairle shall have a specific responsibility for the provision of advocacy services for people with disability. While it is clear that Comhairle is to provide a Personal Advocacy Service (PAS), the other activities by which Comhairle are to support the provision of advocacy services are not precisely specified.

It is crucial that:

- the advocacy services delivered to people with disability meet in some broad measure the expectations of people with disability; and
- are on such a scale as to represent a coherent and effective response to the need for action in this area, as indicated by Government policies.

At the same time, it is clear that there will not be unlimited resources for advocacy services for people with disability and that a value for money approach is required.

8.2 The Broad Options

There are a number of broad options for the delivery of an advocacy service. These are:

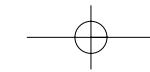
- A comprehensive Personal Advocacy Service (PAS) within Comhairle delivered by directly employed staff that would be rolled out from the beginning as a centrally-based unit to an eventual localised service that would have a presence at, say, county level (A);
- An advocacy service funded and managed by Comhairle but delivered exclusively by disability organisations in the community and voluntary sector (B); or
- A core PAS within Comhairle that would be supplemented by advocacy services delivered by disability organisations in the community and voluntary sector, with appropriate funding lines (C);

8.3 Evaluation of Options

Option A: A comprehensive Personal Advocacy Service delivered by Comhairle

Option A has the following advantages:

- Progress in establishing the service would be assured;
- Delivery of services to priority groups or those most in need would be assured;



- Service standards could be closely controlled;
- Training of advocates would be facilitated; and
- It would be compatible with Government policy as per the Disability Bill (2001)

As against this, there would be a number of disadvantages:

- At least some people with disability may have a preference for advocacy supports other than those offered by a personal advocacy service. These include citizen, peer and self-advocacy approaches. Thus, this option may not conform readily with the principles of empowerment and independence.
- Recognising that resources are limited, the roll out of such a service might be delayed. While, alternatively, harnessing voluntary effort could be a means of ensuring that a more comprehensive service is developed more quickly; and
- Voluntary effort may prove to be more effective than a personal advocacy service in a range of circumstances and give rise to diverse approaches to advocacy that would encourage innovation in the development of advocacy services;

Option B: A service funded and managed by Comhairle but delivered exclusively by disability organisations in the community and voluntary sector

This is the most prevalent approach abroad and the one that some consultees favoured. This approach would have the following advantages:

- The presence of voluntary and community effort in this area would enhance the independent nature of advocacy service provision overall;
- The community and voluntary sector is currently expanding its commitment to formal advocacy services, and this would provide an opportunity to rapidly enhance advocacy service provision;
- People with disability would be engaged directly in the provision of advocacy services;
- There would be increased scope for people with disability to exercise choice with regard to advocates;
- It would accommodate a variety of advocacy needs and delivery methods; and
- It could prove to be an efficient use of the resources available for advocacy.

The disadvantages of this approach are:

- There would be no certainty that advocacy services would be rapidly delivered in a structured way, as progress would be dependent on the willingness and capacity of community and voluntary bodies to develop advocacy services;
- International experience shows that community and voluntary organisations are often unwilling or lacking in capacity to deal with the more complex advocacy issues;
- It would be difficult to ensure that the advocacy needs of priority groups would be met; and



- It may not be compatible with Government policy as per the Disability Bill (2001), which envisages a Personal Advocacy Service operated by Comhairle.

Option C: A core Personal Advocacy Service within Comhairle that would be supplemented by advocacy services delivered by disability organisations in the community and voluntary sector

This option would involve a smaller scale PAS within Comhairle, which would deal with more complex cases and those involving persons at risk, supplemented by community and voluntary activity.

Option C is regarded as the best way forward, as it would combine the advantages of Options A and B in three fundamentally important ways:

- Through the core PAS, it would ensure progress in implementing advocacy services and facilitate prioritisation of services to those most in need;
- By involving the community and voluntary sector, independence, empowerment and use of a variety of advocacy models would be promoted; and
- It would be compatible with Government policy as per the Disability Bill (2001).

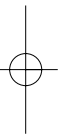
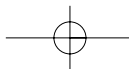
Section 9 provides a further elaboration of this approach.

8.4 Meeting the Needs of the Institutionalised Population

A key consideration in the development of advocacy services is that of ensuring that people with disability are aware of the services and have ready access to them. This obviously is an issue for people with intellectual or cognitive disability or suffering from mental health problems. In many cases, of course, people in these categories will have parents or carers that can help them access advocacy services. However, this is not always the case, and particularly so for people who are institutionalised. Yet the institutionalised population are particularly disempowered and may be most in need of advocacy supports.

The Inspector of Mental Hospitals (soon to be the Inspector of Mental Health Services) inspects approved psychiatric hospitals and other centres on a routine basis, and addresses issues whether of a systemic or individual nature arising from these visits and from direct contact by patients or their relatives. While some people with intellectual disability continue to reside in psychiatric units, the trend is to provide non-psychiatric community-based residences for this group.

Significant numbers of people with intellectual disability now reside in residential centres, on-campus homes and community group homes. Advocacy services to people with intellectual disability that are resident in these facilities might best be delivered by a visitation programme that would complement the Inspector of Mental Health Services' role in relation to those with mental health problems. The Community Visitors Programmes in Australia offer a useful model in this regard. These recruit volunteers to visit the relevant institutions on a routine basis and draw up reports on conditions and circumstances of residents. They also act as a channel through which requests for advocacy support are transmitted to the personal advocacy service. A Community Visitors Programme managed by





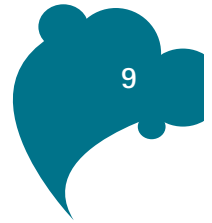
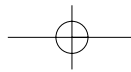
Comhairle would ensure that this particularly vulnerable group would have access to advocacy services.

8.5 Summary of the Strategic Approach

In summary then, the recommended strategic approach has three strands:

- A Personal Advocacy Service;
- A Community Visitors Programme; and
- A Programme of Support for Community and Voluntary Organisations delivering individual advocacy services.

These services will need to be supported by research, standard setting, and educational and training activities.



Key Features of the Proposed Advocacy Service

9.1 Introduction

This Section examines the key features of the three elements of the proposed advocacy service viz. the Personal Advocacy Service, the role of the community and voluntary sector, and the Community Visitors Programme

9.2 Strategic Issues: the Personal Advocacy Service (PAS)

There are a number of strategic issues that need to be decided with regard to the PAS. These relate to the following:

- Scope of advocacy activity;
- The basis on which clients access the service;
- Client and case prioritisation; and
- The advocacy stance that the service adopts.

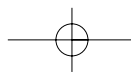
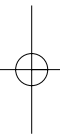
9.2.1 Scope of Advocacy Activity

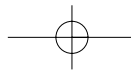
There is a range of advocacy activity that could be supported by the PAS, revolving around:

- Assessments of Need;
- Access to Services;
- Making complaints concerning the above;
- Delivery and operation of services;
- Personal and social issues

In the above context, personal and social issues refer to those issues that are not directly associated with service delivery. These include issues such as restrictions on people with disability with regard to freedom of movement, sexual activities and so on.

It is clear that Government policy requires the PAS to deliver services in regard to the first three areas. On the grounds that the fourth category, represents a natural progression from the first two and that in practice it would be difficult to separate issues of this type from issues surrounding access to services, it is recommended





that delivery and operation of services be included. However, the extent to which the PAS will in practice deal with these issues will be determined by the priorities established in relation to clients for services (see below).

It is considered that the PAS should be involved in personal and social issues only by exception. Again client prioritisation processes will determine when these exceptional circumstances arise.

These personal and social issues would be most effectively dealt with in a local setting. In normal circumstances therefore, they will be addressed through services provided through the community and voluntary sector. However, there is a need to treat the client and their needs in a holistic fashion. If, in the context of dealing with service related issues, the client raises other issues of a personal or social nature, then the PAS should be free to address the totality of the client's concerns.

9.2.2 The Basis on which Clients Access the Service

The basis on which clients will avail of the service also needs to be delineated. There are three broad options in this regard:

- Complaints based: the client must be making a complaint about assessments of need, access to services, or the delivery and operation of services
- Complaints and request based: as above but the client may also be seeking support in relation to obtaining assessments of needs, and access to and delivery of services
- Continuing support: clients are allocated an advocate who provides ongoing support that is not time-delimited.

Continuing support for clients would not be an efficient use of PAS resources. It is also probably best delivered through community/voluntary-based citizen advocacy initiatives. A purely complaints-based service would be quite restrictive and would rule out advocacy to pre-empt bad practices or the escalation of difficult issues. Accordingly, it is considered that access to the service should be on the basis of requests for support or in relation to redressing an issue that is subject of a complaint.

It is clear from the above that the PAS services will be case-based. The next issue is to identify criteria to be applied to client or case prioritisation.

9.2.3 Client and Case Prioritisation

There are two broad approaches to client prioritisation. The first could be built around client categories that the research and consultation has identified as having the greatest need for advocacy services viz.

- People with intellectual disabilities;
- People with brain damage;
- Mentally ill; and
- The above categories in institutions.

The second would be a discretionary approach based on a prioritisation of "most vulnerable" clients. In practice, the most vulnerable clients would be those considered to be at risk of harm from abuse, neglect or exploitation. It is considered that the discretionary approach would be appropriate because it would:

- Ensure that the really needy cases are dealt with, irrespective of the nature of the disability of the client; and
- Be less divisive in terms of the community of people with disability.

The discretionary approach would be based on a set of criteria that would determine the priority to be attached to the case. These could revolve around the following:

The nature of the issue presented: higher degrees of priority would be accorded to cases where there is an element of personal safety or risk to health, with lower priority for, say, quality of service issues.

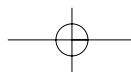
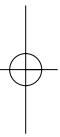
The capacity of the client to act on their own behalf: cases where the client, by virtue of their disability, has particular difficulty acting on their own behalf would be prioritised. This is not a categorisation of clients, but an assessment of the client's capacity in respect of a particular issue.

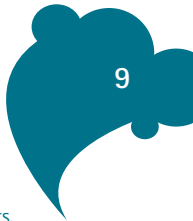
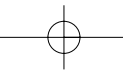
The wider impacts of the case: The PAS is charged with delivering an individual advocacy service. However, many cases have systemic impacts. Cases where advocacy would help achieve system change deserve a degree of priority.

The availability of other advocacy supports: If there are advocacy services available in the community and voluntary sector, to which the case could be referred or which could act as a first port-of-call in relation to the issue, then it may not be a priority for the PAS. Obviously, where the case involves a concern about personal safety, this would outweigh any consideration of the availability of other advocacy services.

9.2.4 Advocacy Stance

The stance of any advocacy service should be to view the client instructed approach as the basic or default option in delivering an advocacy service. That is, that there is a presumption of competence on the part of the person with disability.





This, in turn, will require a clear set of operating principles that informs any decision to depart from the client's wishes and act in the client's best interests. The challenge for the PAS will be to promote the autonomy of the individual, while at the same time ensuring that the client is protected against exploitation, abuse and neglect. This will require a trade-off between the degree of intrusiveness that a best-interest approach would entail and the degree of benefit to the client that would ensue.³² Where the degree of benefit is low, a best-interest approach may not be justified, even if the scale of the intervention is also low. Where the degree of benefit to the client is substantial, for example where client could be harmed if intervention on other than a best-interest approach were to occur, then that approach is to be preferred.

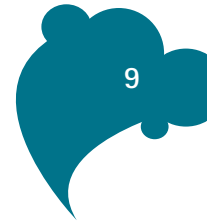
Having considered this trade-off and concluded that a best-interest approach is appropriate, the PAS has a number of options:

1. To continue to advocate in the client's wishes;
2. To continue to support the client generally but to stop short of advocacy actions not considered in the client's best interests;
3. To refuse or withdraw the advocacy service; or
4. To continue to advocate in the client's best interests irrespective of their wishes.

Because the PAS is a State service, it would not be appropriate for it to ignore the best interests of the client and to continue to advocate in the client's wishes. The other extreme of advocating, irrespective of wishes, would need a strong legislative foundation that may not be forthcoming. The alternatives for PAS would appear to lie between (2) and (3). The general presumption should be in favour of continued support, as there may be other issues with which the client requires advocacy support and the process of "standing with the client" may have significant benefits in itself. Depending on the degree of seriousness of the other issues, the PAS could delegate the advocacy to a community or voluntary body.

A principle that is of value in advocacy and may be of particular value in cases where there is conflict between best interest and client's wishes is the principle of the least restrictive option. This suggests that *ceteris paribus* both the advocacy approach adopted and the solutions advocated for should be as least restrictive of the person's freedom of decision and action as is possible.

³² See: David Sykes, 'Towards a Model of Disability Advocacy Practice'. Paper presented at the 36th Annual National Conference of the Australian Society for the Study of Intellectual Disability, Melbourne 2001.



9.3 Strategic Issues: the Community and Voluntary Sector

9.3.1 Introduction

A number of issues arise in relation to the Programme of Support for the Community and Voluntary Organisations. These are:

- Whether the focus should be on representative or service delivery organisations;
- Whether support should be directed to specialised or non-specialised organisations;
- Whether individual or systemic advocacy should be prioritised;
- Whether there should be priority bodies for funding; and
- How rural dwellers will be serviced.

9.3.2 Representative versus Service Delivery Organisations

This relates to the type of community and voluntary organisations that should be supported. At present, there are two types of community and voluntary disability focussed organisations in Ireland. The first type are organisations representing people with disability, either on a general basis or in relation as specific type of disability. These organisations usually have systemic advocacy as a prime focus of their activities, and engage in informal individual advocacy. Some are now setting up more formal structures to deliver individual advocacy, albeit on a small scale.

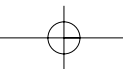
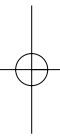
The second relates to organisations largely focussed on delivering services to people with disabilities. They are in fact delivering services that in other jurisdictions would be delivered by the State. Some of these organisations are aware of the need for advocacy for clients of their services, and a minority is putting in place structures and supports to enhance the capacity of their clients to advocate for themselves.

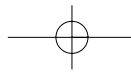
The preferred approach to advocacy is one that supports advocacy that is independent of service providers. Therefore, the focus of funding should be on organisations that are less involved in service delivery. Some of these organisations may in turn provide advocacy services to people in institutions.

9.3.3 Specialised versus Non-specialised Organisations

If "representative" community and voluntary organisations are to be the focus of support, should these be organisations that specialise in advocacy? This is the approach adopted in Australia, where the fear was that, as some voluntary bodies engage in delivery of services, their independence could not be guaranteed.

The counter argument is that information, advice and advocacy is a continuum and that as these organisations are, in the Irish context, engaged in information and advice giving, they are best placed to deliver advocacy services. An additional consideration is that by supporting existing organisations, progress in delivering advocacy services will be more rapid. This, of course, is not to say that organisations that specialise in advocacy should not be supported.





9.3.4 Role of CICs

It is envisaged that individual CIS/CICs would be eligible for grant funding in the same way as other community and voluntary organisations. To the extent that CIS/CICs engage in advocacy for people with disability, then there would be valuable benefits in terms of the mainstreaming of advocacy activities.

9.3.5 Individual versus Systemic Advocacy

To date, community and voluntary disability organisations have emphasised systemic advocacy. If community and voluntary organisations are to support the work of the PAS, then they must be supported to provide in addition individual and group as well as systemic advocacy. By working at the individual level, these organisations will ensure that issues facing individual clients are dealt with at a local and more informal level, thus helping to conserve the resources and expertise of the PAS.

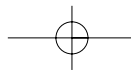
Comhairle will need to put in place monitoring and evaluation procedures to ensure that community and voluntary organisations do indeed deliver individual advocacy services commensurate with the resources provided to them.

9.3.6 Priority Bodies for Funding

A feature of the approach in Australia is that peak bodies are identified that are largely representative of different types of disability or adopt a particular model of advocacy. Funding is then focussed on these bodies. This has the advantage of focusing scarce resources and promoting a higher level of coordination of advocacy services. For such an approach to succeed there must be a certain degree of coherence among community and voluntary organisations. In the Irish context, it is apparent that, for certain categories of people with disability such as the visually impaired, there are at least two bodies that are representative of them. Formal designation of one of these bodies as peak would be viewed as divisive and exercising choice would be problematic. It is therefore proposed that funding strategies would stop short of formal nomination of peak bodies, while recognising that a strategy of spreading funding over a large number of bodies is unlikely to prove effective.

9.3.7 Geographic Scope of Services

Ensuring some measure of equity in access to advocacy services is important. Given that the PAS will, at least initially, be developed on a relatively small scale and is unlikely to be regionally let alone locally based, there will be a particular onus on ensuring that community and voluntary organisations support advocacy for rural dwellers. This is all the more important, as some members of the client group are likely to have mobility problems. Organisations supporting advocacy for rural dwellers should thus be given some priority in funding.



9.4 The Community Visitors Programme

9.4.1 Role of Community Visitors

Given the role of the Mental Health Commission, it is envisaged that the Community Visitors Programme will focus on children and adults with cognitive disability in residential institutions, including respite care.³³

Visitors would:

- Undertake regular visits to facilities;
- Identify issues and problems from the perspective of the resident;
- Respond to requests from residents and look into complaints;
- Identify and record problems of a systemic nature;
- Refer cases to both the PAS and the community and voluntary organisations, where action by the service provider is not forthcoming.

9.4.2 Target Facilities

Residential institutions primarily comprise residential centres, on-campus homes and community group homes, with some additional specialist facilities such as boarding schools. Service providers may typically have residential centres, on-campus homes for those less capable of independent living, and group homes in a community setting that are often supported by volunteer workers. According to the Health Research Board, there are 346 residences for people with intellectual disability in Ireland.

9.4.3 Community Visitor Personnel

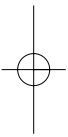
It is proposed that the Visitors be volunteers, who will be subject to appropriate education and training. These would operate on a regional basis, under the guidance of a regional co-ordinator. In Victoria, the regional coordinators are also volunteers, but problems have arisen in recruiting and retaining them because of the more onerous nature of their duties. It is proposed, therefore, that the regional coordinators be employees of Comhairle (see Section 10.4.2 below).

9.4.4 Scale of Activity

Ideally, institutions should be visited on a regular basis, to ensure that advocates build relationships with both residents and service providers. It is difficult to gauge the resources required, as this would be dependent on both the level of engagement of volunteers and the number and severity of the issues that arise. In Victoria, there were 165 community visitors making 2,389 visits to 1,007 facilities for people with disability in 2002–2003.

On this basis, it is considered that an initial target for the service in an Irish context should be to recruit and train some 100 volunteers. It is envisaged that this would facilitate visits to residences once every quarter.

³³ It would ultimately be extended to people with physical disability in residential care.





Implications for Comhairle

10.1 Introduction

The previous sections have outlined the strategic approach to the development of advocacy services for people with disability. It is clear that Government policy is that Comhairle should have responsibility for the PAS. This section examines the overall role that Comhairle should adopt, and the financial and budgetary implications. It then proceeds to set out the changes within Comhairle structures that are needed to deliver the advocacy service.

10.2 Comhairle's Role

10.2.1 Background

Before considering Comhairle's overall role in relation to advocacy services, it is worth noting two aspects of the environment into which the proposed advocacy services will be delivered.

The first relates to the fact that advocacy should not be regarded as an alternative to customer service actions, including the setting of standards of service, and the establishment of consumer councils and formal complaints mechanisms. The development of advocacy services should take place in the context of renewed efforts on the part of service providers to put these other mechanisms in place.

The second acknowledges that other Government bodies currently provide support for advocacy services in the community and voluntary sector, most notably the Department of Health and Children and the Health Boards. It is anticipated that these bodies will continue to fund advocacy services in the future. Thus, it is envisaged that responsibility for funding advocacy will not rest with any one organisation in the future.

10.2.2 Developing a Coherent Approach

Within the above context, the overall role for Comhairle remains to be delineated. One of the key factors in delineating such a role is that there is a synergy between the activities of the PAS, the Support Programme for the Community and Voluntary Sector and the Community Visitors Programme. As the PAS will be able to deal with only a minority of more critical cases, there is a need for alternative service provision, so that clients can be referred onwards. This means that a significant community and voluntary activity in this area must be developed in tandem with the PAS. Indeed, there are strong arguments that the establishment of a Support Programme for the Community and Voluntary Sector should precede the establishment of the PAS.



Similarly, the Community Visitors Programme, by dealing with systemic issues arising in the institutions, has the capability to reduce the caseload on the PAS, and improve the efficiency and effectiveness of advocacy services in general.

These factors argue for an integrated and coherent approach to the development of advocacy services, and that one organisation should be charged with this task.

Additional resourcing of the community and voluntary sector will be required to ensure that a reasonable comprehensive and viable service is put in place. The issue of whether these additional resources should be channelled through Comhairle needs to be resolved.

There are two viewpoints on this: The first argues that the interdependencies between the PAS and the Support Programme for the Community and Voluntary Sector will be such as to require that community and voluntary activity be focussed to complement the PAS activities. This will be best achieved if the additional resources are channelled through Comhairle. An alternative viewpoint is that if Comhairle is put in this position, then the organisation runs the risk of alienating the community and voluntary sector and thus its advocacy service clients, especially if resources are tight, as they undoubtedly will be from time to time.

On balance, it is felt that the effectiveness of the advocacy service would be enhanced if these additional resources were to be channelled through Comhairle. This will ensure an integrated approach to the development of advocacy services.

It is clear that Comhairle should have responsibility for both the development of the Support Programme for the Community and Voluntary Sector and the Community Visitors Programme. It should also have an overall lead role in monitoring the development of these and other advocacy services and advising Government on where advocacy resources should be best directed.

10.2.3 Budgetary Treatment

A subsidiary issue is how the additional resources for the PAS, the Community Visitors Programme and the Support Programme for the Community and Voluntary Sector should be treated within the Comhairle budget. With regard to the PAS, it is clear that a separate Budget line should be established.

With regard to the Support Programme for the Community and Voluntary Sector and the Community Visitors Programme, a separate budget line is favoured because:

- This is a substantial addition to the functions currently performed by Comhairle and will require significant additional resources and could not be encompassed within existing budgets;
- It will provide a measure of transparency in relation to the funding being made available for this purpose, which will help demonstrate that progress is being made on delivering a service for people with disability.



10.3 Institutional and Organisational Implications for Comhairle

If advocacy services are to be developed along the above lines, then a number of issues of an institutional and organisational nature arise for consideration.

10.3.1 The Board

A committee of the Board, to include the CEO, should be established to oversee the advocacy service. It is essential that people with disability have a strong say in the running of the service. To this end the committee should have substantial representation from the community of people with disability.

10.3.2 Advocacy Service Management Structure

The advocacy service will contain four main strands of activity:

- The PAS;
- The Support Programme for the Community and Voluntary Sector;
- The Community Visitors Programme; and
- Research, training and standard setting

It is clear that the PAS will be established as a separate entity within Comhairle, with a Director reporting to the Chief Executive. An appointment at senior management level would be appropriate.

With regard to the Support Programme for the Community and Voluntary Sector, there are synergies between this and the CIC/CIS structure. In content, it will be very different to the PAS, in that it will be a programme of grant aid, not involving the direct recruitment of advocates. It is considered that the Support Programme for the Community and Voluntary Sector should be managed separately under the direction of the Senior Manager with responsibility for the regions. The other area of voluntary activity is the Community Visitors Programme. As this is to be organised on a regional basis, it would make sense that it should also come under the Regional Senior Manager.

The final element relates to monitoring and evaluation, research, training and standard setting. There is potential for considerable synergies with these activities as they relate to other areas of advocacy within Comhairle. In this context, it is considered that responsibility for research, training and standard setting should reside with the Senior Manager, Development and Support.



10.3.3 CIS/CIC Structures

These will be eligible to be funded under the Support Programme for the Community and Voluntary Sector in respect of advocacy services for people with disability. They will also act as a source of referral to both the Support Programme for the Community and Voluntary Sector and PAS services.

10.3.4 Citizen's Information Phone Service

This will act as a point of contact with clients and referral to both the Support Programme for the Community and Voluntary Sector and PAS services.

10.3.5 Client Visitor Facilities

There will be a need to provide walk-in facilities for clients wishing to avail of PAS services.

10.4 Budgets and Phasing

10.4.1 Budgets

The PAS

It is difficult to gauge the extent of demand for this service in advance, particularly as the contribution of the community and voluntary sector will depend on the response of that sector. Initially, it is proposed that the PAS be staffed by a Director and ten professional advocates, with another ten support staff. Professional advocates would be recruited at a level equivalent to those in other agencies such as the Equality Authority and the Office of the Ombudsman. The support staff will deal with less complex cases, and provide support to the ten advocates.

Based on experience elsewhere, it is envisaged that this staffing level will support up to 1,000 requests for advocacy support. It is envisaged that approximately 80 per cent of the cases arising will require a short-term response only, with the remaining 20 per cent being more substantial in nature. This level of staffing together with accommodation and other support resources would require an annual budget of €2m.

Support for Community and Voluntary Activity

The target for this area should be that of supporting between 25 to 30 organisations to deliver a range of Advocacy Services. This scale of activity would facilitate both a variety of advocacy approaches across a broad spectrum of voluntary bodies. A budget of €70,000 would be required to finance an advocacy officer with appropriate resources and administrative back-up. This suggests an annual budget of €2.1m.³⁴

³⁴ This does not imply that individual organisations should not be resourced to a level greater than €70,000 per annum.



The Community Visitors Programme

The initial target for the programme is for 100 volunteers. These volunteers would be paid an honorarium and have their expenses reimbursed. The direct costs of operating such a system are estimated at €0.450m.

Additional Resources for Comhairle

It is proposed that both the Community and Voluntary Sector Support Programme and the Community Visitors Programme be administered through the regional offices of Comhairle under the direction of the Senior Manager with responsibility for the regions. It is estimated that this will require the equivalent of five additional full-time posts at regional level at a cost of some €430,000 per annum, inclusive of administrative expenses.

Two additional full-time posts are envisaged in research, training and standard setting under the Senior Manager, Development and Support. This would cost €150,000 per annum.

Total Budget

The total required budget is therefore estimated at €5.1m per annum initially. This will need to be kept under review, as the scale of voluntary effort both in respect of the Community and Voluntary Support Programme and the Community Visitors Programme becomes apparent.

10.4.2 Phasing

It is important the community and voluntary sector be actively and substantially engaged in individual advocacy services prior to the initiation of the PAS service. As the Support Programme for the Community and Voluntary Sector will take some time to reach critical mass, it is recommended that it be initiated two years prior to the commencement of the PAS and the Community Visitors Programme.

It is envisaged that the PAS will also be introduced on a phased basis. This will facilitate an assessment of the demand for its services, in the context of significant community and voluntary advocacy activity

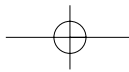
An approximate phasing of the introduction of the advocacy service is set out in Table 10.1 overleaf.



Table 10.1: Phasing of Activity and Budgets

| Year | Activities | Annual Budget €m |
|------|--|---------------------|
| 1 | Establishment of Support Programme; planning for PAS, recruitment of regional staff; recruitment of research and training staff. | 1.9 |
| 2 | Full implementation of Support Programme; Recruitment and training of PAS staff. | 4.3 |
| 3 | PAS service commences; planning and recruitment for Community Visitors Programme | 4.8 |
| 4 | Full Advocacy Service in place | 5.1 |
| 5 | First full review of service | 5.1 |

Source: A Map of Independent Advocacy across Scotland, Edition 2003-2004. Advocacy Safeguards Agency.



Recommendations

A coherent advocacy service should be developed to incorporate the following:

- A Personal Advocacy Service (PAS);
- A Support Programme for the Community and Voluntary Sector; and
- A Community Visitors Programme; and

These services should be supported by research, standard setting and educational and training activities.

The Personal Advocacy Service should be set up on a paid professional basis to deal with critical and complex advocacy issues only. It should focus on advocacy in relation to assessments of need, access to services, complaint mechanisms, and delivery and operation of services. It should be a case-based service targeting the most vulnerable cases.

The Community Visitors Programme should focus on inspection of residential institutions for people with cognitive disability. It should be set up on a volunteer basis, and overseen by a central and regional support structure.

The Support Programme for the Community and Voluntary Sector should be focussed on the provision of individual advocacy services, employing a range of advocacy delivery models. Representative rather than service delivery organisations should be accorded priority in funding. Organisations providing advocacy services to rural dwellers should also be accorded some priority. CIC/CIS bodies should be encouraged to play a part in the delivery of individual advocacy services in the community.

These services should be phased in. It is recommended that the Programme of Support for the Community and Voluntary sector be initiated two years before the commencement of the PAS.

Comhairle should hold the budgets for the above programmes. It should also have an overall lead role in monitoring the development of these and other services and advising the Government on resource organisation. The estimated cost of the services, when fully operational, is €5.1m annually.

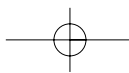
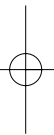
Existing funding of advocacy from other sources should be continued and there should be renewed efforts on the part of service providers to put customer service mechanisms in place.

A committee of the Board, to include the Chief Executive, to oversee the advocacy service should be established. The committee should have substantial external representation from the community of people with disability.

It is recommended that the Director of the PAS be appointed at senior manager level.

The Support Programme for the Community and Voluntary Sector and the Community Visitors Programme should be managed by the Senior Manager with responsibility for the regions.

Research, standard setting, and training activities for the advocacy programme should be the responsibility of the Senior Manager, Development and Support.



Appendix 1: Bibliography

Australia

Australian Institute of Health and Welfare, *Unmet Need for Disability Services, Effectiveness of Funding and Remaining Shortfalls*. Canberra: 2002.

Australian Institute of Health and Welfare, *Disability Support Services Census: First Report*. Canberra: 2003.

Burdekin, B., *Human Rights and Mental Illness: Report of the National Inquiry into the Human Rights of People with Mental Illness*. Canberra: Australian Government Printing Service, 1993.

Chenoweth, L, 'Protecting the Gains of the Decade: Contemporary Threats to the Humanity of People with Disabilities', in Cross, A., Sherwin, J. Collins, P., Funnell, B. and Rodgers, M., *Gathering the Wisdom*. Brisbane: 1999.

Clear, M. and Gleeson, B., 'Disability and Materialist Embodiment'. *Journal of Australian Political Economy* (No 49): pp. 34-55, 2003.

Clear, M., (ed.), *Promises Promises: Disability and Terms of Inclusion*. NSW: Federation Press, 2000.

Cockram, J., *Justice or Differential Treatment? Adult Offenders with an Intellectual Disability in the Criminal Justice System*. Perth: Edith Cowan University, 2000.

Cocks, E. and Duffy, G., *The Nature and Purpose of Advocacy for People with Disabilities*. Perth: Edith Cowan University, 1993.

Cocks, K., et al, *Safeguarding Advocacy for People with Disabilities in Australia: Recommendations by the Disability Advisory Council of Australia*. DACA, 1993.

Cox, E., *A Truly Civil Society*. Australian Broadcasting Corporation, 1995.

Cross, A., et al. (eds.), *Gathering the Wisdom: Changing Realities in the Lives of People with Disabilities*. Brisbane: Australia, 1999.

Cross, J. and Zeni, L., *Safeguarding Advocacy for People with Disabilities in Australia*. Disability Advisory Council of Australia, 1993.

Department of Family and Community Services, *National Disability Advocacy Program: Review Report*. Canberra, 1999.

Department of Human Services, *Review of Disability Legislation in Victoria*. Victoria: Department. of Human Services, 2003.

Flynn, C., *Disability Discrimination in Schools*. Sydney: National Youth and Child Legal Services, 1997.

Herbert, A., *An Evaluation Framework for Disability Action Inc: The missing dimensions of citizenship. An exploration of the current issues for people with*

disabilities and the role of advocacy. Adelaide: Disability Action Inc, 1997.

Newell, C and Wilkinson, R, 'Tasmania Together? A disability critique of a social plan'. *Disability and Society*, Vol. 18 (4): pp. 457 – 70, University of London, 2003.

Nicholls, R. and Andrew, R. *"A" stands for Advocacy*. Melbourne: OPA, 1990.

Office of the Public Advocate, *Annual Report of Community Visitors Appointed under the Mental Health Act, 1986*. Melbourne: OPA, 2002.

Office of the Public Advocate, *Annual Report, 1988*. Melbourne: OPA, 1988.

Office of the Public Advocate, *Annual Report, 2001-2002*. Melbourne: OPA, 2002.

Office of the Public Advocate, *Vigilant Vocal Vital - An Oral History of OPA Volunteers*. Melbourne: OPA, 2001.

Parsons, I., *Oliver Twist has asked for more: the politics and practice of getting justice for people with disabilities*. Geelong: Villamanta 1994.

People First ACT Inc., *Annual Report, 2002*. Australian Commonwealth Territory, 2002.

Perske, R., *Unequal Justice: What happens when a person with retardation or other developmental disabilities encounter the criminal justice system*. Nashville: Abingdon Press, 1991.

Peter, D. (ed), *Better and Worse: Overview of formal advocacy for people with intellectual disabilities in Australia*. London, Jessica Kingsley Publishers Ltd., 2002.

Planning for Outcomes, *Evaluation of the Community Visitors Programs - Final Report*. Melbourne: OPA, May 1998.

Simpson, J, et al. *The Framework Report*. Sydney: Fineline Printing, 2001.

Stiker, H. J., *A History of Disability*. USA: University of Michigan, 2000.

Sykes, D., 'Towards a Model of Disability Advocacy Practice'. Paper presented to 36th Annual National Conference of the Australian Society for the Study of Intellectual Disability. Melbourne: OPA, 2001.

Victorian Advocacy League for Individuals with Disability (VALID), *Response to Review of Disability Legislation in Victoria*. Victoria: VALID, 2003.

Ward, J, 'The Importance of Advocacy and Advocacy Development' in Cross, A., et al. (eds.), *Gathering the Wisdom: Changing Realities in the Lives of People with Disabilities*. Brisbane: Australia, 1999.

Wills, D, et al., *Visual History of People with Disabilities*. Bundbury: PLEDG, 2000.

Canada

Lightman, E. and U. Aviram, 'Too Much, Too Late: The Advocacy Act in Ontario'. *Law and Policy* Vol. 22, No. 1, January 2000.

England and Wales

- Atkinson Dorothy, *Advocacy: A Review*. Research into Practice, 1999.
- Barnes, D. and Brandon, T. with Webb, T., *Independent Specialist Advocacy in England and Wales: Recommendations for Good Practice*. Durham: University of Durham, Centre for Applied Social Studies, June 2002.
- Department of Health, *Involving Patients and the Public in Healthcare*. London: 2001.
- Department of Health, *Learning Difficulties and Ethnicity*. London: 2001.
- Department of Health, *Making Change Happen, The Government's Annual Report on Learning Disability*. London: 2003.
- Department of Health, *The NHS Plan: A Plan for Investment, A Plan for Reform*. London: 2000.
- Department of Health, *Valuing People: A New Strategy for Learning Disability for the 21st Century (A White Paper)*. London: 2001.
- Goodley, D. and Armstrong, D., *Self-Advocacy, Civil Rights and the Social Model of Disability*. Economic and Social Research Council, University of Leeds, 2001.
- Learning Disability Taskforce, *Making Things Happen: First Annual Report of the Learning Disability Task Force*. London: 2003.

Ireland

- Buckley Helen, *Child Protection and Welfare, Innovations and Intervention*. Dublin: Institute of Public Administration, 2002.
- Comhairle, *Developing Advocacy Services, A Report on the Deliberations of Regional Consultation Fora*. Dublin: 2002.
- Comhairle, *Entitlements for People with Disabilities*. Dublin: May 2002.
- Comhairle, *Report of the CIC/Comhairle Working Group on Advocacy*. Dublin: 2003.
- Comhairle, *The Jigsaw of Advocacy*. Dublin: 2003.
- Daly, A. and Walsh, D., *Irish Psychiatric Hospitals and Units Census 2001*. Health Research Board, 2002.
- Daly, Antoinette and Walsh, Dermot, *Activities of Irish Psychiatric Services*. Health Research Board, 2001.
- Department of Health and Children, *Quality and Fairness – A Health System for You*. Dublin: Stationary Office, 2001.
- Department of Health and Children, in association with the National Disability Authority, *National Standards for Disability Service (2nd Draft)*. 2003.
- Department of Health and Children, *Health Statistics 2002 (Part 1)*. Dublin: 2003.
- Department of Health and Children, *Health Statistics 2002 (Part 2)*. Dublin: 2003.
- Department of Health and Children, *Report of the Inspector of Mental Hospitals for the year ending 31st December, 2001*. Dublin: 2002.
- Department of Health and Children, *The Health Service Reform Programme*. Dublin: 2003.

Fitzsimons, Miriam, *Advocacy Report – A Pilot Paper conducted at Sligo Citizen's Information Centre 2002-2003*. Comhairle, 2003.

Forum of People with Disabilities, *Advocacy: A Rights Issue*. December, 2001.

Gallagher Pamela, *Report of the National Physical and Sensory Disability Database Development Committee*. NPSDD, 2001.

Goodbody Economic Consultants, *Analysis of Labour Market Situation of Travellers, Other Minority Ethnic Groups, Older People and People with Disabilities in Ireland*. GEC, November 2002.

Government of Ireland, *Child Care Act, 1991*. Dublin: 1991.

Government of Ireland, *Comhairle Act, 2000*. Dublin: 2000.

Government of Ireland, *Criminal Law (Insanity) Bill, 2002*. Dublin: 2002.

Government of Ireland, *Disability Bill, 2001*. Dublin: 2001.

Gray, B. and Jackson R. (ed.s), *Advocacy and Learning Disability*. London: Jessica Kingsley, 2002.

Hickey, T., Moran, R. and Walsh, D., *Psychiatric Day Care – An Underused Option?* Health Research Board, 2003.

Irish Human Rights Commission, *Observations on the Proposals Paper of the Disability Legislation Consultation Group (DLCG)*. Dublin: 2003.

Mental Health Commission, *Annual Report, 2002*. Dublin: 2002.

Mulvany Fiona, *National Intellectual Disability Database Committee, Annual Report 2001*. Dublin: Health Research Board, 2003.

Mulvany Fiona, *National Intellectual Disability Database Committee, Annual Report 2000*. Dublin: Health Research Board, 2001.

Mulvany Fiona, *National Intellectual Disability Database Committee, Annual Report 1998/1999*. Dublin: Health Research Board, 2000.

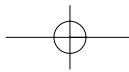
National Disability Authority, *Exploring Advocacy*. Dublin: 2003.

National Intellectual Disability Database Committee, *Annual Report 1996*. Dublin: Health Research Board, 2000.

The Equality Authority, *Accommodating Diversity in Labour Market Programmes*. WRC Social and Economic Consultants, 2003.

Watson Wyatt (on behalf of Department of Health and Children), *Audit of Structures and Functions in the Health Service*. Dublin: 2003.

Western Health Board, *Western Health Board Service Plan 2003*. Galway: 2003.



New Zealand

- Bogard, M., *The Legal Rights of People with Intellectual Disabilities*. Wellington: Legal Resources Trust, 1995.
- Bray, A. and Dawson, J. with van Winden, J., *Who Benefits from Welfare Guardianship?* Dunedin: Donald Beasley Institute, 2000.
- Diesfeld, J. D., O'Brien, P. and Miller-Burgering, W., *Interface between the criminal justice system and people with intellectual disability: Stage 2 Training and Advocacy*. Auckland: Auckland College of Education, 2002.
- DPA (NZ) Inc., *Annual Report: 1st July 2001 to 30 June 2002*. Wellington: 2002.
- DPA (NZ) INC., *Our Vision (2000-2002)*. Wellington: 1999.
- Education Review Office, *The New Zealand Disability Strategy in Schools*. Wellington: 2003.
- Government of New Zealand, *The Protection of Personal and Property Rights Act 1988 (PPPR Act)*. Courts of New Zealand, 1988.
- Health and Disability Commissioner, *Annual report for the year ended 30 June 2002*. HDC, 2002.
- Health Funding Authority, *Statement of Intent 1999/2000 to 2001/2002*. Wellington: 1999.
- Hinds, P., 'The Return of a National Consumer Network'. *Tu Tangata Motuhake*. Issue 3, June, 2002.
- Human Rights Commission, *Pre-employment Guidelines: based on the Human Rights Act 1993*. Auckland: 1995.
- I. H. C., *National Self-Advocacy Team Business Plan 2003/04*. Wellington: 2003.
- I. H. C., *What we believe in, why we believe in it*. Wellington: 2002.
- Minister for Disability Issues, *Progress in Implementing the New Zealand Disability Strategy 2002: Report of the Minister for Disability Issues to the House of Representatives*. Wellington: Office for Disability Issues, 2002.
- Ministry of Health, *Disability Support Services: increasing participation and independence*. Wellington: 2002.
- Ministry of Health, *The Health and Disability Sector Standards Residential Audit*. Wellington: Standards New Zealand, 2001.
- Ministry of Health, *The Health and Disability Sector Standards Te Awarua O Te Hauora*. Wellington: Standards New Zealand, 2001.
- Ministry of Health, *The New Zealand Disability Strategy: making a world of difference Whakanui Oranga*. Wellington: 2001.
- O'Brien, P., *A Parent Advocacy Perspective on Inclusion: Conflict or harmony?* Set. Special, 1-4, 1999.
- O'Brien, P., Miller-Burgering, W. and Vickery, R., *Interface between people with intellectual disability and the criminal justice system*. Auckland: Auckland College of Education, 1999.

O'Brien, P., Miller-Burgering, W., Diesfeld, J.D., Vickery, R. and Lett, L., *Interface between the criminal justice system and people with intellectual disability: Stage 2 Training and Advocacy*. Auckland: Auckland College of Education, 2002.

People First New Zealand, *People First Constitution*. Auckland: 2003.

Royal New Zealand Foundation of the Blind, *Annual Report for 2002*. Wellington: 2003.

Royal New Zealand Foundation of the Blind, 'Executive View'. *Outlook*, winter, 2-3. Wellington: 2003.

Statistics New Zealand, *Disability Counts 2001*. Wellington: 2002.

Scotland

Advocacy 2000, *Principles and Standards in Independent Advocacy Organisations and Groups*. Edinburgh: 2000.

Advocacy Safeguards Agency, *A Map of Independent Advocacy Across Scotland, 2003 - 2004*. Edinburgh: ASA, 2003.

Scottish Development Centre, *Developing Collective Advocacy for People who fall within the Remit of the New Mental Health (Scotland) Bill*. Edinburgh: SHS Trust, 2003.

Scottish Executive, *Adults with Incapacity (Scotland) Act 2000*. Edinburgh: 2000.

Scottish Executive, *Independent Advocacy, A Guide for Commissioners*. Edinburgh: 2001.

Scottish Executive, *Mental Health (Care and Treatment) (Scotland) Act 2003*. Edinburgh: 2003.

Scottish Executive, *The Framework for Mental Health*. Edinburgh: 2001.

Scottish Executive, *The Same as You?* Edinburgh: 2000.

Scottish Health Advisory Service, *Advocacy: A Guide to Good Practice*. The Scottish Executive.

SHS Trust, *A Map of Independent Advocacy Across Scotland. Updated Edition, 2002 - 2003*. Edinburgh: 2002.

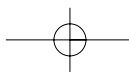
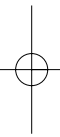
SHS Trust, *From Patchwork to Blanket: Developing Independent Advocacy*. Edinburgh: 2002.

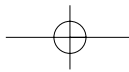
SHS Trust, *Independent Advocacy and the Law: A summary of acts of parliament for Scottish Advocacy Agencies*. Edinburgh: 2002.

Sweden

Ministry of Health and Social Affairs, *From Patient to Citizen - A National Action Plan for Disability Policy*. Stockholm: 2000.

The Swedish Institute, *Disability Policies in Sweden*. Stockholm: 2000.





United States

Gross, G., 'The Protection and Advocacy System and Collaboration with Legal Services Programs'. Boston: *Management Information Exchange Journal*, Summer Issue, 2001.

Kendrick, Michael J., *A Brief Overview Of The American Publicly Funded National Protection And Advocacy System For Persons With Disabilities*. September 2003.

Protection and Advocacy Inc., *PAI Advocacy Services Plan, 2003-2008. Advancing the human and legal rights of people with disabilities*. California: 2002.

TASC, *2003 P & A/CAP System Annual Report*. Washington: NAPAS, 2003.

Unzicker, R. *Mental Health Advocacy, from Then to Now*. Texas: NARPA, 2002.

General

Altman, B.M., 'Disability Definitions, Models, Classification Schemes and Applications', in Albrecht, G. L., Seelman. K. D. and Bury. M., *Handbook of Disability Studies*. USA: Sage Publications, 2001.

Baumer. Z., *Modernity and Ambivalence*. Cambridge: Polity Press, 1991.

Brown. S. C., 'Methodological Paradigms that Shape Disability Research', in Albrecht, G. L., Seelman. K. D. and Bury. M., *Handbook of Disability Studies*. USA: Sage Publications, 2001.

Campbell, J. and Oliver, M., *Disability Politics: Understanding our Past and Changing our Future*. London: Routledge, 1996.

Danaher, T., et al., *Understanding Foucault*. St Leonards: Allen and Unwin, 2000.

Fujiura, G. T. and Rutkowski-Kmitta, V., 'Counting Disability' in Albrecht, G. L., Seelman. K. D. and Bury. M., *Handbook of Disability Studies*. USA: Sage Publications, 2001.

Luckasson, R. (ed.), *The Criminal Justice System and People with Mild Cognitive Limitations. The Forgotten Generation*. Baltimore: Paul H. Brooks Publishing, 2001.

Oliver, M., *The Politics of Disablement*. Basingstoke: Macmillan, 1990 and 1991.

Oliver, M., *Understanding Disability: From theory to practice*. Basingstoke: Macmillan, 1996.

Williams, G., 'Theorizing Disability' in Albrecht, G. L., Seelman. K. D. and Bury. M., *Handbook of Disability Studies*. USA: Sage Publications, 2001.

Wolfensberger, W. and Thomas, S., *PASSING (Program Analysis of Service Systems' Implementation of Normalisation Goals)*. Toronto, National Institute on Mental Retardation, 1983.

Wolfensberger, W., 'Citizen advocacy for the handicapped impaired and disadvantaged: An overview', in Wolfensberger, W. and Zauha, H. (ed.s), *Citizen advocacy and protective services for the impaired and handicapped*. Toronto: National Institute on Mental Retardation, 1973.

Wolfensberger, W., *The principle of normalization in human services*. Toronto: National Institute on Mental Retardation, 1972.

Appendix 2: List of Persons Consulted

| Organisation | Contact |
|---|---|
| Brothers of Charity Waterford | Cabrini de Barra |
| CIC Crumlin | Anne McCloskey |
| CIC Sligo | Sean Staunton and Joe McElhinney |
| Department of Health and Children | Frank Treacy, Bairbre Nic Aongusa, Frances Fletcher and Brendan Ingoldsby |
| Department of Justice Equality and Law Reform | Ann Doyle |
| Department of Social and Family Affairs | Brian Flynn |
| Disability Federation of Ireland | John Dolan |
| Forum of People with Disabilities | Mary Keogh |
| Irish Advocacy Network | Paddy McGowan |
| Irish College of Psychiatry | Mary Clarke-Finnegan |
| Irish Wheelchair Association | Seamus Thompson |
| Mental Health Commission | John Owens |
| Midlands Health Board | Richard Walsh and Gerry Raleigh |
| NAMHI | Deirdre Carroll and Lisa Kelly |
| National Disability Authority | Claire O'Connor |
| People with Disabilities in Ireland | Michael Ringrose |
| Schizophrenia Ireland | John Saunders |
| The Equality Authority | Niall Crowley |

