



people matter

ADVOCACY

Framework for the Eastern Region

In the current context of the modernisation of the Irish healthcare system the theory and practice of advocacy is being addressed.

Modern healthcare is accepting of the participation of health service users and holds person-centeredness as one of its core principles. Therefore it is imperative that health service users be empowered and facilitated to access the services and entitlements they require.



Eastern Regional Health Authority



FOREWORD

Emergence of Advocacy

The Eastern Regional Health Authority, which was established on March 1, 2000 brings a regional dimension to the planning and delivery of health services. The dimension is shaped by a new vision of holistic healthcare and introduces a new perspective. The new perspective moves the planning and delivery of care from a service driven approach to a needs-led programme of care. This shift is significant as the service offered now places the person who uses the service at the centre.

The emergence of advocacy is a feature of an overall social, culture, political and economic change in western society.

The purpose of this document is to set out a framework to develop advocacy in the region. The central principle in developing this framework is the belief that people matter. A people-centred health service helps individuals to participate in decision-making and supports, empowers and encourages them to have an increased involvement. This vision promotes transparency and accountability and places a high value on treating people with dignity and respect.

To support the development of advocacy the Authority has initiated a work programme. The implementation of the programme will involve, service users, members of the board of the Authority and service providers from the region.

The Authority would like to thank everyone who has been involved in the preparation of this document. I am confident that the development of this framework will be of benefit to the population that avails of health, personal and social services in the eastern region.

Martin Devine
Director of Corporate Services
February 2004

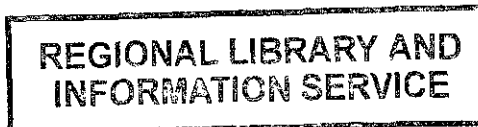
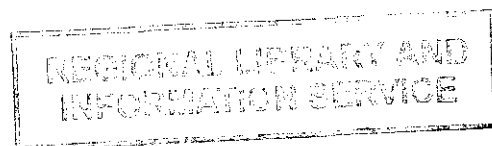




Table of Contents

Emergence of Advocacy.....	4
A Brief Description of Advocacy.....	5
Formal Advocacy.....	6
Common Advocacy Principles.....	10
Person Centered Healthcare.....	11
A New Dialogue.....	12
A New Partnership.....	13
Review of the Handling of Complaints.....	13
The Authority's Response.....	14




ADVOCACY FRAMEWORK

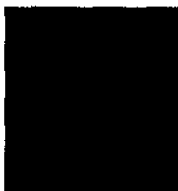
In the current context of the modernisation of the Irish healthcare system the theory and practice of advocacy is being addressed.

Modern healthcare is accepting of the participation of health service users and holds person-centeredness as one of its core principles. Therefore it is imperative that health service users be empowered and facilitated to access the services and entitlements they require.

Emergence of Advocacy




The emergence of advocacy is a feature of an overall social, cultural, political and economic change in western society. Traditional attitudes and behaviours are changing. Individualism is becoming more obvious in our society. No organisation, community or individual, remains unaffected by the influence of these changing human and social patterns, and our society and culture is reshaped as a consequence.



Two prominent social phenomena of the last century have contributed significantly to influence the direction of healthcare in western society.

The first of these is the growth and influence of consumerism. The second is the emergence of people-centeredness.



The philosophy of person-centeredness recognises each person's life domains. A person centred health care system responds in a holistic way to meet the needs of each domain. A person centred health care system also recognises that each individual plays a critical and essential role in the assessment of their needs and that quality of care is inextricably linked to both life domains and the involvement of the user in determining their health care.

A Brief Description Of Advocacy

The character of what is meant by "advocacy" can be quite elusive, as its usage varies from country to country, and listeners in some countries may lack familiarity with advocacy developments that are not usual in their life experience. The roots of the word advocacy come from the Latin word for speaking or voicing which is "vocare". The prefix "ad", is also from the Latin language, and refers to speaking towards something, or in favour of something. The combining of them results in the new word "advocare" which means "to speak in favour of something". This idea, that the advocate is someone who is essentially partisan, stems from their selection of a person, position, idea or priority that they prefer to others, thus making them an advocate of the particular preference or conviction. Consequently, one becomes an advocate by speaking on behalf of a person and supporting some interest, need or priority of that person. If the person is one of many with a similar need or priority, then the advocacy can be collectively done for all of the persons within the collection e.g. some advocates speak on behalf of the poor, immigrants, or the disadvantaged etc.

Advocacy can take many forms depending on who is doing it, for who they are doing it on behalf of, and what the target of the advocacy is. A further distinction can be made between whether the advocacy is done informally or via a formal advocacy initiative. Most people who speak up on behalf of others and defend their interests do so informally i.e. not as part of an organized advocacy program. So, whenever we stick up for others we are conducting advocacy. In fact, this is the most common form of advocacy, as it is so very much part of everyday life that we may not recognize that it could be distinguished as being advocacy.

Formal Advocacy

Legal Advocacy - In terms of formal advocacy the most common form since the Roman period, has been that of legal advocacy. In Roman times, the ordinary citizen did not appear on their own behalf in court, as the custom was to have a legal professional speak on your behalf. By modern times, this role had broadened considerably into a much more diverse form of representation of legal practice, but its essence has endured as someone acting on behalf of a person. In fact the term "avocat" in the both French and Spanish refers to a qualified legal professional. In some countries, persons with lesser legal training may also play limited representational and support roles on matters of legal importance.

Citizen Advocacy - Another common form of advocacy in many countries that is very much akin to informal personal advocacy on behalf of another person is Citizen Advocacy. Citizen Advocacy, (or CA), involves the intentional recruiting of an interested citizen into playing the role of personal advocate for a person that seeks such assistance. It can also involve the two people forming a relationship that can, at times, extend to becoming close friends. This matching process is supported by a formal program of support that is organized and led as a small grass roots voluntary community initiative that can be either formally incorporated or perhaps exist more informally as a communal voluntary undertaking by people concerned about the situations of the people being advocated for. Such people might not be able to enlist others to play an advocacy role on their own, and thus may need the assistance of such a program.

The most common form of individual advocacy effort that does not utilize ordinary citizens as unpaid personal advocates, is the creation of various forms of paid, but not always professionalized individual advocates, whose job it is to act on behalf of persons requiring advocacy assistance. This latter type of advocacy shares the common characteristic of informal and Citizen Advocacy forms of individualized advocacy, of being able to identify, recruit or provide people who will either act on someone's behalf, or act to assist the person to be their own advocate to whatever degree this may be possible. Often this form of paid advocacy will be contained within an organization whose mission it is to provide advocacy. The most typical organization of this kind would be community based voluntary organizations, but there are examples of statutory organizations that provide this assistance. In both instances, some amount of government funding may be present, though there would be many independent advocacy organizations in the voluntary sector that refuse to rely on government funds, so that they can more independently challenge governments and their agents directly.

A variation of this latter form of paid individual advocacy is often called "peer advocacy". This usually occurs where there is a deliberate attempt to ensure that the person in the advocacy role shares some important personal characteristics such that the two people are "peers". The "peer" in the advocacy role is typically seen as a more experienced resource person, who shares some of the life experiences of the person seeking advocacy, but who is in a position to help because of a more extensive set of qualifications or experiences. These "peer" advocates are often paid, and work for an organization that has a mission involving advocacy, but they can also be unpaid volunteers associated with a self-help organization.

It is quite common for people who share the same concerns and experiences, to form groups to support themselves in both their personal and collective advocacy. Often these groups are called "self advocacy" groups, as this term captures the sense that they are attempting to speak for themselves, rather than having others speak for them. The term might also refer simply to persons who are informally speaking up for themselves, though

self advocacy organizations also tend to include some manner of "shared" or collective speaking up in the interests of having a common voice on important matters.

When advocacy moves from being concerned with individuals to being concerned with influencing broader trends or concerns then it is often referred to as "systemic" advocacy i.e. advocacy oriented to changing the "system of things". This can be seen in the examples of advocacy groups that are founded to address some broad systemic issue such as the environment, political rights, attitudinal change or whatever. The particular system that is in need of change can be governments, corporations, bureaucracies, private organizations or even churches. Thus, "systemic" advocacy is not defined by the specific target of its interest, just that a broad or "systemic" issue is at stake, rather than matters principally concerning an individual. Normally, systemic advocacy is undertaken by voluntary or community organizations, but it can also be initiated under special conditions by statutory advocacy organizations. "Legislative Advocacy" is essentially a specialized form of systemic advocacy that usually focuses on law reform or government priorities.

On many occasions there may arise groups of people who share a deep interest in a systemic issue, and then form a "voluntary association" that acts as the common conduit and voice for their advocacy concerns. Not all voluntary associations become advocacy organizations, nor are all advocacy organizations voluntary independent community based organizations, but this is certainly the most common base for systemic advocacy. A variation on this would be advocacy coalitions that form a united vehicle, i.e. a "coalition" that seeks to strengthen their influence by acting jointly to some degree. These can include both statutory and voluntary advocacy organizations but might also include any number of non-advocacy organizations that are also concerned with the matters that confront the coalition.

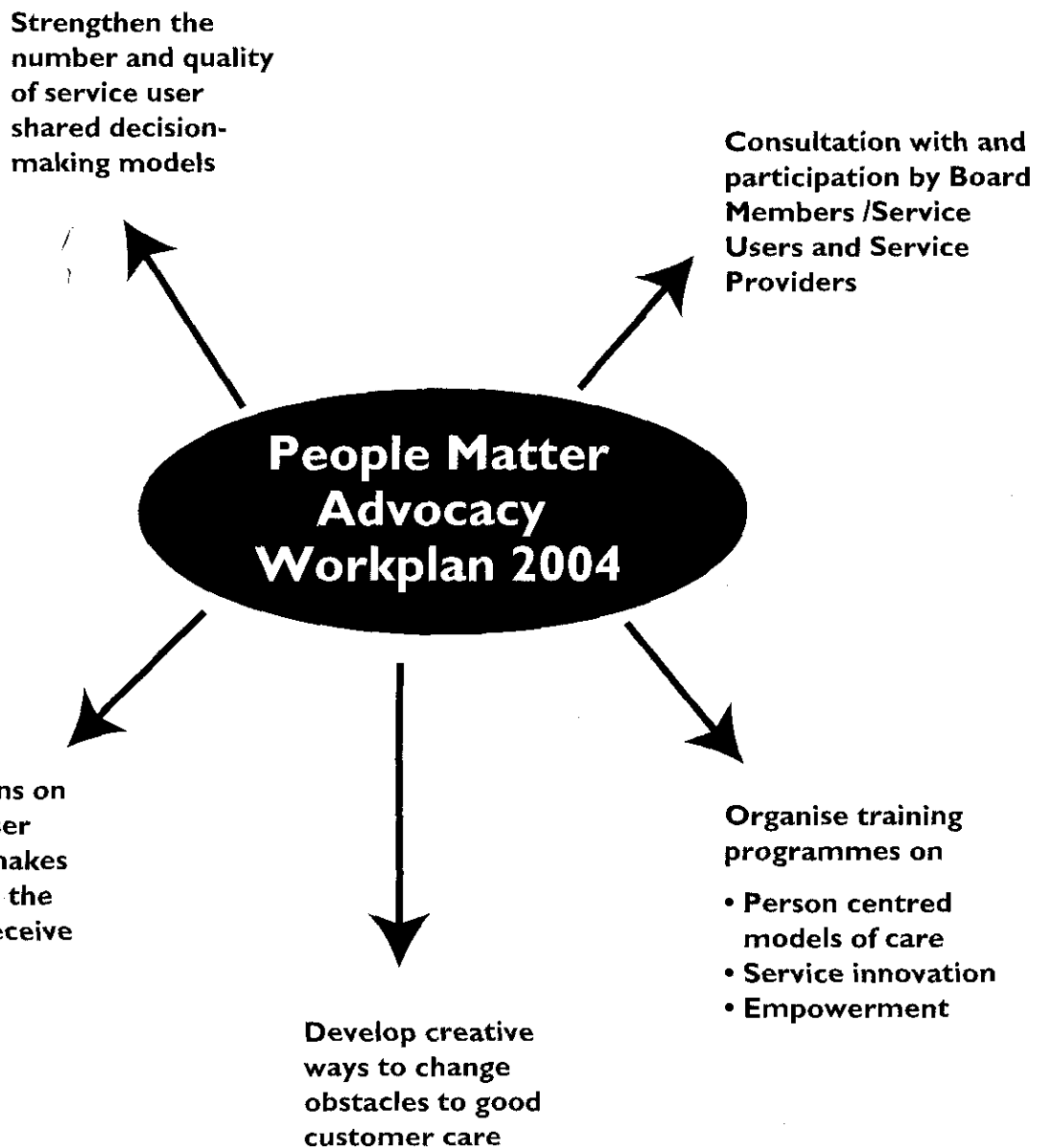
Sometimes, when self-help groups decide to undertake an advocacy role, it is because they have determined that such advocacy is needed to address their interests, needs and concerns. A common form of this "collective self advocacy" that involves families as the principal actors might be termed "family advocacy". Such advocacy can on occasion take a direction that leads to individual advocacy for given families, but if they move in another direction it can result in systemic advocacy for families.

A last form of advocacy that may be familiar to many people would be that of "singular personal advocacy" efforts that are meant to be a campaign by a single person to alter some systemic issue. Such singular personal advocates may not have any organization to back them, and may simply be content for themselves, and their personal example, to be the embodiment of what they see as their advocacy mission. Others may form an organization in order to generate another level to their advocacy, but may still hold onto their singular dominance of the advocacy issue that animates them.

Authority Workplan 2004

Strengthen the number and quality of service user shared decision-making models

Consultation with and participation by Board Members /Service Users and Service Providers



People Matter Advocacy Workplan 2004

Demonstrations on how service user involvement makes a difference to the service they receive

Organise training programmes on

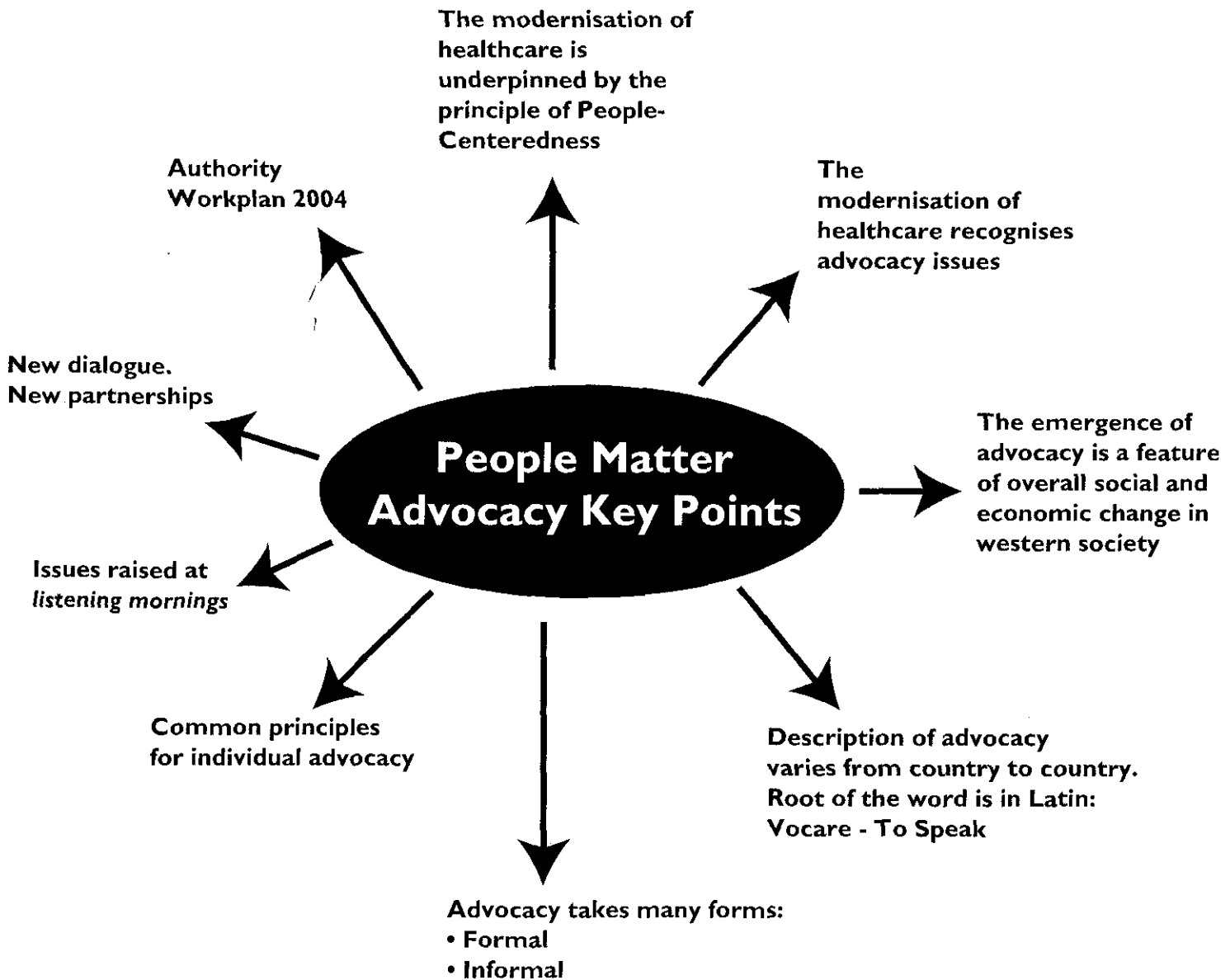
- Person centred models of care
- Service innovation
- Empowerment

Develop creative ways to change obstacles to good customer care



Advocacy Framework

Key Points



Common Advocacy Principles

Common Advocacy Principles (For Individual Advocacy)

- Effective advocacy requires that the person advocated for is fully informed of the options available to them
- Effective advocacy requires that the person advocated for is fully involved in the decisions that affect them
- Effective advocacy requires that the advocate be independent from any conflict of interest that could compromise the advocacy
- Effective advocacy requires that the advocate be faithful to the person's best interests and take into account their wishes
- Effective advocacy requires that the advocate defend the rights, dignity and well being of the person being advocated for
- Effective advocacy is expected to be enabling of the person doing as much of their own advocacy as is possible
- Effective advocacy requires that the advocacy that people need be available in amounts sufficient to defend the persons interests, resources permitting
- Effective advocacy requires that advocates both challenge the system to do better and to recognize good faith efforts to do so that may result
- Effective advocacy requires that advocates act with ethical integrity including a respect for truth and fairness
- Effective advocacy includes more than an obligation to make demands, it also requires that the advocate make all additional reasonable efforts to secure as beneficial outcomes for the person as may be possible at a given moment



Person-Centered Healthcare

The Health Strategy states - A **'person-centred'** healthcare system of the future will have dynamic integrated structures which can adapt to the diverse and changing needs of society generally and of individuals within it. These structures will empower people to be active participants in decisions relating to their own health.

Participation and Involvement of Patients/Clients

This changing context of healthcare necessitates a view of the patient as an active participant rather than a passive recipient. Traditionally the patient/client has been viewed as an external entity. Until recently, patients have not been prominent in articulating their needs or in exercising influence over the decisions that affect the services they receive. However this is giving way to a new recognition of the centrality of the patient in determining the acceptability of healthcare. In this climate patients seek a new vision of care firmly established on the important principles of respect, dignity and choice. This vision highlights the need for a holistic approach and an acceptance of the importance of home and community care. This vision introduces a new perspective. The new perspective moves the planning and delivery of care from a service driven approach to a needs led programme of care. This shift is significant as the service offered now places the person who uses the service at the centre. Patients should be empowered to make choices concerning the decisions that affect their lives.

New Public Health Paradigm

This new public health paradigm introduces a broader definition of the needs of individuals. Within the conceptual framework of the new model of health is the notion of health encompassing all facets of our daily lives. In that sense, issues such as pollution controls, environmental protection, food safety and social well-being are intimately involved with physical, mental and psychological well-being.

Effectively, this acknowledges that health is not solely an activity and a responsibility of health and social care professionals, each facet of the environment contributes significantly to good health. The task of providing good health care, which encompasses the total needs of the individual, belongs to everyone in the community. Cultural factors also need to be recognised in order to understand health behaviour.

This ushers in an era of new partnerships, which are socially inclusive. The partnerships seek to achieve a satisfactory blend of Board, professional, managerial and service user perspectives and each perspective is important in the determining of needs. The outcomes of these partnerships promote service integration and cross-departmental initiatives, the development of links with other information giving bodies and build and strengthen the relationships between voluntary and statutory providers.

There is growing appreciation among service providers that establishing a good quality of life for patients requires their involvement in the planning of the services that are important to them and which support their choices. The perspective of the patient and their carers needs to be understood and appreciated.

A New Dialogue

To facilitate this, and to include patients in the planning of the services and in the decisions that affect their lives, a **new dialogue** between patient, management and health professionals needs to be initiated. This **new dialogue** may well challenge the priorities set by the Board of the Authority, management and health professionals and well-established patterns of delivering care.

In modern healthcare, services should be responsive to the needs of patients and tailored to their individual requirements.

A distinctive feature of patient centred care is the re-configuration and re-engineering of existing services to meet the needs of patients requiring seamless and integrated hospital and community services.



A New Partnership

It would be somewhat unproductive to develop a much needed new dialogue if it were not also accompanied by a new partnership between those who provide services and those who must rely on them. A new partnership would create:

- Opportunities to move beyond disputes to (mutually) creating the enduring solutions that would make them go away
- Opportunities to propose and change service practices for the better
- Opportunities to improve problem solving at the everyday level so that complaints and disputes do not have to be launched
- Opportunities to link service recipients with people in the system that share their sense of what would constitute progress
- Opportunities to make joint decisions on how to use resources better for people

Review of the Handling of Complaints

The Authority undertook a review of the handling of complaints in the region in June 2001. From the outset it was evident that the effective handling of complaints should be underpinned by the core principles of the *Health Strategy Quality & Fairness* - equity, people-centredness, quality, and accountability. It also emerged that the handling of complaints is inextricably linked to customer services, staff training and advocacy.

As part of the review a number of meetings were held with representatives of identified support groups. The outcome of these meetings has helped inform the proposed advocacy framework. In this regard the framework addresses the following questions,

1. How do the providers of health care empower the most vulnerable in our society to receive the information necessary for them to make informed decisions in relation to their healthcare?
2. How do we empower the most vulnerable to have their voice heard and have equal opportunity to partake in decisions and discussions affecting their healthcare?
3. How do we empower vulnerable people to articulate their expectations of us as healthcare providers and to communicate their dissatisfactions when their needs are not being satisfactorily addressed?
4. How can we make complaints procedures accessible to vulnerable people to enable them to complain when standards of care, treatment and practice are perceived to fall short of that which is acceptable to patients/clients and their families.

The Authority's Response

1. Information is a very important part of advocacy. Access to information helps people to make choices and facilitates them in their decision making. The Authority is currently preparing a customer service action plan. The action plan will provide easy access to information on a range of services and will present the information in different formats to meet the needs of those from all backgrounds and cultures.
2. The framework for handling complaints, which was launched by the Chair of the Authority Alderman Joe Doyle on the 1st September 2003, provides a mechanism to deal with individual advocacy issues. This framework which is underpinned by the principle of the belief that people matter has a number of important components which also address the issues raised at the listening mornings.
 - The right of each individual to make a complaint and enabling them to do so
 - Independent review support for complainant
 - Patient/client information and patient/client feedback
 - Common complaints procedures and process
 - Organisational commitment and learning
 - Education and empowerment of staff
 - Information management through a common database
 - Quality assurance through provider agreements
3. The Authority has appointed a working group on advocacy. The working group, which comprises of service users, board members and service providers, seeks to:
 - Facilitate the participation of people in the issues that matter to them. Shared decisions to ensure joint solutions.
 - Establish collaborative assessment to ensure effective and enhanced care
 - Develop an openness to change and innovation that makes a difference to people's quality of life.
 - Promote services that are personalised by design
 - Learn how to deliver services with a person centred perspective
 - Engage in a programme of pathway investment
4. The Authority has agreed a Workplan for 2004 to support the development and implementation of models of advocacy.
 - Strengthen the number and quality of service user shared decision making models
 - Develop creative ways to change obstacles to good customer care
 - Demonstrate how service user involvement makes a difference to the service they receive
 - Organise training programmes on person-centered models of care, service innovation and empowerment