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PathFinder

Evaluation of the
Programme of Advocacy Services for People with Disabilities
in the
Community and Voluntary Sector

Final Report

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Citizens Information Board
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Contact

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EXECUTIVE SUMMARY

Every person with a disability (including people with mental health difficulties) would be supported to enable them, as far as possible, to lead full and independent lives, to participate in work and in society and to maximise their potential.

Towards 2016, S33 p66

There are 400,000 people with disabilities in Ireland. Of these, 24% are unable to carry out everyday activities, while a further 43% experienced difficulty carrying out these same activities. (CSO, 2008)[1] Approximately 32,000 of people with disabilities live in a residential home or hospital. People with disabilities can be marginalized in terms of health, housing, employment and social participation.

In sustained endeavours to draw those who are marginalised from the periphery there have been developments in legislation, social policy and programmes. The Programme of Advocacy for People with Disabilities in the Community and Voluntary Sector is one such programme that was developed by the Citizens Information Board[2]. The Programme offers an advocacy service to those with disabilities who require an independent advocate to help them secure services that they might otherwise not receive. The advocates make a significant impact in the lives of those who used the service.

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[1] The most commonly occurring disabilities include mobility and dexterity disability (56%); pain (47%), remembering and concentrating (35%) and emotional, psychological and mental health (34%). (CSO 2008)

[2] The Citizens Information Board was formally known as Comhairle. To maintain clarity and consistency, all reference to Comhairle, with the exception of legislation, will be as the Citizens Information Board.

Introduction and Background

Disability is one of the key priorities in a number of key government initiatives, including the National Disability Strategy (2005) and the Partnership Agreement, *"Towards 2016"* An important part of the Disability Strategy is the provision of independent advocacy. The government has a vision where people with disability are afforded an opportunity to live full lives with their families and as part of the local community.

Advocacy has become a key element in the promotion of independence and choice in the lives of those with disabilities who are marginalised.

The Citizens Information Board, since its establishment as a Statutory Body under the Department of Social and Family Affairs, has been involved in advocacy in the mainstream context of Citizens Information Services. In its Sectoral Plan under the Disability Act 2005, the Department of Social and Family Affairs prioritises a number of initiatives to support access for people with disabilities. These include supporting the Citizens Information Board's Programme of Support for Community and Voluntary Sector Advocacy and the introduction of the Personal Advocacy Service.

Development of an Advocacy Service

People may need advocacy at some time in their lives. For many reasons, a person may not be able to assert him/herself, and may need the help of another to do so. Advocacy enables people to have a voice and to articulate their needs in order for others listen to them. There are different advocacy models, but each has an underlying principle of empowering others to speak for themselves and providing unbiased representation to marginalised people who are unable to speak for themselves.

The Citizens Information Board's involvement in advocacy comes from its role as an information provider and its statutory responsibility to develop advocacy for people with disabilities. In 2004, after consultation with a range of Irish stakeholders and substantial research on advocacy services abroad, Goodbody Consultants produced a report (2004) for the Citizens Information Board which identified and examined the components of an advocacy service that would meet the needs of people with disabilities in Ireland. In anticipation of the expected legislation on advocacy, the

Goodbody report *Developing an Advocacy Service for People with Disabilities* recommended that the Citizens Information Board adopt a three strand approach to advocacy, incorporating a:

- Personal Advocacy Service (PAS) – this service to be set up on a paid professional basis to deal with critical and complex advocacy issues only
- Support Programme for the Community and Voluntary Sector – this service to focus on the provision of individual advocacy services, employing a range of delivery models
- Community Visitors Programme – this service to focus on people with cognitive disability in residential institutions, to be established on a volunteer basis, overseen by a central and regional structure.

It was agreed following the 2004 Goodbody Report, that two main streams would be concentrated upon, the immediate establishment of the Advocacy Programme for People with Disabilities in the Community and Voluntary Sector (Strand 2) and the preparations required to initiate the Personal Advocacy Service, PAS (Strand 1). In 2007 the Citizens Information Act was passed enabling the delivery of the programmes. In 2008, PAS, as initially envisaged, was placed on hold due to lack of resources. The Sections of the Citizens Information Act (2007) relating to the Personal Advocacy Service have not been implemented to date. The Community Visitors Programme (Strand 3) has not been developed to date.

The Advocacy Programme for People with Disabilities in the Community and Voluntary Sector

In 2004 the Citizens Information Board began the process of engaging with the community and voluntary sector in order to develop advocacy provision. The programme was highly innovative, as nothing similar had been undertaken by a state agency prior to this time. In 2005 and 2006 expressions of interest were sought from organisations representing people with disabilities, from service providers, from the voluntary sector and from partnership groupings. Regional information seminars were held. Each year a number of projects were chosen for three year funding (later extended to five) on the basis of their capacity to employ an advocate and reach a service user grouping specified by them. The Citizens Information Board prepared the document, *Advocacy Guidelines,* to support the projects. It provided training days for advocates and collaborated with Sligo Institute of Technology in the development of a distance learning qualification in Advocacy.

Under the present programme, 46 projects have provided representative advocacy to upwards of 5,000 Service Users. The projects are hugely diverse, covering a wide range of disability groups and partnerships between organisations, including people with physical/sensory disabilities, people with intellectual disabilities and people with mental health issues. Each of the projects employs an advocate to meet the needs of their target service users. There is significant, but not complete, geographic spread involving both community and residential based projects and a smaller number serving service users in residential centres. Supporting the advocate are the line manager, lead agency and steering group. The Citizens Information Board is responsible for ensuring that effective corporate governance is in place for each project operating within the programme, and that there is adherence to guidelines laid down for projects. Funding and support from the Department of Social and Family Affairs is critical to the delivery of the service.

Evaluating the Programme

Round Table Solutions and PathFinder were appointed by the Citizens Information Board to carry out the evaluation of the Programme of Advocacy Services for People with Disabilities in the Community and Voluntary Sector. The evaluation is the result of a programme of work undertaken from January to December 2009 composed of two elements: ***case review and analysis*** and ***structural review and assessment***. The focus of the evaluation is to consider the impact of the advocates' work and that of their projects on the lives of people with disabilities and the form that the overall Advocacy Programme should take beyond the pilot phase in 2010. The evaluation serves as an input into the future strategic design of advocacy services, as intended by legislation and required by those with disabilities.

On completion of the initial evaluation, the team were engaged to carry out supplementary research to enquire if there was a need to implement the legislation governing the provision of a Personal Advocacy Service. This report includes the findings and recommendations of this additional research.

Summary of the Research Methodology

The evaluation is characterised by a plurality of research methods that enabled the evaluation team to understand the structures and work of advocacy, the diversity of provision and the impact on service users. The evaluation was based on documentation, interviews and case studies by way of a longitudinal study carried out during 2009. The evaluation approach had four phases:

Phase 1:	Information review and preparation
Phase 2:	Setup, design and planning
Phase 3:	Case analysis and programme evaluation
Phase 4:	Report and recommendations.

Document Review: This involved reviewing documents relating to advocacy from a number of sources both national and international; reviewing the relevant legislation; the published reports and policy document submissions and internal Citizen Information Board project guidelines and annual reports.

Case Analysis: From the forty six projects, 2,400 cases were analysed across a number of criteria, including gender, age, type of disability, residential setting, advocacy issues and length of case. From the 2,400 cases, 200 cases were analysed in depth and in parallel 20 live cases were tracked where the evaluators met with service users, advocates and line managers.

Interviews: Interviews were held with key stakeholders to inform a comprehensive understanding of the programme. A SWOT analysis was carried out with a number of different groups.

A qualitative and quantitative assessment was made to assist the selection of the projects. A shortlist of 17 projects was drawn up and a number of qualitative criteria used in the further refinement of the selected projects, to a final selection of eight. The chosen projects represented an acceptable spread across location, disability type, setting and steering group type.

In adherence with ethical research practices, this research was carried out within the guidelines of data protection, confidentiality and collection of data for defined purposes.

Summary of Main Findings

In the four years since its commencement, the programme has worked with a significant number of service users, disability organisations, residential institutions, agencies, service providers, volunteers, public, carers and community representatives. From the evaluation, findings cover five main themes:

- The scope, focus and level of the advocacy work undertaken and the outcomes for people with disabilities using the services.
- The geographical spread and reach of the programme.
- The appropriateness of the lead agencies involved and their level of independence.
- The governance and support structures including the effectiveness and sustainability of the steering group.
- The provision of a Personal Advocacy Service.

The Scope, Focus and Level of Advocacy

- Advocacy for people with disabilities is delivering significant value and is changing people's lives in a real way.

- The majority of people accessing the service are between 18 and 64 years, with a significant tapering of access for people with disabilities over the age of 65. There is small representation of people under 18 years.

- Advocates' impact on the lives of service users is considerable. The advocate focuses on what the needs of the service user supporting them in asserting their rights.

- Advocacy has been a transformative experience for those using the service.

- Advocacy brings a significant improvement in the lives of people who are vulnerable, marginalised, hidden, ignored or overlooked.

- Advocacy cases can be categorized as high complex; complex; and low complex cases. Some high complex cases fall within the legislative scope of the proposed Personal Advocacy Service. Most cases are complex cases. Low complex cases often develop into complex cases.

- The relationship between the advocate, line manager and steering committee is key to the delivery of advocacy in the programme. There is a wide variation of practice in terms of supervision (both internal and external) case management, support, and expectations.

The Geographical Spread and Reach of the Programme

- The programme's ability to reach people with disabilities particularly those who are most vulnerable has improved over the duration of the pilot programme.

- Over the period of the pilot, a number of projects have expanded their footprint, by removing restrictions that belonged historically in the host organisation, by expanding into new geographies and by moving between community and residential settings.
- There are a number of areas where there are clear gaps in the delivery of service.

The Appropriateness of the Lead Agencies Involved and their Level of Independence.

- Independence of the advocate is critically important in enabling them to act on behalf of the service user.

- The structural arrangements of the project can challenge the independence of the advocate.

- Independence of the advocate is a particular issue where the advocate is employed by a service provider.

- Independence of the advocates and their ability to operate without fear of inappropriate influence is dependent not only on their own principles, competencies and ethics, but also on the independence of decision making and advice from their steering group and line management.

- The role of line manager, of advocate and the working practices between them are core ingredients in an effective project.

- The success of a project is heavily reliant on individual relationships.

Governance and Support Structures including the Effectiveness and Sustainability of the Steering Group.

- Lack of understanding of advocacy and differing expectations within steering groups led to initial difficulties for advocates.

- Steering group structures differed in terms of support and accountability.

- All projects have policies and procedures in place, which underpin the practice of advocacy but these vary from project to project.

- The lack of standardisation of expectations, policies and procedures militates against unified standards.

- Advocates are isolated by the current organisational structure and the geographical reach of the programme.

- The majority of advocates use the agreed mechanism for upward feedback of social policy issues. There is evidence that some advocates make individual submissions.

The Provision of a Personal Advocacy Service

- Some cases undertaken by experienced advocates should have come under the remit of the Personal Advocacy Service. In the absence of statutory powers, there are considerable delays in offering advocacy to those most in need.

- Advocates are experiencing difficulty in gaining access to some residential settings. In the absence of this access, it is difficult to determine need.

- Based on the evidence of the need in residential settings where advocates do have access, it can be taken that there are vulnerable people in residential settings who are not given the opportunity to access advocacy.

- In some residential settings, advocates are given permission to work on behalf of some service users and denied permission to work on behalf of others.

- In the absence of the powers of the Personal Advocacy Service and in certain circumstances, advocates are excluded from representing and/or supporting service users, by some service providers.

- Advocates can be denied access to information pertinent to their work with service users.

- Some advocates are excluded from meetings and consultations including medical consultations; court proceedings, legal consultations, care planning conferences

Conclusions and Recommendations

The findings of the evaluation point clearly to the fact that the advocacy service has had a hugely positive impact on the lives of people with disabilities. Findings show that the project staff, their steering groups, their hosts and their supporters in the Citizens Information Board and the Department of Social and Family Affairs have been hugely successful in establishing and consolidating forty six projects, covering twenty three counties. In addition, they have delivered real change for people with disabilities that otherwise would not have happened. The case studies provided in this report testify to this.

Considerable learning has occurred during the pilot phase as a result of innovative and dedicated work of all those involved in the programme. This learning must now be used to strengthen the advocacy service, deliver increased value to its users, ensure it delivers better value for money, while upholding the principles that have delivered its success to date.

Several conclusions point to the need for change which if addressed will significantly enhance the ability of the advocacy service to deliver on its aims. They include the need to:

- Enhance and protect the ***independence*** of the advocate to represent people with disabilities.
- Improve the ***quality, capacity and level*** of advocacy response to a point where the service is capable of developing and sustaining itself and is not limited by structural arrangements.
- Demonstrate and communicate the ***worth and value*** generated for the money invested and the time given by all involved in the provision of advocacy.
- Maximise the ***collaboration and partnership*** between all stakeholders which is central to the success of the advocate's work with service users.
- Increase the ***level of diversity*** among those advising on or working to improve the situation for people with disabilities who use the advocacy service, as it has a direct impact on the quality of the solutions found.
- Build ***capability and confidence*** that the most vulnerable are being reached.
- Ensure that the ***voice of the service user*** is at the centre informing the ongoing design of the advocacy service.

In the absence of the implementation of the Personal Advocacy Service, people with disabilities who are isolated and vulnerable are dependent on the consideration of senior managers within service providing organisations to decide on their access to advocacy. In addition to this, the report finds that there is sometimes considerable loss of time within the current advocacy programme in negotiating permission to provide advocacy services to people with disabilities and in progressing advocacy cases. The lack of the statutory powers of PAS can allow service providers to delay access within the current Community and Voluntary Programme.

The project approach has succeeded in delivering value. A different response is needed, however, if enhancements are to be achieved. Any response has to serve all of the stakeholders involved, The concerns of each must be taken into account, as to alienate or ignore any one, will lead to a poorer outcome for the service user. The future approach must be consistent with Central Government strategy and with what the users of advocacy need.

The findings point to the need to change the structure of how projects are managed and organised. To take advocacy to the next level and deliver increased value, with the same or fewer resources, requires change. The implementation of a new model of representative advocacy is recommended. In addition, it is recommended that the legislation governing the personal advocacy service be implemented and become an integral part of the delivery of advocacy services in Ireland. The recommended changes will impact positively on the needs and interests of service users, other stakeholders, and advocates in line with government policy.

Future Advocacy Service

Advocacy needs to respond to a range of complexity of cases, from cases that require limited involvement and intervention, to a level of complexity that requires significant and direct personal intervention, some of which may require the backing of statutory powers.

The evaluation team recommends the bringing together of the experience and learning from all stakeholders into a ‘single service’ with the ability to provide improved services to people who need them, regardless of location, disability type or level of vulnerability. The architecture shows the Citizens Information Board as the funder, supporter and holder of advocacy provision at a statutory level on behalf of Government. Delivering advocacy across the full range of complexity requires the enactment of the Personal Advocacy Service (PAS). Without the availability of these powers, advocates may not be able to gain access to clients in residential centres, may not have sight of documents and files and may not be able to provide full representation and/or support to vulnerable people who are involved in official processes or who wish to take a serious complaint against a service provider. It is recommended that the three strand approach, as defined in *Developing an Advocacy Service for People with Disabilities*, be transformed into a single arc providing advocacy to People with Disability according to need.

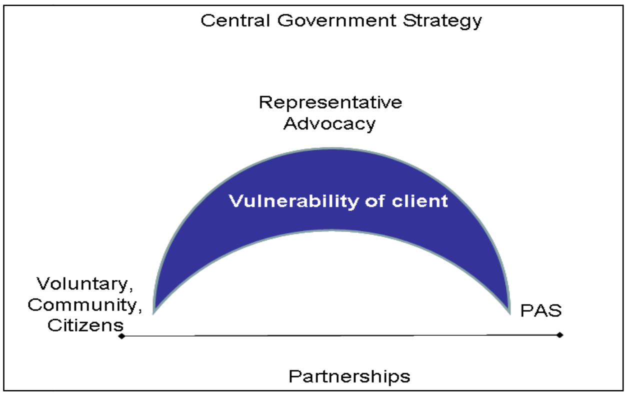

Figure 1: Single Arc providing Advocacy Services to People with Disability

A national service that can truly function as a seamless service for both service users and stakeholders, requires a structure that is capable of responding, adapting and growing as the need changes over time. The national service, those who work in it, those who are served by it and those who support it, require clarity on the services, goals, effective measurement, management of performance and operating conditions that will ensure its success.

The implementation of PAS is critical to the development of a full national advocacy service. Not only has it a function under its legislative provisions, but its presence or absence has consequences for the effectiveness of other advocacy services.

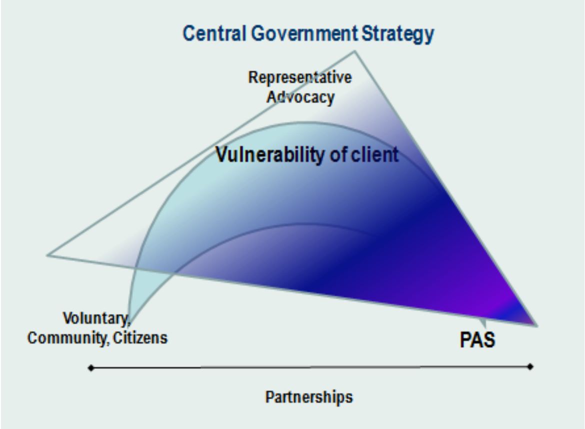

Figure 2: Model of Legislative and Consequential Effect of the implementation of the Personal Advocacy Service

The evaluation team recommends that the following service principles are adopted as a starting point in moving the advocacy service from a project based structure, towards a mature and fit-for-purpose advocacy service beyond 2010.

- ***People with Disabilities at the Centre:*** where people with disabilities will be at the centre of service provision as user, advocate or provider.

- ***Professional Development, Professional Delivery:*** where each staff member, paid or volunteer will achieve a minimum standard of competency in their role, will be assessed on an ongoing basis and will be led by a competent authority in their area to deliver a competent, professional, independent and satisfying service to all service users.

- ***One Team, One Service:*** where advocates will offer a consistent, quality-assured, valued service, nationally, that is accessible to all people with disabilities and actively seeks out those who are most vulnerable regardless of disability type.

- ***Work with, Work for:*** where advocates will actively work to create and develop partnerships between disability organisations, service providers, service users, community and other stakeholders so that all get value from their involvement.

- ***Share the Success:*** where the value of the investment and the benefit that it brings, will be communicated openly while safeguarding confidentiality as determined by the service user.

The evaluation team believes that in adopting these principles, the future advocacy service will address many of the challenges raised regarding the current configuration. Furthermore, in order to effectively and efficiently deliver the required change in a consistent manner with consistent outcomes, the service must be managed through a national structure organised and delivered locally.

A national structure requires a national organisation to be established or identified, that at the very least offers a consistency of approach within which the new advocacy service can be delivered. The national organisation model would be supported and influenced by national and regional advisory groups, similar to what the steering group currently does for each project, but with increased focus on change and action in support of the advocates' work. The national organisation, through its regional remit, would act as the employer and would be governed by a board structure. All services would be delivered locally through regional and local structures.

While several organisations met a number of the criteria, only one stood out as being independently capable of supporting the delivery of the advocacy service nationally, without significant change being required, while also addressing the vast majority of the concerns raised throughout the evaluation. The Citizens Information Service network (CIS), long established, with an existing infrastructure offering information, advice and advocacy services, matched many of the criteria outlined.

The CIS network offers free services to citizens in over 250 locations across the nation, not counting the locations that advocates already operate from, and, with agreement, may continue to do so. This affords a level of mainstream contact not offered by any other organisation. The CIS network with staff, management and boards, representatives of local community and key organisations, represents an existing vehicle to offer advocacy as a service locally and nationally.

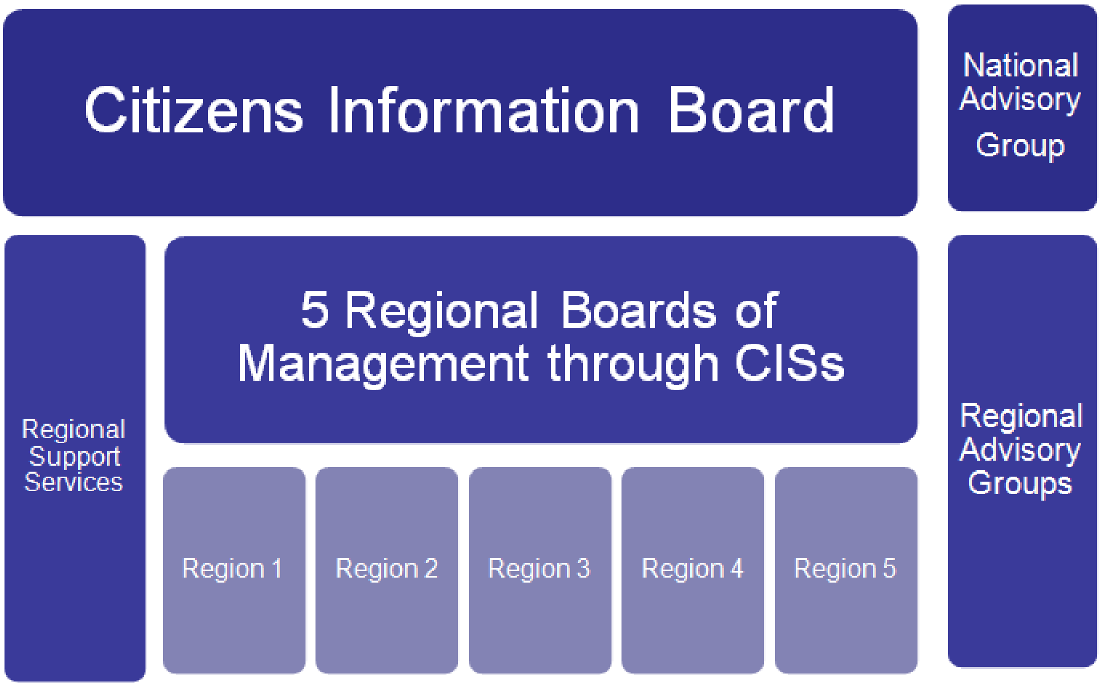

Figure 3: Structure of National Advocacy Organisation

The Citizens Information Board will retain overall responsibility for the Programme, and will seek agreement from five established CIS Boards of Management to take up responsibility for delivering the service locally in each of five regions. A director of PAS to be appointed within the Citizens Information Board and with this appointment, PAS delivery will be managed to ensure its effective use.

Each region will have responsibility for a local advocacy service comprising a team of advocates and an advocacy manager, which will be separate from the CIS information service. They will be team-based and form part of a national team providing advocacy services. They will be advised and partnered by regional and national advisory groups. They may also be supported by local fora as necessary if directed by the Regional Advisory Group. The recommended advisory groups will supplement any shortfall in knowledge, experience or influence that may be required specifically in the area of advocacy for people with disabilities.

In considering the organisational and structural aspects of the future National Advocacy Service the following components should be considered:

- Advocacy operating model
- Governance
- Strategy development and deployment.

Advocacy Operating Model

The basic operating model addresses the needs of service users, the needs of those working in the service and the needs of the stakeholders supporting or funding the service. A team-based approach within each region is proposed, delivering services locally where they are needed. Five regions are proposed.

Regional Team

A regional team led by an advocacy manager and comprising senior advocates, advocates, citizen advocacy co-ordinator and administrator.

The citizen advocacy co-ordinator, advocates, senior advocates and advocacy manager will each satisfy minimum experience and qualification requirements which will be set out as part of ongoing competency development and succession planning. Depending on the position, these will include experience and qualifications in management, disability and advocacy.

In the delivery of PAS, it is envisaged that PAS powers will be devolved to senior advocates in each of the regions for those who are eligible under the legislation and by agreement with the Director of PAS.

Advocacy Support Services and Structures

Throughout their interaction with service users, each advocate will be supported by an advocacy manager, peers, internal/external supervision and a professional network. This model ensures that advocates are no longer isolated; standards are set and maintained through peer support, management structures and professional development.

Advocates will be supported by a number of regional and national support services provided through the Citizens Information Service (CIS) network and the Citizens Information Board. The CIS network will support the advocacy teams with their expertise in information provision, governance and facilities located in selected CIS's. CIB will provide support in Information Communications Technology (ICT), human resources, financial Services, public relations, communication and promotional work.

Governance

The National Advocacy Service headed up by the Citizens Information Board will be established regionally through selected CISs. It will be managed through existing structures within the Citizens Information Board, through the CIS network and the Citizens Information Board regional management structures.

Governance through one CIS Board for each Region

The board of each selected CIS will take on responsibility for the delivery of advocacy services within a defined region. Each selected CIS board will take on the governance and employer responsibility for the regional advocacy team and these will be integrated with the services already provided by the CIS. Advocacy, however, will remain a dedicated service in its own right with each advocacy manager reporting directly to the CIS board. The CIS board will report on its advocacy service in the same way that it reports on its information, advice and advocacy services.

Regional and National Advisory Groups

Each regional advocacy team and its board will be supported by an advisory group set up to ensure the critical elements of successful advocacy provision are maintained i.e. independence protected, diversity among stakeholders created, service users reached, access achieved, change implemented and value delivered. The advisory groups will be created at both national and regional level. At regional level, they will be inter-linked by having a member of each regional advisory group join each selected CIS board. The five regional advisory groups will be linked to the national advisory group through regional representation.

The National Advocacy Service will require an operating definition of how it will conduct its work; the standards by which to assess outcomes, and a measurement system that will evaluate its success. Key components of this are:

- **Reach:** to define and establish what constitutes someone who is vulnerable, how they should be identified and reached by the advocacy service and how such service users should be prioritised while maintaining open access.
- **Independence:** to define and establish the role of independence in the delivery of advocacy so that the service users can be assured that their wishes will be respected and their interests and rights safeguarded.
- **Diversity, Collaboration and Partnership:** to define and establish how diversity, collaboration and partnership will be maintained within advisory groups and how wider collaborative relationships can be facilitated at local and national level contributing to the richness of services for service users.
- **Performance, Efficiency, Effectiveness and Quality:** to define and establish how best practice will be maintained to guarantee standards of performance and quality in the delivery of services and how outcomes will be measured to determine the effectiveness of the service.

In moving into its next phase of development, the Citizens Information Board, with responsibility for Citizens Information Service (CIS), will continue to be one of the key support agencies of representative advocacy in Ireland. It is imperative it retain a significant role within this arena. Having a national identity and renewed programme structure will enable it to build on the strength of the pilot programme.

Should the recommendations of this report be implemented, the revised national structure of advocacy will consolidate representative advocacy provision for people with disabilities, ensure a greater reach and the use scarce resources to the optimum.

It is envisaged that the new structures will make better use of the present annual funding, making possible greater equity of provision and supporting the National Disability Strategy and the State's social policy initiatives. They will also demonstrate how the public service is meeting its obligations to people with disabilities and most importantly, support and empower individuals with disabilities to be heard effectively.

1. STRATEGIC CONTEXT

1.1 Background

> ***We "share a vision of an Ireland where people with disabilities have, to the greatest extent possible, the opportunity to live a full life with their families and, as part of their local community, free from discrimination."***
>
> ***Towards 2016:33:66***

People with disabilities form 9.3% of the population in Ireland representing almost 400,000 people (Census 2006). The range of disability includes physical and intellectual disabilities, affects all age groups, can be long-term or short-term, a lifelong disability or an acquired disability. 96,000 people with a disability are unable to carry out everyday activities and a further 172,000 have a lot of difficulty in carrying out these activities. Eight percent of people with a disability live in a residential home or hospital. (CSO, 2008).[3]

As a group, people with disabilities are at a greater risk of poverty and marginalisation. While some people within this group participate in society in a similar way to those who do not have a disability, for others, there are many barriers in obtaining and maintaining services that those who do not have a disability may not encounter. In addition, some of the group are particularly vulnerable as they may be partially or wholly unable to speak up for themselves or assert their rights. They may need additional support to claim their entitlements and to make their voices heard on issues that affect their lives.

> "*What ... needs to be borne in mind.....is that vulnerable people are often afraid to complain as they fear their entitlements to services may be affected*" (NESF 2006:49).

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[3] The most commonly occurring disabilities include mobility and dexterity disability (56%); pain (47%), remembering and concentrating (35%) and emotional, psychological and mental health (34%). (CSO 2008)

Considerable advances in legislation, social policy and programmes have been made to include people with disabilities. However, despite these advances, there can be extreme marginalisation in terms of health, housing, employment and social participation. There is "a major deficit ... when comparison is made with other advanced countries" (NESC 2006:168). In addition, there are still many services provided in settings that lead to exclusion from community and family life and restrictions of life style.

> "*The societal barriers manifest themselves in a number of ways, through inaccessible environments, negative and ill informed attitudes, and exclusion from participation in social and economic spheres such as education, employment, leisure and culture"* (NESC 2009:238).

Disability is one of the key priorities in a number of key government initiatives including the National Disability Strategy (2005) and the Partnership Agreement *Towards 2016*. An important part of the Disability Strategy is the provision of independent advocacy. Notwithstanding the current economic climate, the State has reiterated its commitment to prioritising the interests of people with disabilities and implementing the *National Disability Strategy*.

> "*We will maximise the efforts of the State and the voluntary disability sector in order to deliver cost effective services that promote independence and choice for people with disabilities"* (Renewed Programme for Government 2009:19).

The government has a vision where:

> "*people with disabilities have, to the greatest extent possible, the opportunity to live a full life with their families and as part of their local community, free from discrimination"* (Towards 2016: 66).

Some of the priorities that the Government has identified in services for people with disabilities stem from obligations under the *UN Convention on the Rights of People with Disabilities*[4] and the *European Convention on Human Rights and Fundamental Freedoms.* Articles 19 and 28 of the *UN Convention* are particularly relevant. Article 19 covers the right to *live independently and be included in the community,* with an emphasis on *"choice in the matter of living arrangement and support services."* Article 28 covers the right of persons with disabilities to social protection and access to public facilities, which are among matters addressed in the Disability Act 2005 and in HSE initiatives to make care packages available to people with disabilities in the community.

Article 3 of the European Convention prohibits torture and degrading treatment, with Article 8 guaranteeing privacy and these are particularly relevant to the rights of people with disabilities. The Government has already started the process of addressing areas where its compliance with these Articles might be in doubt, through the establishment of the Health Information and Quality Authority (HIQA). HIQA plans to initiate an inspection system for residential centres for people with disabilities and through the HSE Project on *Good Practice Alternatives for People currently residing in Congregated Settings* – established in 2007 and due to report shortly.

HIQA's latest corporate plan aims to:

> *"develop coherent person-centred standards to drive quality improvements across services in line with identified priorities"* and "monitor, investigate and, where necessary and appropriate, enforce quality". (HIQA 2008)

Advocacy is particularly important in the drive to improve standards in these areas in a person-centred way. In other countries, advocacy support has been put in place for residents moving from institutions to community based accommodation and a number of the current Community and Voluntary Projects have concentrated on this area.

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[4] Ireland signed the *UN Convention on the Rights of People with Disabilities,* but has not yet ratified it.

Advocacy is also needed if vulnerable residents with disabilities are to understand their options, make informed choices and process complaints to inspection teams.

In 2006, the National Economic and Social Forum (NESF), in its publication *Improving the Delivery of Quality Public Service*, states that public service providers need to adopt a '*case management approach*' to service delivery, whereby the needs of the service user are assessed; the services and supports required to address these needs are identified; and the services are secured. The provision of an *'advocate'* who can '*cut through the bureaucracy*' and help people '*navigate the system'* to help them draw down the range of services they require is essential. Advocacy services have an important role in assisting more vulnerable people to access their rights and entitlements.

Advocacy has become a key element in any move to promote independence and choice in the lives of those who are marginalised. Advocacy can be defined as a process of enabling people to have a voice about matters of concern to them. *"The use of Advocacy should not be about overcoming inadequacies in the system"* (NESF 2006:110), but rather to empower people by supporting them to assert their views and claim their entitlements and, where necessary, represent and negotiate on their behalf. One element of advocacy is the provision of an independent and skilled person who will assist people to discover and state their needs, alert them to possible options and put them in touch with services. The role of the professional advocate ensures that the views and perspectives of the person with a disability are expressed. Advocacy is a demanding role and there are complexities and dilemmas attached to advocacy practice. Advocacy and support for advocacy-based approaches should be a long term policy requirement, particularly for vulnerable groups.

The Citizens Information Board provides independent information, advice and advocacy on public and social services. Since its establishment as a statutory body under the Department of Social and Family Affairs in 2000, the Board has been involved in advocacy in the mainstream context of Citizens Information Services (Comhairle Act

2000). The Disability Act 2005[5] requires six government departments to prepare Sectoral Plans. In its Sectoral Plan, the Department of Social and Family Affairs prioritises a number of initiatives to support access for people with disabilities. These include supporting the Citizens Information Board's *Programme of Support for Community and Voluntary Sector Advocacy* and the introduction of the Personal Advocacy Service. Within its range of public services, the Citizens Information Board provides a Programme of Advocacy Services for People with Disabilities in the Community and Voluntary Sector. Through this programme, the Citizens Information Board has worked with community, voluntary and disability organisations to develop forty six projects employing advocates to deliver advocacy services to people with disabilities. This document reports on the evaluation of the Citizens Information Board's programme of Advocacy Services for People with Disabilities in the Community and Voluntary Sector.

1.2 Advocacy

> ***"Advocacy is a means of empowering people by supporting them to assert their views and claim their entitlements and where necessary representing and negotiating on their behalf. Advocacy can often be undertaken by people themselves, by their friends and relations, or by persons who have similar experiences. Delivering a professional advocacy service means providing a trained person who, on the basis of an understanding of a client's needs and wishes, will advise and support that client to make a decision or claim an entitlement and who will, if appropriate, go on to negotiate or make a case for him/her"***
>
> ***Citizens Information Board, 2007***

People with a disability often need support in standing up for themselves. Advocacy is a means of supporting someone to speak for themselves or pleading on their behalf.

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[5] Part 3, Disability Act 2005

Advocacy is a widespread activity, delivered informally by parents, relatives, neighbours friends and professionals. In its more formal setting it has been defined as

> *"...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 individuals' or groups, in a fashion which strives to be emphatic and vigorous."* (Goodbody, 2004:5)

It is important to distinguish advocacy from information giving, offering advice and social work. While information is an important aspect of the advocate's role, it is the empowering of the service user to access or use the relevant information which distinguishes that role. While the advocates may occasionally take on some of the tasks of a social worker, they differ through their independence of service providers and through the fact that their involvement, while intensive, is not ongoing.

The basic principles of advocacy enunciated by *Developing an Advocacy Service for People with Disabilities* are as follows:

- **Empowerment:** providing people with a disability, the support necessary to make their own decisions and choices, enabling them to have more control over their lives.
- **Autonomy:** advocacy plays a key role in enabling people to make informed choices about, and to remain in control of, their lives.
- **Inclusion:** inequalities in access and opportunity can lead to isolation. Advocacy can help to increase all levels of access, thus offering equal opportunities to people with disabilities.
- **Citizenship:** advocacy can protect the rights and privileges that should be available to all citizens within a society. It fundamentally identifies, promotes and defends a person's basic human rights.

Advocacy provision in Ireland is rich and diverse. It is delivered through a variety of settings and in many forms, including self-advocacy, peer advocacy, family advocacy, group advocacy, citizen advocacy and professional advocacy. The distinction between legal and social advocacy and/or individual and systemic advocacy can be artificial as in many cases they operate on a continuum.

- ***Self Advocacy*** occurs when people are empowered to speak for themselves. Depending on the level of disability it is not always possible and the service user may need the support of other forms of advocacy.

- ***Peer Advocacy*** occurs when someone in a similar situation or with a similar experience, acts as advocate for another. Peer advocacy is a feature of advocacy in the mental health arena. Knowledge of relevant systems and past experience can make peers informed and powerful advocates.

- ***Family Advocacy*** where a family member acts as Advocate for an individual. This is often where a person with disability finds their first and key Advocate.

- ***Group Advocacy*** is a form of self-advocacy where individuals act collectively to achieve a shared goal. It can be particularly empowering for less confident individuals, and has some overlap with peer advocacy where group members may have some experience of advocating.

- ***Citizen Advocacy*** involves unpaid volunteers who work with vulnerable individuals. It is an ongoing relationship and strong friendships can develop. The impartiality of citizen advocates is particularly valued as enhancing the independence of advocacy. Citizen advocates can act as supportive enablers or can speak up for those without a voice.

- ***Professional Representative Advocacy*** involves advocates who are paid to provide a service, until a specific problem is resolved or can be taken no further. Professional representative advocates can deal with very complex issues.

Each of these types of advocacy play an important role in enabling the person with disability to access his/her rights. At particular times and in particular circumstances within the life cycle of the individual, one or more of these advocacy types may be needed.

The main focus of the Programme of Advocacy for People with Disabilities is representative advocacy. A small number of projects within the programme use the citizen advocacy model. The Department of Health & Children resources the Irish

Advocacy Network (IAN) to provide a peer advocacy service within some psychiatric hospitals.

1.3 The Development of Advocacy in Ireland

> ***"Advocacy which has always existed in human relationships is a process of empowerment and can take many forms. It is a way of enabling those who may have difficulty speaking up for themselves to do so and thus can be key to involvement in decision-making. It generally means representing the view of a person or supporting them to exercise or secure their rights"***
>
> ***Comhairle 2001:13***

Advocacy, in the broad sense, is a traditional concept, linked both to the individual's right to speak up for him/herself and to the societal notion of the citizen taking responsibility not just for him/herself, but also for his/her neighbour. The link between information and advocacy forms the rationale for the Citizens Information Board's involvement in this area, given that its mission is:

> *"to ensure that individuals have easy access to accurate, comprehensive, integrated and clear information on social services and to assist individuals, including those with disabilities, to identify their needs and access their entitlements to social services"* Comhairle 2001:3

When the Citizens Information Board was given the statutory responsibility to develop advocacy for people with disabilities, the Government's rationale was that the Board had the capability of delivering an unbiased service to people with disabilities. Underpinning this rationale was the Board's organisational independence, in terms of funding and influence, from health and disability service providers in both the statutory and voluntary sector. Disability organisations saw this as important, especially against the background of the contentious atmosphere surrounding the first Disability Bill (2001). This Bill, published in December 2001 met with widespread concern and criticism and was subsequently withdrawn by the Government with a revised Disability Bill (2004) published after an extensive consultation process.

Advocacy comes in many models with the underlying common principles of empowering people to speak up for themselves and providing unbiased representation to vulnerable people who cannot do this on their own. In its early years, the Citizens Information Board put its main emphasis on working with Citizens Information Services (CIS) to ensure accessible information was available to all citizens, particularly those who are marginalised. In its first Strategic Plan (2001-2003), the Citizens information Board stated that "*where necessary, the information service will be supported by an advocacy service*". (Comhairle 2000:15) Following the Report of the Commission on the Status of People with Disabilities, *Strategy for Equality* (1996), there was a concerted effort at official level to prohibit discrimination and to mainstream services for people with disabilities. It was envisaged that this would result in an increased number of people with disabilities using Citizens Information Services and other mainstream services. However, this did not happen to the expected extent and led to a demand for independent advocacy, particularly for the assessment of need process which was to be introduced under the disability legislation.

People with disabilities saw independent advocacy as crucial to enable and assist them to claim the services they required. The demand for the provision of advocacy for people with disabilities emerged from the sector through reports from the Commission on the Status of People with Disabilities (1996), the Establishment Group *Building a Future Together* (1998) and the Forum for People with Disabilities (2001) *Advocacy: A Rights Issue*. These reports reflected the aim that services for people with disabilities should be mainstreamed as far as possible. The Disability Bill 2001 (later withdrawn and replaced by a revised Bill that became the Disability Act 2005) considered the issue of advocacy services in some detail committing personal advocates *"to provide help and support....to qualifying people with disabilities for assessment of needs....or for other public services" (Disability Bill 2001 – Explanatory Memorandum p5)*.

The Department of Health and Children had also set out its policy on advocacy within the context of mental health in its Health Strategy - *Quality and Fairness* (2001), stating *"in terms of the principle of people-centred health services, the strengthening of Advocacy Services is a priority.*" (Dept of Health & Children 2001:147)

In the launch of the National Disability Strategy in 2004 the then Taoiseach Mr Ahern outlined the integrated Government response to include a "*series of actions that would involve:*

- *Laws to protect against discrimination, but also the provision of services and supports to make inclusion and participation a reality;*
- *Ensuring that people with disabilities are not excluded from education, employment and social activities by attitudes and procedures that (are now considered) unacceptable;*
- *Recognising that many impairments were turned into disabilities by a physical environment that was not accessible;*
- *Maximising independence and self-reliance; and*
- *Integration in the mainstream wherever possible, and minimum segregation where necessary."* (Speech at the launch of the National Disability Strategy, An Taoiseach, 2004)

Prior to 2005, a number of reports were commissioned by the Citizens Information Board on the development of advocacy namely:

- *Developing Advocacy Services – a Report on the Regional Fora, (2002)* – the Regional Fora Report
- *Findings of the Joint Comhairle/Citizens Information Centres (CIC) Working Group on Advocacy* (2002)
- *The Jigsaw of Advocacy,* Comhairle (2003) – (Weafer Report)
- *Developing an Advocacy Service for People with Disabilities*, Goodbody Economic Consultants (2004) – (Goodbody Report)

The Regional Fora Report detailed the consultation with community and voluntary groups in 2001. The *Joint Working Group* report dealt with advocacy as delivered to everyone through the CIS network and considered ways of strengthening that delivery. In 2003, the Weafer Report analysed concepts of advocacy and values implicit to it within the context of disability and of practices and policies developing nationally and internationally, with a view to the development possibilities open to the Citizens Information Board following the emergence of the expected disability legislation.

In 2004, through consultation with a range of Irish stakeholders and substantial research on advocacy services abroad, the Goodbody Report identified and examined the components of an advocacy service that would meet the needs of people with disabilities in Ireland. The purpose of the Goodbody Report was to:

- Identify an advocacy service that would best fit the needs of the Irish system;
- Set out a strategic framework for establishing and developing an advocacy service;
- Estimate its cost;
- Identify funding and accountability structures that would guarantee independence, and
- Set out a five year programme to implement the strategic framework identified.

In anticipation of the expected legislation on advocacy, *Developing an Advocacy Service for People with Disabilities* recommended that the Citizens Information Board adopt a three strand approach to advocacy, incorporating:

- Personal Advocacy Service (PAS)
    - This service to be set up on a paid professional basis to deal with critical and complex advocacy issues only. Its focus would be on assessment of need, access to services, complaint mechanism and delivery and operation of services targeting the most vulnerable of cases.
- Support Programme for the Community and Voluntary Sector
    - This service to focus on the provision of individual advocacy services, employing a range of delivery models.
- Community Visitors Programme
    - This service to focus on people with cognitive disability in residential institutions, to be established on a volunteer basis, overseen by a central and regional support structure.

It was agreed, following this report, that two main streams would be concentrated upon: the immediate establishment of the Advocacy Programme for People with Disabilities in the Community and Voluntary Sector (Strand 2) and the preparations required to initiate the Personal Advocacy Service (PAS) (Strand 1). Both of these strands were complementary as it was always envisaged that Community and Voluntary Sector advocates would refer the most vulnerable and complex cases to the PAS.. In 2007 the Citizens Information Act was passed but PAS, as set out in the Act, was placed on hold in 2008 due to lack of resources.

Goodbody recommended that Strand 2 be initiated two years before commencement of the Personal Advocacy Service. The rationale underpinning this recommendation was, firstly, to explore demand for the service at a local level and, secondly, to involve disability organisations, while safeguarding independence. The report also recommended that the Citizens Information Board should hold the budget and have an overall lead role in monitoring the development of the programme and advising the government on resource organisation in this area.

The Personal Advocacy Service set out in the Disability Bill (2001) was omitted from the Disability Act (2005), but was included in the separate Citizens Information Act (2007). This legislation gave the Citizens Information Board statutory responsibility for the development and delivery of advocacy services specifically for people with disabilities. The Personal Advocacy Service was intended to deal with more complex and intractable issues and to, work with the most vulnerable people.

The Community Visitors Programme (Strand 3) has not been developed to date. The establishment of the Health Information and Quality Authority (HIQA) which has introduced guidelines for the accreditation of a range of residential services, along with increased supervision of nursing homes by the HSE means that this programme may be reconfigured. In 2009 the HSE started advocacy within some nursing homes through a Volunteer Advocacy Service for Older People in Residential Care.

Following the recommendations emerging from *Developing an Advocacy Service for People with Disabilities* (2004), the Citizens Information Board established an Advocacy

Programme for People with Disabilities in the Community and Voluntary Sector (Strand 2) on a phased basis between 2005 and 2007. A number of reasons underpinned the rationale for this development. There was considerable expertise and interest in the disability sector and it was important for the Citizens Information Board, that there was a cohesive partnership with disability groups in the development of this Programme. This pilot programme was subject to less constraints than would have been the case with the set-up of the Personal Advocacy Service, so funding could be disseminated to projects and advocates employed relatively quickly. Forty six projects were established across the country. Initially, this was a pilot programme for three years, but in 2008 this was extended to five years in order to give an enhanced period for learning and development. As a key component in the delivery of several of the objectives laid out in the *Citizens Information Board Strategy 2006 to 2009*, the Citizens Information Board required a full review of the programme, its effectiveness and its impact. The findings from this evaluation will be used in assessing the future of the programme beyond 2010 when the pilot funding is due to expire.

In 2004, the Citizens Information Board began the process of engaging with the community and voluntary sector in order to develop advocacy provision. The proposed programme was highly innovative, representing a new initiative by a state agency. In 2005 and 2006 advertisements were placed seeking expressions of interest from organisations representing people with disabilities, from service providers in the voluntary sector and from partnership groupings. Regional information seminars were held, providing information on:

- The Citizens Information Board's approach to advocacy;
- The legislative framework;
- The supports available;
- The standards required, particularly in terms of independence;
- The review of learning and development from the programme, and
- The evaluation to take place.

Each year, a number of projects were chosen for three year funding (later extended to five) on the basis of their capacity to employ an advocate and reach a service user grouping specified by them. By 2007, the Citizens Information Board had become aware of gaps in the programme's coverage, and in advertising for new projects, targeted geographical areas where none existed. The Citizens Information Board prepared the document, *Advocacy Guidelines,* to support projects with their work and also provided training days for Advocates each year. It collaborated with Sligo Institute of Technology to develop a distance learning qualification in advocacy.

At the beginning of the programme, consideration was given to establishing the service through the CISs around the country. However, because advocacy was still in its infancy in Ireland, and not widely understood, it was felt that a wider partnership would capture more effectively the different strands within the disability sector during the pilot phase and give greater and quicker access to people with disabilities.

Under the present programme, the 46 projects have provided representative advocacy to upwards of 5,000 service users since they began. The projects are hugely diverse covering a wide range of disability groups, including people with physical/sensory disabilities, people with intellectual disabilities and people with mental health issues. Each of the projects employs an advocate to meet the needs of their service users. There is a significant, but not complete, geographic spread, with most projects based in the community and a smaller number serving service users in residential centres.

The partnership approach during the pilot phase has created a solid foundation for advocacy in Ireland and the strength of this foundation will support new structures and decisions in the post-pilot phase of the programme.

1.4 The Programme of Advocacy Services for People with Disabilities in the Community and Voluntary Sector

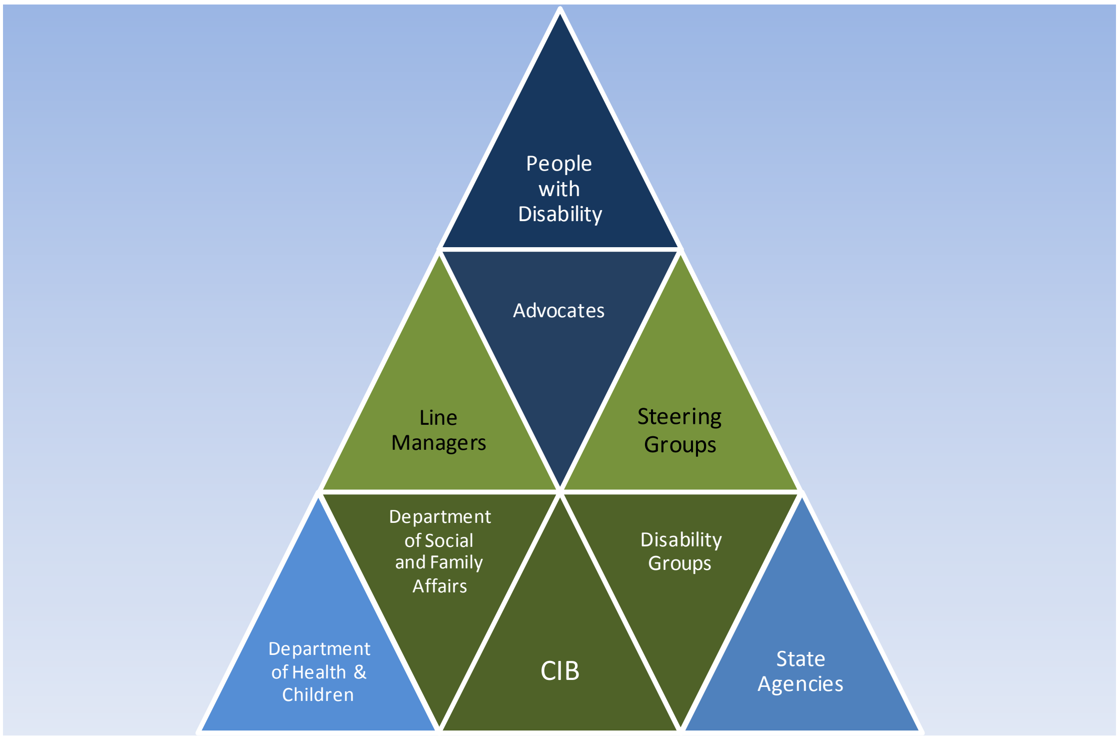

Figure 4: Supporting Structure

Supporting Structures of Advocacy

When the service user seeks support from the advocate, his/her relationship with the advocate is central to this support and for the service user there is no sense of the wider structure of the advocacy service.

Supporting the advocate's work are the line manager, lead agency and steering group. Advocates reported varying experiences in their interactions with their line managers.

The relationship with line manager and steering group is extremely important in the delivery of service. In addition, it is important that the line manager has a good understanding of advocacy and disability to ensure good service delivery.

There is also evidence of diversity as between lead agencies; some successfully managing the independent delivery of the advocacy service, while others were inappropriate for the task. This is a critical factor in the successful delivery of advocacy and its ability to be independent.

The composition of the steering group and its effectiveness are also important to the success of the advocacy service, particularly as regard to diversity of the group. Clear differences emerged in the governance, composition, structure and process among steering groups, which impacted on the delivery of advocacy in different projects.

At a national level, the three key stakeholders enabling the delivery of service are the Department of Social and Family Affairs, the Citizens Information Board and disability groups.

The partnership between the Citizens Information Board and disability groups was considered very important in the development of the Programme. There was consistent reporting from stakeholders that the Advocacy Pilot Programme has strengthened this partnership through the delivery of advocacy and that the Citizens Information Board is best placed to continue to deliver advocacy services.

The Citizens Information Board is responsible for ensuring that effective corporate governance is in place for each project operating within the programme and that there is adherence to guidelines laid down for projects. All stakeholders involved in the delivery of advocacy agree to be bound by the principles that underpin advocacy including empowerment and inclusion of the service user, independence of the advocate, diversity among stakeholders, reach to those most vulnerable and ultimately that service users' lives are enhanced through being enabled to choose and assert their rights.

The ability to reach and advocate on behalf of the most marginalised people in society is a key objective and justification for the Advocacy Programme. Ongoing evaluation of how this is being achieved, any barriers preventing it and how advocacy can be further enhanced is an important part of any future programme of advocacy.

Independence has been central to the delivery of advocacy since its inception. It is the central premise upon which an advocate can claim to speak for or represent a service user. The question of independence is a complex one and has been interpreted in different ways over the course of the pilot programme. The role of independence, its varying definition and the need to protect it, must be clearly articulated if advocacy in its current form is to be or to remain true to its original objectives.

The role of the advocate, clarity of purpose and the principles of engagement with all stakeholders are central to the provision of a professional, quality service to service users, or in the case of citizen advocates, critical to the development of a trusting and long-term relationship. Understanding the differing experiences that have emerged throughout the pilot phase and the resulting learning is important in ensuring that service users' needs are met, that those most vulnerable are reached and that the appropriate service is available nationally to those who require it.

Many new partnerships have been established among stakeholders that heretofore did not exist. The ability of these partnerships to achieve outcomes for service users, while generating value for the stakeholders involved, is important when seeking a commitment of time, energy and resources in consolidating this Advocacy Programme for People with Disabilities. Understanding how effective this has been is important in designing the partnerships and practices that are required to ensure any new advocacy programme is sustainable.

Understanding the need for diversity, its role and how it should be underpinned is critical to the future of the Advocacy Programme.

The constitution of steering groups, their mission and their role in the provision and support of the advocates and line-management is an important part of ensuring advocacy is delivered as intended by the Citizens Information Board. Governance, project performance, quality of service, support to line management, promotion and cross referral, project focus and advocate support are all elements intended to be within the remit of steering groups. Providing a better understanding of where this has been effective in adding value is central to planning the future role of advisory groups within the programme.

The effectiveness of project management practices and processes in the delivery of advocacy are impacted not only by the methods, policies and agreements agreed between line manager and advocate but are also impacted by the way in which the various roles, particularly that of line manager and advocate are set up in the first instance. While these relationships can mature and change over time, structural considerations play a significant role in the dynamic that is created and the resulting outcomes. Understanding what can be learned from the pilot phase in defining the relationships that must exist to ensure advocacy delivers value, is critical to the future of the programme.

The role of strategy is an important one as it provides context and direction, clearly articulating the intended outcome of any programme. Considering the need for a clearly defined strategy and structures needed to implement its strategic intent are a significant part of what this evaluation must consider. This includes the need to understand where value is being created for service users; where certain structures enable value and where others do not; and ultimately where those who need to have a stake in the delivery of these services are recognised in order to sustain the value of the service nationally.

The strategic approach of the Citizens Information Board is determined by its legislative brief.[6] Defined advocacy strategy must give effect to the legislative brief in the context of the current economic crisis and its ramifications. In consolidating the advocacy

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[6] Comhairle Act (2000), S7

programme into the future, there is a need to consider how structures and services can be provided within the current economic climate.

Any Strategy that emerges must consider:

- How simple and complex cases are dealt with.
- The likely demand for advocacy.
- What can be mainstreamed through Citizen Information Services (CISs).
- The capacity of the current advocacy resource base.
- How advocacy can be utilised to its maximum benefit for service users.
- How balance between advocacy and empowerment can be achieved.
- How one group of marginalised citizens can be supported to assert their rights while concurrently ensuring they gain no unfair advantage over another.
- Ways in which findings and feedback of the programme are used to effect change in order to prevent issues occurring in the first instance.

At present, advocacy within the Community and Voluntary Sector Programme is focused on representative advocacy at an individual level, is largely issue-based and is still evolving. For this reason, it is critical that for the stage at which this programme exists in the evolution of advocacy, that it has a clear understanding of:

- what advocacy is,
- what it is aiming to achieve,
- how it can be achieved and
- how it will continue.

....in essence, a clear strategy.

1.5 The Personal Advocacy Service – the Legislative Context

In 2007 the Citizens Information Act was passed. Section 4 amends the Comhairle Act 2000 with regard to an expansion of the role of the Citizens Information Board to advocacy for people with disabilities beyond its remit of mainstream information, advice and advocacy. In 2008, the implementation of PAS was placed on hold due to lack of government resources. As a result, the Sections of the Citizens Information Act (2007) relating to the Personal Advocacy Service have not been implemented to date.

The provisions of the PAS, as expressed under the legislation, stipulates that the Citizens Information Board provides, or arranges to provide, a personal advocacy service.[7] This provision is subject to public finance and whether the qualifying person can obtain advocacy services otherwise than under the Act.[8]

The legislation recognises the need for Personal Advocates to have relevant qualifications, experience and expertise[9]. The role of the personal advocate is to assist, support and represent the qualifying person with disability in the Assessment of Need process; in obtaining social service or services and to pursue a review, reference or appeal to a body other than a court.[10] The Personal Advocate is entitled to enter premises, access information, attend meetings and consultations, and identify relevant family members who may assist the person with a disability.[11]

The legislation envisages that the Citizens Information Board can decide how the personal advocacy Service would be made available to those who have a disability. Not all people with disability require the assistance of an advocate. For those who do, the vast majority will be assisted through mainstream information, advice and advocacy services and through the Community and Voluntary Programme Advocacy Service for people with disabilities. The legislation envisaged the PAS as targeting those who are

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[7] S4 (a) Citizens Information Act 2007

[8] Ibid.

[9] S5 Citizens Information Act 2007, amending the Principal Act under section 7A (2)

[10] S5 Citizens Information Act 2007, amending the Principal Act under section 7D

[11] Ibid.

most vulnerable particularly in relation to the proposed Assessment of Need and other formal complaint and review projects. This “most vulnerable” sector includes people with very significant levels of disability, those in residential centres, particularly those who are inappropriately accommodated, those who are socially isolated and those with limited communication skills.

The Citizens Information Act [2007] sets out criteria for a person to qualify for the Personal Advocacy Service[12]. These are

- The Person is not less than 18 years of age and in the opinion of the Director of Advocacy
    - Is, by reason of their disability, unable to obtain or has difficulty in obtaining a particular social service or services without the assistance or support of a personal advocate; and
    - There are reasonable grounds for believing that there is, in relation to the person, a risk of harm to his or her health, welfare or safety if he or she is not provided with the social service or services that he or she is seeking to obtain
- The Person is under 18 years of age and
    - his or her sole parent or guardian is a qualifying person

      or
    - He or she has a disability or in the opinion of the Director, there are reasonable grounds for believing that he or she has a disability, and in either case the circumstances are such that it would be unreasonable to expect a parent or guardian of the person to act on his or her behalf in obtaining a particular social service or services without the assistance or support of a personal advocate.

      And in the opinion of the Director there are reasonable grounds for believing that there is, in relation to the person, a risk of harm to his or her health, welfare or safety if he or she is not provided

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[12] S5 Citizens Information Act 2007, amending the Principal Act under section 7A (3)

with the social service or services that he or she is seeking to obtain.

The legislation also sets out the criteria to be considered when determining priority for cases within the Personal Advocacy Service[13]. These are:

- The needs of the qualifying person
- The degree of risk of harm to the health, welfare or safety of the qualifying person if they are not provided with the social service or services that they are seeking to obtain
- The benefits likely to accrue to qualifying persons if personal advocates are assigned to them.
- The availability to qualifying persons of other Advocacy Services

The legislation does not prescribe how the Personal Advocacy Service will be provided, but rather devolves this function to the Citizens Information Board.

In the absence of the implementation of the legislation, some of the most vulnerable people in our society cannot avail of advocacy services.

1.6 Scope of the evaluation

With the implementation of Strand 2 of *Developing an Advocacy Service for People with Disabilities* (Goodbody, 2004) there are now 46 projects delivering Advocacy to people with disabilities across Ireland. The projects:

- are diverse in nature;
- have developed independently of one another, under the guidance of CIB;
- consist mainly of representative advocacy;
- cover a wide (but incomplete) geographical range, and

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[13] S5 Citizens Information Act 2007, amending the Principal Act under section 7A (5)

- have different dynamics.

Round Table Solutions and PathFinder were appointed by the Citizens Information Board to carry out the evaluation of the Programme of Advocacy Services for People with Disabilities in the Community and Voluntary Sector. The focus of the evaluation is to consider the impact of the advocates' work and that of their projects on the lives of people with disabilities and the form that the overall advocacy programme should take beyond the pilot phase in 2010.

The evaluation is the result of a programme of work undertaken from January to December 2009 and additional research undertaken from January to April 2010. The evaluation was carried out in conjunction with advocacy projects, the Citizens Information Board and other stakeholders and the evaluation is based on this research and is contained within this report.

This evaluation serves as an input into the future strategic design of the advocacy services as intended by legislation and required by those with disabilities.

The evaluation focuses on two main areas;

- Case Review and Analysis
- Structural Review and Assessment

The final output makes recommendations on:

1. the scope, focus and level of the advocacy work undertaken and the outcomes for people with disabilities using the services.
2. the geographical spread and reach of the programme.
3. the appropriateness of the lead agencies involved and their level of independence.
4. the governance and support structures including the effectiveness and sustainability of the steering group.

In addition, there is an identification of the resources required to support the development in line with recommendations and the proposed future plan, while maximising the utilisation and competencies of current resources.

The evaluation team evaluated a number of critical elements at programme level and case-management level including.

- ***Structures, processes and practices*** in place across the range of projects in the programme, involving all aspects of required practice in governance, referral processes, involvement of stakeholders, line management and other supports and quality of service provided.

- The ***effective use of resources***, matching available capacity to the demand.

- The ***outcomes achieved*** as a result of the resource allocations made.

- ***Geographical spread and the level of reach***, especially out to those who are more vulnerable in isolated areas and those in residential care.

- The ***sustainability of current steering group design*** particularly the involvement of a diverse range of relevant groups.

- The ***role of the Citizens Information Board in the provision of supports*** such as standards, training, networking and direct involvement in steering groups.

- ***Specific cases where progress will be tracked and assessed***, including the nature and quality of advocacy interventions, referral processes, the nature and extent of liaison with other services/agencies in respect of individual users, management of cases, including closure and most importantly, the actual outcomes for individuals using the advocacy service.

The strategic approach to the evaluation was twofold, considering the parallel streams within the projects of:

- **Case analysis**: cases selected across the projects, representative of all types of service user, reflecting the complexity of the cases in order to determine the effectiveness and efficiency of the advocacy service.

- **Programme evaluation**: concentrating on the structures, processes and practices within the projects in line with the Citizens Information Board requirements.

The findings from the evaluation will inform the recommendations to the Citizens Information Board on moving forward the Advocacy Programme for People with Disabilities in the Community and Voluntary Sector on completion of the pilot projects in 2010.

2. GENERAL APPROACH AND METHODOLOGY

2.1 Introduction

This section describes the evaluation process and the methods employed to carry out the evaluation. It sets out the approach, the research objective, sampling and ethical considerations.

In this evaluation, the team set out to examine and evaluate the Citizens Information Board funded Programme of Advocacy Services for People with Disabilities in the Community and Voluntary Sector. It was important to do so in an organisational context that would provide a rich setting for examining the programme structure and analysing cases associated with the delivery of advocacy services for people with disabilities. Furthermore, the evaluators addressed associated issues with a multiplicity of participants. This enabled the evaluators to gain a perspective that provides a strong basis for understanding the many aspects of advocacy delivery to people with disabilities.

2.2 Evaluation Methodologies

The evaluation is characterised by a plurality of research methods that enabled the evaluation team to understand the structures and work of advocacy, the diversity of provision and the impact on service users.

Documentation

The evaluation team carried out a review of all relevant information and documentation and gained an in-depth understanding of the high-level make-up of the programme including projects, stakeholders involved, up to date guidelines, policies, performance reports and project evaluations. The documentation provided a rich source of data. It enabled the evaluation team to build an in-depth view of the plan and approach to both the case analysis and the wider programme review.

Interviews

Interviews were an essential source of information in this evaluation. Interviews were held with a large group of stakeholders. The interview process enabled the team to access participants' views, experiences and interpretations of the pilot phase of the advocacy programme. Several different types of interviews were used in this evaluation:

- Open-ended interviews focused on a conversation with the interviewee to ascertain and understand his/her experience and reflection on events and actions.
- Structured interviews that followed an organized set of questions.
- Semi-structured interviews that dealt comprehensively with a set of critical issues and questions, and also provided an opportunity for the interviewee to divert into unforeseen areas.

Case Studies

A central premise of this evaluation was the analysis of advocacy through case study. The case study method allows for an in-depth understanding of advocacy and its context. The case studies enabled the team to describe and analyse the experiences within advocacy and to evaluate processes and outcomes. The analysis of multiple case studies within four different categories enabled a cross-case analysis and comparison within diverse situations.

2.3 Data Collection

The evaluation was a longitudinal study carried out throughout 2009. As such it was important to collect data in a number of forms and at a number of levels in order to get an in-depth understanding of the pilot phase of the Advocacy Programme for People with Disabilities in the Community and Voluntary Sector.

The evaluation approach had four phases:

  - Phase 1: Information Review and Preparation
  - Phase 2: Setup, Design and Planning
  - Phase 3: Case Analysis and Programme Evaluation
  - Phase 4: Report & Recommendations

The evaluation combined a number of different methodologies in order to best evaluate the organisation, capture events, monitor change and identify issues from the perspective of people within the organisation and those using the services.

Documentation Review

Documentation reviewed, fell into four different categories:

- Published reports produced by or on behalf of the Citizens Information Board covering advocacy, in particular:
  - *Developing an Advocacy Service for People with Disabilities Volumes 1 & 2 (International Research Papers)* – Goodbody Economic Consultants
  - *Advocacy Guidelines (Revised Edition, 2007)* Citizens Information Board
  - *Jigsaw of Advocacy 2003,* Weafer Associates

- National and international literature on advocacy, in particular
  - Reports and policy submissions from Disability Groups

- Irish and international legislation and strategies, in particular
  - Citizens Information Act (2007)
  - Disability Bill (2001)
  - Disability Act (2005)
  - National Disability Strategy (2004)
  - UN Convention on the Rights of People with Disability (2006)

- Internal Citizens Information Board and project Reports, in particular
    - Citizen Information Board Strategy Plans
    - *Advocacy Resource Pack,* 2008, revised 2009, CIB in-house publication
    - Annual Reports from each of the projects
    - Submissions from various projects on advocacy practice

Case Review and Analysis

The evaluation looked at cases from a number of perspectives. From the 46 projects, all cases open during the period July 2007 to February 2009 were evaluated. 2,400 cases were analysed. From this group, 200 cases were selected for in-depth analysis. There was a case return of 82%. In line with data protection criteria, each of these cases was anonymised to protect the identity of the service user. 50 cases were analysed for the interim finding stage of the report, with at least one case from each of the projects. The balance of cases was subsequently reviewed. Parallel to this, 20 live cases were tracked where the evaluators met with service users, advocates and line managers. Permission was sought from each service user to analyse the case and to hold an interview.

Inventory

Each project submitted an inventory of cases that were open between July 2007 and February 2009. Details requested for each case were:

Gender	**Age**
County of Residence	**Type of Disability**
Residential/Community	**Urban/Rural Location**
Main Advocacy Issue	**Secondary Advocacy Issue**
Date Case Opened	**Date Case Closed**

Figure 5: Details requested in the Inventory of Cases July 2007-February 2009

This inventory produced details of 2,400 cases from across the projects. This enabled the evaluation team to build up a nationwide profile of advocacy within the programme.

Case Review

From this inventory, a random sample of one case per project was received for evaluation. This random selection provided a range of cases that fell into three categories – high complex cases, complex cases and low complex cases, with the majority of cases in the mid range of complexity.

Each project was requested to submit a further three cases. Of these three cases, the advocate was required to submit one case from each of the categories below:

- A case that had recently opened
- A case that had recently closed and had taken a considerable time
- A case that the advocate believed best represented the complexity of advocacy.

The advocate was requested to forward all documentation concerning the case. In the subsequent analysis of cases, on average three further cases were reviewed from each of the 46 projects.

In summary, case data was collected through five different channels:

- Initial cases selected randomly from the inventory of cases submitted
- A recently opened case during the month of September 09
- A recently closed case that took considerable time to complete
- A complex case which the advocate thought best demonstrated the complexity of advocacy.
- Live cases in which the evaluators worked with the service user and the advocate.

Live Cases

Twenty cases were selected across a wide geographical range, representing diverse projects. The reports on these cases were evaluated and the evaluators held in-depth face-to-face interviews with service users, advocates and line managers. These live cases were geographically spread across the country and across different types of projects.

Selection of the Projects

There were a number of important considerations, from a structural point of view, in choosing the sample of projects to evaluate. The goal was to select projects that would offer a range of learnings that were a result of their differences, not their similarities. In making the selection a high level assessment was made on the several key factors inlcuding:

1. ***The level of independence:*** Projects selected with a spread from low to high levels of independence based on any of the following conditions; the employer is involved in service provision to the target service user base, the line manager is an employee of the service provider; the steering group is made up of members of the service provider.

2. ***The level of governance in place*****:** Projects selected with varying degrees of governance. This would include meeting and reporting practices, policies, previous experience and response, role of chair and clarity of purpose.

3. ***The diversity among stakeholders involved***: Projects selected with a spread of diversity among their steering group members and contact with wider stakeholders.

4. ***The influence of line management*****:** Projects selected where there is a range of the level of influence or involvement of the line manager from 'low to high'.

5. ***The level of partnership and collaboration*****:** Projects selected where collaboration and partnership levels vary from 'fair to good' as measured by the level of activity between organisations that would not have interacted to the same degree previously.

6. ***The involvement of service users*****:** Projects selected where service users are members of the steering group and projects where they are not.

7. ***The level of reach to those most vulnerable offered by projects*****:** Projects selected whose success in reaching vulnerable service users ranges from 'low to high'.

A qualitiative and quantitative assessment was made to assist the selection. A shortlist of seventeen projects was drawn up. A number of qualitative criteria was used in the further refinement of the selected projects, resulting in a final selection of eight projects. The criteria used to refine the selection and to ensure an acceptable spread of projects can be seen in the table below. The detail of the selected projects is not included in order to protect confidentiality.

Criteria	Choices
The Lead Organisation	CIS, CIL, Partnership, Association or Service Provider.
Location of the project	Urban / Rural
Footprint of the project	Countywide, multiple counties, local.
Breadth of the project	Cross-disability, specific disability.
Disability Type	Intellectual, Physical & Sensory, all, specific.
Reach of the project	Most Vulnerable.
Setting of the project	Residential, Community.
Type of Project	Representative Advocacy, Citizen Advocacy.
Steering Group	Diversity, Governance, Partnerships, Service User Involvement.
Project	Level of Independence.

Figure 6: Criteria considered in selection of projects

The chosen projects represent an acceptable spread across location, disability type, setting and steering group type. The eight projects provided an acceptable group from which to draw conclusions based on repeated patterns across each. The selection was made to include a good mix between those meeting different criteria. The selection of projects was finalised and each was engaged. The projects were evaluated at steering committee level; line management level; advocate level and service user level.

SWOT Analysis

Meetings were held with 32 advocates; 8 line managers and 22 Citizens Information Board area executives. Selection was through open invitation to all members in each group.

Advocate Profile

All advocates were profiled to gain an understanding of the qualifications and experience that advocates brought to the programme.

Interviews

Interviews were held with key stakeholders to inform a comprehensive understanding of the Programme of Advocacy Services for People with Disabilities in the Community and Voluntary Sector.

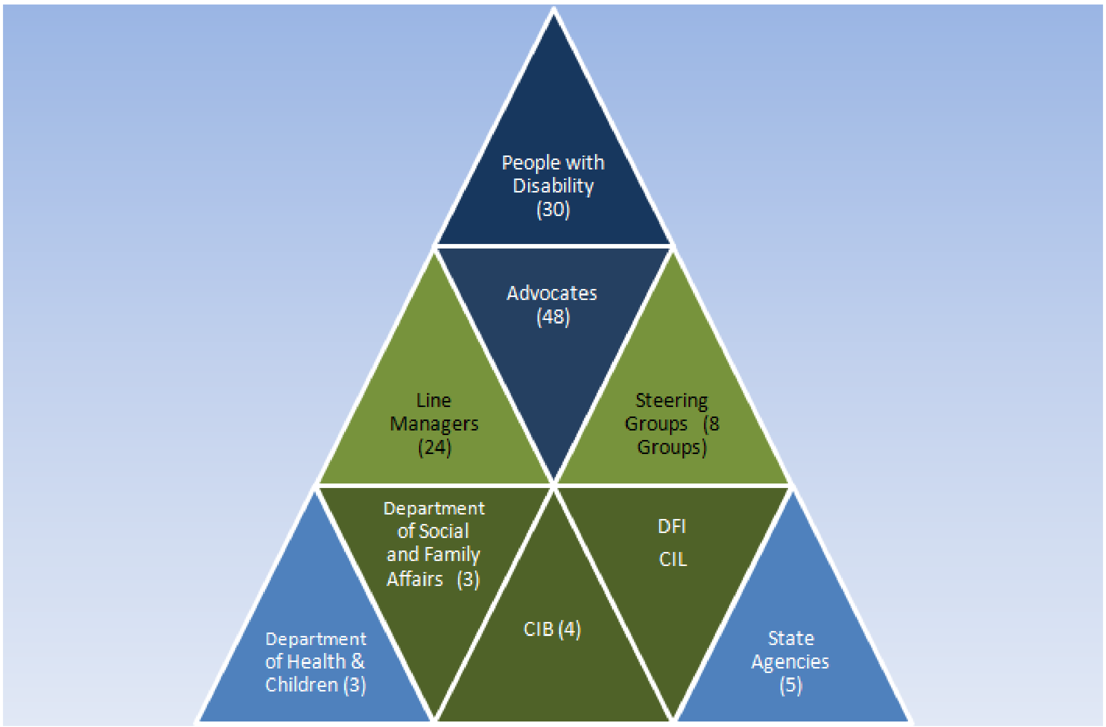


Figure 7: Overview of Interviews held with stakeholders

Interviews with Service Users

Service users were invited for interview as part of the project structural review and as part of the live case review. Open interviews were used with the objective of assessing the advocacy experience for those who used the service.

Interviews with Advocates

Interviews with advocates were carried out face-to-face, by telephone and in large group settings. Advocates were interviewed on the advocacy experience.

Project Interviews

Each project was evaluated through a series of interviews conducted with a range of stakeholders including service users, advocates, line managers, steering group members, service providers, and disability organisations.

Interviews with State Agencies and Disability Organisations

Interviews were held with the following:

Government Departments:

- Department of Health and Children – Director of the Office for Disability and Health
- Department of Social and Family Affairs, Director General and staff

State Agencies:

- Citizens Information Board – Board members, management and staff
- Health Information and Quality Authority - Chief Inspector of the Social Services Inspectorate
- Health Service Executive – Assistant National Director of Mental Health
- Health Service Executive – Senior Manager Consumer Affairs
- National Disability Authority – Director

National Disability Organisations:

- Centre for Independent Living
- Disability Federation of Ireland

Discussion

The discussions concentrated on perspectives on a number of key areas including:

- The impact of the programme on service users and the value created for them.
- The position of the service user in the programme, involvement and influence on the design and delivery of the service.
- The advocate's independence and its impact on their ability to deliver the service as required by the service user.
- The operating practices between advocate and line manager, advocate and steering group. The role of steering groups and their value.
- How the project stakeholders know they are reaching the most vulnerable.
- Relationships between stakeholders; are they effective, trusting, explicit and/or necessary?
- The diversity within the programme and its importance to the service delivered. Promotion, cross referral and understanding.
- Strategy of project within the overall programme, strategy of the programme, ownership of the strategy.
- Partnership, what this means and if it has changed and how service users assert their rights.
- The practices for governance, performance management and personnel management.
- The challenges at the beginning of the project, how they have changed and what has been learned.
- The future for the project, for the stakeholder, the advocate, the service user
- The responsibilities of the service providers, the advocate, the service users and those who provide the resources.

2.4 Ethical Considerations

To adhere to ethical research practices, this research was carried out within the guidelines of data protection, confidentiality and collection of data for defined purposes. In carrying out this evaluation, guidance was received from the Data Protection Commissioner. All cases submitted were anonymised and where appropriate, consent of the service user was obtained. In the writing of this report, all identifying factors have been removed from cases. In addition, all names used in cases are fictitious and used for purposes of clarity only. No geographical locations are given in the cases.

3. EVALUATION OF FINDINGS OF ADVOCACY CASES

3.1 Introduction

> ***"Through the provision of professional representative advocacy...we aim to ensure that adults who face challenges associated with physical, sensory and intellectual disability, mental health issues .....are supported to avail of information and services to which they are legally entitled or to which they otherwise have a just claim in order to achieve optimum wellbeing and security."***
>
> ***Advocacy Project - Annual Report 2008 – The Project Plan***

The development of the Programme of Advocacy Services for People with Disabilities emerged as a result of a number of planned choices made during the implementation of the Goodbody Report, *Developing an Advocacy Service for People with Disabilities*. Advocacy in the Community and Voluntary Sector (Strand 2 of this Report) has developed to a significant level with a substantial geographical spread, where 5,000 people with disabilities have availed of the services of an advocate. The Community Visitors Programme (Strand 3) will require further research because of the changed regulatory environment, and the Personal Advocacy Service (Strand 1) has not yet been implemented due to the current economic climate.

The Citizens Information Board, in taking the decision to work in partnership with different disability groups, CISs and service providers, has led the way in developing a uniquely delivered advocacy service that has responded to the needs of service users. The remit of the programme is to provide representative advocacy, working with and on behalf of the person with disabilities. A small number of current projects within the programme use the citizen advocacy model. The current mode of delivery seen in the Community and Voluntary Sector Programme is a private relationship between the service user and advocate. This relationship is supported by a line-manager, project steering group and, in turn, the Citizens Information Board.

In Ireland, there are fifty one advocates employed by 46 projects. Each project has one advocacy post and in a small number of projects, the post is shared amongst two or more advocates. Each advocate reports to his/her line manager and a steering group. The steering group consists of representatives from local stakeholders and can include service users, disability groups, local authorities, HSE, Department of Social and Family Affairs, a representative from the Citizens Information Board. The Advocate is supported weekly by the line manager of the project and attends regular meetings with the steering group. In addition, the advocate is supported by the Citizens Information Board which resources the projects and provides training and guidelines for the advocate.

> *"In order to persevere, particularly when cases take a toll, I seek support from others – my manager, colleagues, external supervisor. They each bring different perspectives and qualities, which I greatly appreciate". (Speaking up for Advocacy 2009:11).*

In carrying out this evaluation, there were two evaluation streams running parallel, both focusing on different aspects of the Programme:

- Case Analysis
- Management Structure

This chapter focuses on the case analysis, with the next chapter focussing on the management structure.

In focusing on the cases, the evaluators reviewed 2,400 cases. Through this lens, this report presents the practice of advocacy and how principles underpin this practice, and the impact of advocacy on the lives of people with disabilities.

In this analysis, the evaluation of this section was carried out by considering the following themes:

- The scope, focus and complexity of the advocacy work undertaken
- Principles impacting on outcomes

- Social and economic policy
- Outcomes for people with disabilities using the services.

Prior to setting out the findings from this section of the evaluation, an overview of the work of the Advocate and how it differs from the work of other professionals is important in order to best understand the uniqueness and importance of advocacy.

3.2 Principles impacting on Advocacy Practice

> ***Sometimes it is not the outcome, but the involvement in the advocacy process that makes the greatest difference to people's lives. I have witnessed people growing in self confidence and self worth as they come to realise that what they want from life is theirs by right and not by privilege.***
>
> ***Speaking up for Advocacy 2009:12***

In evaluating the *Advocacy Programme for People with Disability in the Community and Voluntary Sector*, an examination was carried out as to how the principles of advocacy were experienced by service users and whether there was a change in their lives as a result of interventions by the advocacy service.

Empowerment

People with disabilities may be the least powerful in our society. Very often, their concerns are neither listened to nor heard. Consistently service users spoke about frustrations they experienced in accessing services from local authorities, HSE, Social Welfare and disability organisations.

By reason of their disability, service users reported that they were unable to obtain, or had difficulty in obtaining a particular service or services. For others, their concerns were trivialised as not being important. In other cases, service users were not able to make decisions for themselves. In these cases, advocacy provided the service users with:

- Assistance by providing specialised information specific to their needs;
- Opportunity to discuss and develop options;
- Help to make decisions on how to move forward;
- Support in their discussions with relevant agencies, and
- Intervention where necessary, on their behalf.

Where service users felt disempowered, the assistance of the advocate enabled them to gain more control over their lives. For some service users, the empowerment that they felt from their engagement with advocacy gave them the skills to work through future issues, and to feel confident in helping others in similar situations to themselves.

Case 1: Multiple agency difficulties

Anthony and Denise both suffered from mental health issues. They have four children. The eldest is 10 years and the youngest is 9 months. Tommy, their second child, has cerebral palsy. This family live in a Local Authority house and have been seeking a new home for many years. There are a number of difficulties with the home. It is too small and Tommy has to be taken out of his wheelchair outside the front door and carried into the house. His wheelchair then is folded and brought into the house. As Tommy is getting older and heavier both parents are suffering from back problems as a result of carrying him. After being on a waiting list for a hoist it was delivered by the HSE without notice. The house was too small to take it and so it had to be returned. The family are back on the waiting list. In addition, the occupational therapist has recommended that Tommy have a bath each day to help relax his spasms. The house only has a shower. The local authority decided that it was sufficient

> *The challenge where multiple agencies are involved is the differing viewpoints in relation to service user requirements; lack of co-ordination, budgetary constraints; duplication of work.*

for the family needs. Finally, there is considerable dampness in the home. This family began using the advocate in January 2008 and the work is still on-going.

Anthony and Denise spoke about their interaction with the advocate. At their first meeting, she clearly outlined her role as an advocate. This she said was to help them represent themselves in seeking services that they needed. She outlined that she was independent and her job was to outline for them the options open to them and to support them in achieving outcomes that they felt were in the best interests of their family. Since that initial meeting, the advocate worked with Anthony and Denise, helping them to identify their needs, develop a plan, implement that plan and outline meetings with them.

From this support, Anthony said he learnt skills from the advocate of having clear objectives in meetings with service providers; having timelines of action and when a commitment was made, to check to make sure they were kept.

The family were offered a home that would be built specifically for their needs, Anthony said that if he did not have the advocate, he would not have thought to assess whether the design of the home would work for the family into the future. With the help of the advocate, he could make a critical assessment of these plans. This family are due to move into their new home in 2010.

Anthony said that on the conclusion of his time with the advocate that he felt empowered to deal with issues himself in the future and that he felt that he could in turn help similar families. In Anthony's words "I felt I was in a hole and she came and threw a rope for me to catch…..what I learnt from (the advocate) will help me deal with issues in the future and to help others in my situation".

Through advocacy, the service user's needs were met and the service user developed skills on how to negotiate on his own behalf and advise others in similar circumstances.

Empowerment of a service user who has had major difficulties in accessing services because of his/her disability is a process that takes time and nurturing. It can be experienced at different levels depending on the disability and experience of the service user.

Similar case examples are replicated throughout the review.

Autonomy

Most people without a disability have autonomy to make decisions affecting their own lives. People with disabilities are entitled to autonomy too but may be dependent on others for support in their everyday living and decision making. However, they should not be prevented from making informed choices.

> *"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."* (Goodbody, 2004:6)

Support for the person's autonomy is evidenced in cases where the advocate assists a person to voice his/her opinions or make choices, even if these involve a certain degree of risk. Enabling an individual's autonomy may mean ensuring his/her choices are fully informed, while engaging with service providers around their understanding of "duty of care," ensuring they allow some room for reasonable risk.

Case 2: Making Decisions

Parents of 9 year old Siobhán wanted their daughter to go into mainstream education. She had learning and intellectual disabilities. This case was opened on 3rd September 2007 and closed on 23rd May 2008.

The challenge can be between the difference in expectation of service users and service providers.

The advocate had considerable work to do in talking to the Principal and class teachers who had reservations about the suitability of Siobhán's placement in the school. Siobhán's parents felt the school staff.... demonstrated a lack of understanding of Siobhán's needs. The Advocate spent time educating the School staff on the type of disability and the structures that would be needed to integrate Siobhán into the school of her parents' choice. Discussions followed with the Resource teacher and the occupational therapist and speech therapist were also involved.

Through advocacy, a greater understanding of need was achieved enabling the service user to make choices.

Siobhán was accepted into mainstream education. Services of a specialised nurse and a care plan were put in place by the school.

***Excerpt from case notes**: "The parents felt that their voice was now heard and they had secured the best available services for their daughter whose progress had not moved on for a long time previously".*

The advocate spent considerable time on this case and it was successful in that the school put resources in place for the admittance of this family's daughter and she was accepted into the school. However, on the day of entry, her parents changed their minds and in reconsidering their options, decided that it was in their daughter's better interest to remain in special needs education and so they declined the place in mainstream education.

This created questions for the advocate around the use of her time and resources. By reflecting on the course of events and in discussion with Siobhán's parents, the advocate found that the critical issue for the family was their autonomy to have options and to make choices from a spectrum of options open to them. When they had choice they were freer to make the appropriate decision for their daughter whereas if only one option was open to them they would have felt pushed into something that might not have been appropriate.

Advocates may experience frustration when people change their mind after considerable work is done but a central principle of advocacy is a person's right to have a choice. A person's right to have a choice is given legislative expression under Article 19 of the UN Convention of Human Rights. The advocate reflected on this in her case notes

> *"This is one of the challenges of providing an advocacy service – that after investing a lot of time over a period of months supporting this family in achieving their outcomes successfully – they changed their mind.......However, I do believe the process was not wasteful for them as they felt empowered and by securing the services in mainstream education they felt that their voices had been heard and they had given their daughter the best opportunity available and felt satisfied with their final decision"*

Respect

This evaluation found that there was a genuine and deep respect among all of the advocates for service users and this was reciprocated. This respect enabled service users to trust the advocate and to believe that as service users, they could achieve outcomes in their best interest. This respect radiated beyond the relationship and encompassed other relationships that were encountered during the resolution of the issue.

> *"We were homeless – we were filthy and smelly.....we could have been in a three piece suit and a ball gown – we wouldn't have been treated with more respect" (Interview with homeless couple)*

Respect was seen by the service user in a number of ways such as arriving on time; speaking to the service user in a private place; insisting that meetings in public bodies were held in private rather than a corridor; when the service user expected a response from the advocate that this response was given quickly.

The Person's best interests

Advocates worked consistently in the best interests of the service user. While it is acknowledged that many people work in the service user's best interests, the position of the advocate means that they have no other perceived agenda except to help and support the service user in ascertaining needs and setting out a plan on achieving these outcomes.

> *"She was dedicated to finding out what could be done" (Elderly lady – legal debt proceedings).*

People with disability who were interviewed as part of the evaluation spoke about the impact on their lives in working with the advocate who focused on what they needed and supported them in asserting their rights. This is different to their experiences with other professionals who have a different responsibility that may cover allocation of scarce resources or meeting the needs of a group rather than an individual. By being able to support the person with disability around their needs, the advocate, in turn, empowers that person to resolve future difficulties for themselves and to assist others.

Throughout the evaluation, service users spoke highly of advocates and their work. They also spoke of how their lives had changed as a result of their interaction with advocacy.

> *"Better than brilliant, I never know such services exist.... I can talk to her.... They walk out after an hour and you know something is after becoming good in the day. Thank God I got (the advocate). (Male 36 years with Acquired Brain Injury)*

Upholding the "best interests" principle can be viewed differently by others who are connected to the service user. In a number of cases reviewed, there was a conflict there was apparent conflict between the desired outcome of the service user and his/her family. In one case, the service user's parent did not want him to leave home because of a concern for his safety. For the previous twenty six years, this parent had cared for the service user and wanted to continue this care. The service user, having considered options with the advocate and developing a plan for independent living, wanted to leave home. Both are legitimate concerns. The role of the advocate in this case was to work solely on behalf of the service user and to be a voice for that user, while at the same time, empathising with the concerns of the family.

Some advocates spoke about the challenge of "best interests" where other professionals working with the service user initially viewed the advocate with suspicion, where there was a fear of the advocate interfering with practice. Advocates consistently reported that as the relationship with other professionals progressed, and as their awareness and understanding of advocacy developed, this suspicion turned to trust and professionals referred other service users to advocates for support.

In some cases, what is in the best interest of the service user might not be what the service user wants. The challenge for the advocate is consistently to reflect on who is making the decision on what is in the best interests of the service user. The skill of the advocate is to present information in an impartial way, to support the service user in their exploration of obtaining their desired outcome and outlining the advantages and disadvantages of various options so that the service user arrives at a decision that is best for him/her.

Confidentiality

The relationship of advocacy is between the service user and the advocate. Confidentiality is critical in this relationship. Advocates demonstrated a strong commitment to confidentiality in protecting service users. This is an important principle within many professions and, in advocacy practice it is critical as advocates work with people who are extremely vulnerable and may be presenting with issues that they are unable to discuss with another person.

In this evaluation, the team found no breach of confidentiality. In some cases, the issue of confidentiality was an obstacle as the advocate did not feel that they could talk in a general way to their line manager about sensitive issues. This created a burden on the advocate. Most advocates have an option of accessing external professional supervision, but this was not afforded to all advocates. A number of line managers felt that advocates would not bring cases to them and felt excluded from supporting advocates in a way that was appropriate.

Independence

Independence is a central principle of advocacy. It is important that the advocate is independent of any conflicts or perceived conflicts of interest between their professional role as advocate to a service user and any connections the advocate may have with service providers.

The evaluation identified independence as a particular issue, where the advocate is employed by a service provider.

> *"As a user of the advocacy service, I felt that the advocate was not independent, and was being treated as part of the host organisation"*

Advocates are very aware of the boundaries required in the delivery of a professional advocacy service. For some, their employment relationship creates challenges in the maintenance of independence. The Citizens Information Board places independence as a central principle for all projects coming under its remit.

The principles of independence and confidentiality are entwined into the fabric of advocacy. The evaluation team found that advocates adhered to these principles. On occasions, the upholding of these principles created vulnerability for some advocates and led to isolation. With advocates working as the sole advocate within the projects and in the absence of peer support from other advocates, their independence set them aside from other co-workers. Implementing strategies into the future to alleviate this isolation will enhance the experience of advocacy for those who expressed concern.

3.3 The Practice of Advocacy

The Process of Advocacy

All advocacy cases are different and specific to individual needs of the service user. The strength of the service is the adaptability of the advocates within the programme to meet the challenge, diversity and creativity needed in enabling service users to have their voice heard in a meaningful way. In evaluating the cases seen by advocates, there are similarities in structure and delivery of service. The case below demonstrates the process of an advocacy case.

Case 3: Walking Through an Advocacy Case

Mary self-referred to advocacy. She lives with her sister and wants to live independently. She looks for support in making her wishes known to the local authority and to access HSE and Dept of Social and Family Affairs entitlements. The advocate asks Mary to fill out a "Consent to Act" form. Both Mary and the advocate complete an advocacy plan.

The advocate works with and on behalf of Mary for 8 months. During that time, there were 16 actions performed by the advocate on behalf of Mary. During these, the advocate and Mary were in contact with Department of the Environment, Enable Ireland, Local Authority, Irish Wheelchair Association, Department of Social and Family Affairs, HSE.

On average, during this period, the advocate was working with another 19 cases. The advocate had weekly meetings with her line-manager where, within the bounds of confidentiality, she discussed issues arising from the case. The advocate also

The Process of Advocacy

Referral –Initial interview

Consent to Act

Presentation of problem and Advocacy Plan

Information gathering & research

Feedback to Service User and review of plan

Active negotiation & advocacy with providers/authorities

Review and Case closed

had meetings with the steering group where information and advice was sought on how best to work through the complexity of the case. The outcome for Mary was successful and she moved into her own home and the case was closed.

The advocate works with or on behalf of the service user. Service users who avail of the service can have differing capacity and understanding. The advocate engages with each service user on an individual basis and responds based on the ability of the service user. The service user engages in the process on a voluntary basis and can withdraw from that process at any time.

The advocate listens to the concerns of the service user and helps him/her identify issues; develop options and reality test possible outcomes. In discussing options with the service user, the advocate can help him/her to distinguish between needs and wants, thus providing clarity for the service user in enabling their voice to be heard effectively.

Where necessary, the advocate will support the service user in discussions with agencies; enable the service user to manage realistic expectations; help the service user to view issues from different perspectives.

Advocates' view of Advocacy

The advocates in the Programme of Advocacy for People with Disability in the Community and Voluntary Sector expressed their view on what they saw as the strengths and weaknesses of the Programme in its current structure.

A summary of the key views of advocates is set out:

- Advocacy is a specialised skilled professional service that is working in a unique way to assist and empower people with disabilities. As a result there is a significant improvement in the lives of people who have been vulnerable, marginalised, hidden, ignored or overlooked.
- The independence of the advocate is critically important to advocacy. Being free from conflicts of interest enables the advocate to take actions.
- Being a free and confidential service is in the best interests of service users.
- Lack of recognition of advocacy by external providers is a challenge for most advocates - a nationally identified organisation could address this lacuna.
- The successful implementation of advocacy in one area raises expectations from other service users and communities.
- The geographical dispersal of advocacy projects and the current organisational structure has the effect of isolating advocates in some areas.
- It is important that the legislation concerning advocacy is implemented as the lack of PAS impedes the work of some advocates.
- Advocates have different experiences of interaction with steering committees in terms of support, expertise and accountability.
- There is a need for policies and procedures that meet unified quality standards so that expectations can be met.
- The value of the advocacy service in identifying social policy issues and the need for a clear reporting structure for making these known.

Advocacy in Residential Institutions

> *"There is, and has been historically in Ireland, a widespread exclusion of disabled people from advocacy mechanisms, to represent their interests and facilitate decision making processes. This is especially true for those living within residential care and total institutions" (Forum of People with Disabilities 2001:4)*

Of the 46 projects providing advocacy in the community and voluntary Sector, nine work exclusively for people with disability in residential settings, twenty three in a community setting, while a further fourteen work in both community and residential settings. The Citizens Information Board has worked in partnership with institutions promoting and supporting advocacy provision.

The vulnerability and isolation of those living in residential institutions in many cases is far greater than those living in the community. Despite the care received within institutions, some residents may have little or no contact with their families, others may have issues about privacy as they share accommodation with others not of their choice, and more may have become institutionalised and become afraid to question any aspect of their lives.

Case 4: Upset and Distress

Joseph has an intellectual disability and lives in residential care. He is a voluntary patient and is not very happy with his situation. He is upset by the night time habits of his room-mate and wants to move to private residential accommodation.

Joseph's sister telephones the residential home following calls from Joseph. Often she is angry because Joseph is upset and distressed. His sister has not visited Joseph in several years and all contact between her and the home is by telephone.

The advocate has worked with Joseph for over one year and has helped him to secure private residential accommodation by working with the Director of Nursing within the residential home.

> *This work has been very slow. At one meeting, in May 2009, Joseph "was not in great form and was cranky and wanted to meet me to discuss a few things". However, at the meeting Joseph could not articulate why he was upset and after much discussion it transpired that Joseph was seeking reassurance that his move to private accommodation was taking place. In November 2009, Joseph "was in great form and he told me that he had a visit earlier this week and was reassured that the move was definitely going ahead and he was to pick out his wall colours".*

This case illustrates the particular needs of those who live in care. Policy means that funding for residential institutions is based on block funding rather than individual funding. This was a barrier to Joseph securing private accommodation. Joseph's sister had wanted him to move completely away from the home. However, not having visited Joseph in several years, she had a limited understanding of Joseph's best interests.

The advocate was best placed to assist Joseph, taking the time to work with Joseph and making representations on his behalf.

Providing advocacy for people with disabilities in a residential setting has been an important priority of the Citizens Information Board. The Board sees this as a key priority into the future as they continue to develop partnerships with residential institutions.

The Advocates' work environment

Amongst the projects, there were significant differences in the experiences of advocates in relation to the work environment. It is key to advocacy that the advocate has a private office to store files, take telephone calls and meet with service users. In general, this was available to the advocate. There were a number of projects that had inappropriate accommodation. There were examples where the advocate had to take calls and meet service users in an open space or where an advocate had a desk under the stairway. Where the advocate did have a private office, the location of that office on the first floor, where there was no lift, made access difficult for potential service users.

Not all advocates were supplied with mobile phones or had access to a dedicated line. This posed a risk to confidentiality and also a risk to advocates working off site.

Many projects had policies and procedures around safety when an advocate was carrying out a home visit. Under these policies, the advocate, when on a home visit, advises his/her line manager of location and estimated time of visit. On completion of the visit, the advocate, again, makes contact with the manager. However, there was some evidence that these policies were either not in existence or adhered to, with some advocates reporting that they attended home visits out of hours or without advising another of where they were.

Time

Cases reviewed had different patterns in terms of workload of the advocate and interaction between the advocate and other stakeholders in the case. Each of these impacted on the time devoted to a case. The particular circumstance of the case will dictate the time spent and cannot be pre-ordained by the advocate or the project.

Case 5: Time

> *The advocate was assisting a 24 year old male, who was registered as blind, to move to independent living. The man was unable to read and had difficulty understanding process. The advocate was helping him to apply for household benefits package, living alone increase, fuel allowance and rent supplement. She had 16 separate meetings with the man. This did not include phone calls to and from him or phone calls and meetings made on his behalf. Each time the advocate met him, she had to update him on all work since the last meeting and all work completed since the start of the process. The case took four months to complete.*

Complex case time-line

First meetings establishing issues

Routine work with service user to help his understanding

Length of Case: 4 months

Complex cases can take a year or more to complete from the time the service user makes contact with the advocate to completion of the case. Some complex cases and most highly complex cases took in excess of a year to complete. Not all cases required weekly interaction. In some cases, especially in housing issue cases, the advocate and service user are informed of a date for completion of a particular element in the case and the case is on hold until that date. In other cases, the advocate interacts with the service user and the service user continues to work on his/her own behalf for a period of time and then returns to the advocate for support.

Case 6: Returning calls

Jacinta is a full time carer, caring for her brother who has a number of impairments, including diabetes, lung and heart failure, acquired brain injury, brittle bones, spinal injury, kidney failure, mobility problems. Jacinta lives with her brother in a house that has been condemned and is a serious risk to herself and a great danger to her brother. Recently, he fell through the rotten floor boards and suffered severe bone breakages.

> *Excerpt from case note:*
>
> *"The service user dedicated her life to caring for her brother who is completely dependent on her for all his basic needs. This person does not have the energy or the confidence to speak up on behalf of herself or her brother. She made an average of 3 calls a week since January (approximately 70 calls) to the council to no avail. Lack of understanding, prioritisation and sensitivity by the*

Complex Case – Person with disability & Family Carer

Housing- condemned home

Key factor – accident at home.

70 calls from the service user to the local authority

22 calls from Advocate to the local authority

Case on-going over 12 months.

Council has led to additional hardship and stress"

After the 70 calls, the service user became aware of the advocate and the advocate supported her in progressing the housing issue. This case came to the advocate in June 2008 and in June 2009, although still on-going, was nearing completion.

During this time, the advocate made 22 calls to three people within the housing unit and while in a number of these calls she held a conversation with the person, whenever she left a message, the call was not returned. This led to significant additional work by the advocate.

A case cannot be rigidly allocated into a series of units of time. Rather, after an initial estimate, the advocate uses his/her judgement as the case evolves to work through it in the most effective way.

3.4. Advocacy Competence

> ***The practice of advocacy depends fundamentally on the competence and integrity of the people it employs.***
>
> ***Advocacy Guidelines 2007:15***

The complexity of advocacy requires competence at high levels amongst advocates. From the outset of this programme, the Citizens Information Board focused on setting guidelines that required the selection of competent advocates. The rationale underpinning this was the knowledge that the advocate works with some of the most vulnerable people in our society. This evaluation considered the competence of advocates with reference to their:

- Dedication
- Knowledge
- Skills
- Competence

Dedication

The evaluators were impressed at the diligence of Advocates in carrying out their duties. Throughout the evaluation, there was significant evidence of dedication in developing the advocacy programme for people with disabilities. The advocates are seen as proactive professionals.

> *"Promises, Promises, Promises .... TDs, HSE, Nurses.... They were all going to do wonderful things – I did not hear from them again.... Then I met (the advocate). She don't put words in my mouth, she listens to what I am saying to her – I would be lost without her – I would not know what to do". (Female (60s) caring for her seriously disabled brother).*

In reviewing the programme in 2009, it is clear that all those involved were committed to developing the programme to the highest level possible. The advocates were in the front line of this development. The work of these advocates has culminated in the development of a successful programme.

The evaluators found that the advocates were dedicated to working in the best interests of the service user. Persistence by the advocate was evident in complex cases reviewed. The advocate stayed with an issue until an outcome was achieved or until nothing more could be done to progress the matter. At all times, the advocate discussed, or stayed in contact with, the service user to up-date him/her on developments.

In many of the cases, the advocates demonstrated a very good balance of supporting the service user at the pace in which they needed to proceed at and focusing on outcomes on the issue. The advocates were very clear on the function of their role in working through specific issues.

The advocates are self-directed in their work, with the support of their line manager and steering group. Their responsibility for problem solving issues and taking initiatives on behalf of service users requires a very particular type of person to be involved in advocacy.

Knowledge

The advocates within this sector are qualified to a high level within the National Framework of Qualifications. In addition to this, they hold a variety of other qualifications and most have undergone further training in key areas. Eighty three percent of advocates hold a Level 8 qualification or higher on the National Framework of Qualifications. These qualifications include Social Science; Psychology; Law; Arts; Business; Counselling & Equality; Nursing; Equality Studies; Occupational Therapy; Education and Early Childhood Education; Community Care, Adult Guidance Visual Arts; Rehabilitation Management; Behaviour Analysis.

This range of qualifications is particularly suitable for the range of issues that advocates work with on behalf of their service users.

In addition to this, the advocates bring extensive experience to the post. With the average age of the advocate within the Programme as mid-thirties, advocates have worked in a variety of areas including:

- National, international and inter-agency advocacy;
- Citizen advocacy; group advocacy, representative advocacy and advocacy for children
- Disability groups; Travellers groups; homeless groups and community groups
- Law, rights and appeals

This experience was critical in developing the Advocacy Programme to the levels it has achieved in the pilot phase and is critical in enabling the advocate to work with the complex issues that consistently present from service users.

With advocates primarily working alone in projects, there is a challenge in developing knowledge in all of the areas that may be needed in any series of cases. The Irish Association of Advocates provides a network for advocates to seek support or information from one another that enhances and develops individual knowledge. In the consolidation of the programme a more formal team approach to sharing knowledge would offer further support to advocates.

Skills

In the range of cases that were evaluated, a number of skills were identified as being important. These skills included:

- Empathy and understanding of the service user
- Effective negotiation and communication
- Influencing a wide range of professionals from diverse organisations
- Developing and building external relationships in diverse organisations
- Planning and organising
- Promoting advocacy and the rights of people with disabilities

Competence

The evaluation identified a variation in the level of competence displayed by advocates. This competence fell into three groups - highly competent, competent and less competent.

Those who were identified as highly competent brought considerable experience to their role and they were highly effective in working with both specialised and generalised advocacy issues that required significant in-depth understanding of issues. Equally they displayed a high level of interpersonal competence in working very effectively with service providers. The advocates who fell into this category had the ability to work on extremely complex cases.

The majority of advocates work very effectively on behalf of service users. These advocates were very competent in working through generalised advocacy issues and some specialised issues.

A small number of advocates struggled in their role. Some advocates spoke about the challenge of representing the service user in an area where they had little experience and described the challenges that faced them in doing this. In the absence of having more senior advocates who could act in the capacity of mentor, the inexperienced advocate learned in an *ad hoc* manner.

Developing team structures will support the exchange of competence between advocates.

3.5. The Scope, Focus and Complexity of advocacy

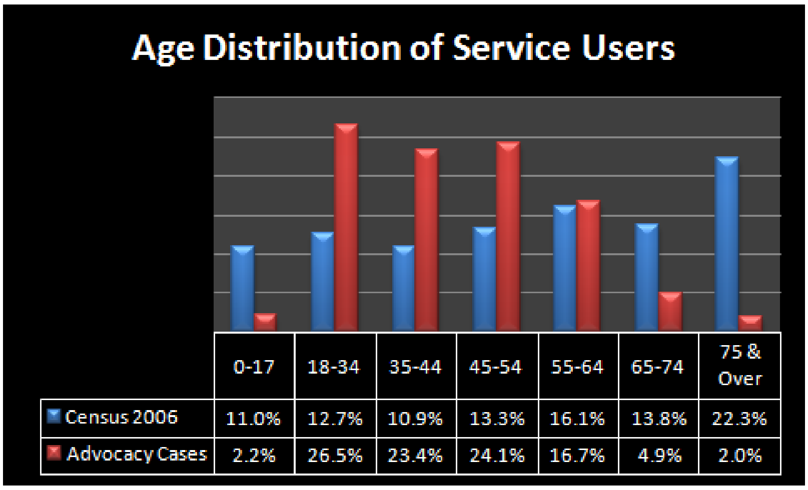
> ***Social exclusion, individual problems, or low levels of literacy coupled with bureaucratic complexity can leave some people at a disadvantage in claiming their entitlements or getting the services they need.***
>
> ***Jigsaw of Advocacy 2003:p4***

The Advocacy Programme for People with Disabilities has had almost 5,000 advocacy cases during the pilot programme stage. The extent of delivery of this programme is widespread, although incomplete. People who use the service come with a varied profile. In understanding the scope of the programme, the evaluation profiled people using the service and the levels of complexity of cases presenting within the programme.

3.5.1. Scope

Profile of Service User

In understanding the reach of the programme, its case data was analysed against data on disability from Census 2006. From the cases analysed, there is almost an equal distribution of males and females using advocacy services, with 49% of female service users and 51% male service users. A slightly greater proportion of men with disability use the service relative to the general disabled population. In the general population 48% of people with disability are male (CSO 2006).



	0-17	18-34	35-44	45-54	55-64	65-74	75 & Over
🟦 Census 2006	11.0%	12.7%	10.9%	13.3%	16.1%	13.8%	22.3%
🟥 Advocacy Cases	2.2%	26.5%	23.4%	24.1%	16.7%	4.9%	2.0%

Figure 8: Age distribution of service users on the reviewed cases, with a comparison to the age distribution of people with disabilities in the 2006 Census

From the case data analysed, the majority of people accessing the Programme of Advocacy for People with Disability in the Community and Voluntary Sector are between the ages of 18 and 64, with a significant tapering of uptake by people over 65.

The proportion of those under 18 in the cases analysed was lower than the general disability population would suggest. This, however, is due to the programme remit of providing services to adults with disability. It also recognizes that other agencies are providing services for children. In the evaluation, when children did access advocacy under this programme they did so through their parents and were included in reviews of a particular case.

A significantly greater proportion of those between 18 and 64 are accessing the advocacy service compared to the proportion of this age-group in the general disability population. However, the actual numbers of people in this group within the disability population are over 200,000. Notwithstanding the fact that not all people with a disability need an advocacy service, the proportion of people within the age group using the advocacy service is one person in one-hundred-and-thirty-one (1:131)

The lower than expected numbers of those over the age of 65 using the service is of concern; given that greater numbers of this age cohort have a disability. One explanation for the lower number could be that a proportion of this cohort is already falling within programmes provided by the HSE. Another explanation could be the isolation that elderly people experience resulting in a lack of awareness of advocacy support. The future programme may need to target people in this age group.

Statistics alone do not demonstrate the vulnerability of many of the people who use the service.

Case 7: People behind statistics

> *David has a mental health difficulty and is placed inappropriately within an acute admissions ward of a psychiatric hospital. The ward is locked at all times. David experienced an acute psychotic episode, but no longer requires hospital treatment; however a suitable placement could not be identified. David is a voluntary patient in the hospital who is encouraged to stay as he has been identified as very vulnerable and is not street-wise. Furthermore, his social skills have regressed significantly since he was taken into the psychiatric hospital. He no longer feels confident enough to walk alone and his consultant psychiatrist believes that he has become "institutionalised". This case is on-going and the advocate is currently negotiating with and on behalf of David regarding a possible placement in a more appropriate setting.*

The case study above is an example taken from the reviewed cases. A case presented on the inventory *as "Male aged 42 with mental health issues".* Comparing the inventory statistic and the case demonstrates the vulnerability, isolation and need for advocacy that some people with disabilities experience. This was replicated across each of the cases that the evaluators reviewed.

This case also demonstrates the importance of this service user having an advocate representing his needs. The advocate helps David voice his issues to those who provide care for him. The partnership of the service user and service provider remains intact as the independence of the advocate helps David raise issues that are of concern to him.

Reach of the service

While extensive, the Programme of Advocacy for People with Disability in the Community and Voluntary Sector does not reach every person who requires the service.

There are a number of reasons why this programme does not reach every person with a disability:

- Many people with a disability advocate on their own behalf and do not need to access the services of an external advocate.
- Given that advocacy is a relatively new service, there is a lack of awareness by some service users and service providers of what advocacy is and its effectiveness. Advocates reported on spending considerable time on raising awareness of advocacy and its role and success in ensuring that the voice of the person with a disability is heard.
- In residential care settings, not all people with a disability have access to an independent advocate. Over the period of the Advocacy Programme, advocacy was introduced to a number of residential centres, with four being specifically targeted in 2007. HIQA views access to an advocate as a mark of quality in a residential service.[14] However, these HIQA standards are not yet enforceable.
- Some community advocacy projects engaged in outreach programmes to local residential centres.[15] However, people in residential centres tend to have significant levels of disability, so advocacy work can take a significantly longer period of time. With approximately 150 centres for people with disabilities in

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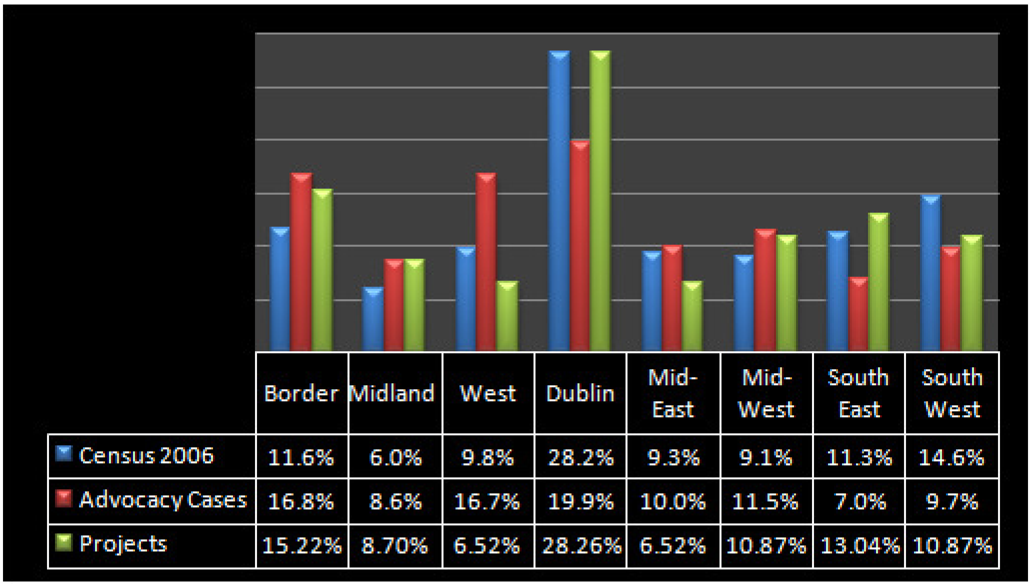
[14] Standard 14.4 *National Quality Standards: Residential Services for People with Disability* (HIQA)

[15] For example, one afternoon per week or per month.

Ireland[16], the proportion of such centres that can be serviced by 46 projects remains low.

- Geographical isolation creates a challenge. In rural Ireland, there were a number of instances where people with disabilities had difficulty in accessing the services because of lack of public transport and lack of financial resources to use private transport. While some advocates travelled to the homes of people in rural areas, advocates and line managers believed there were those who needed the service, but encountered barriers because of their geographical location.



	Border	Midland	West	Dublin	Mid-East	Mid-West	South East	South West
🟦 Census 2006	11.6%	6.0%	9.8%	28.2%	9.3%	9.1%	11.3%	14.6%
🟥 Advocacy Cases	16.8%	8.6%	16.7%	19.9%	10.0%	11.5%	7.0%	9.7%
🟩 Projects	15.22%	8.70%	6.52%	28.26%	6.52%	10.87%	13.04%	10.87%

Figure 9: Distribution of projects and cases by region, with a comparison to the population distribution of people with disabilities in the 2006 Census

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[16] HSE list 2007. This figure does not include residential centres for older people.

The evaluation compared the numbers of sample cases reviewed and the percentage distribution of projects, with the population of people with disabilities in the relevant regions.

In its initial seeking of applications, the Citizens Information Board's purpose was to spread advocacy countrywide, but the final spread of projects depended on the type of applications received and the capacity of the lead organisations in different regions to take on the work.

In making a comparison between this distribution of people with disabilities according to the Census (2006) and the relative distribution of advocacy cases that were reviewed in this evaluation, there are a number of interesting findings on regional distribution. There was some provision of advocacy in each of the regions. Twenty eight percent of people with disabilities live in Dublin and only 20% of the total number of advocacy cases came from Dublin, a significant shortfall. Thirteen projects service this area.[17] Three of these projects provide advocacy in residential settings only, four in community settings only and the remainder in both residential and community settings. While each of the projects carry a full case-load, the boundaries of coverage leave gaps in service delivery, with the result that service user demand in Dublin is not fully met.

This is replicated in other areas, such as the South West region that covers Cork and Kerry. In Cork, there are four projects delivering the service, two in residential settings only and two in community settings. Two of the projects are situated within a radius of 10 km of Cork City[18], one in North Cork[19] and the final project in East Cork[20], with no service delivery in West Cork. In Kerry, only one project exists[21] providing a service for

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[17] Acquired Brain Injury Advocacy Association; Ballyfermot Advocacy Service, Blanchardstown Area Partnership, Cheshire Ireland, Clondalkin/Peamount Hospital Disability Advocacy Services, Clondalkin Disability Advocacy Service, Dementia Rights Advocacy Service, Dublin 15 Advocacy Service, Dublin Leader Advocacy Service, Eastern Vocational Enterprises, National Learning Network, Shine, Tallaght Disability Advocacy Service.

[18] Cork City South CIS and the Social and Health Education Project (SHEP)

[19] DATA Irish Wheelchair Association

[20] Youghal Advocacy Project

[21] Saoirse Advocacy North and East Kerry

the North and East Kerry community but confined to people with intellectual disability. This project endeavoured to advocate for people outside its region (i.e. in South Kerry), but because of the increased workload a decision was made to offer the service only within its target reach area.

Despite the coverage, there are serious gaps in service delivery in both urban and rural settings. As part of its plan in 2008, the Citizens Information Board expected to target these areas and encourage new projects in areas where there were gaps. However, in light of economic constraints, these plans were not implemented.

By providing the Programme of Advocacy through forty six projects that have definite boundaries and target groups it is not possible to have full geographical coverage. Even if all boundaries were removed it would be difficult for the same number of advocates to service the likely demand.

3.5.2. Focus

The Advocacy Journey

> ***"Those who have started on their advocacy journey will no longer just accept what is given, but will seek what is theirs by right, as equal citizens and valued human beings....Advocacy has power. It has the power to change people's lives in little and big ways... Why Advocacy? This is the why. Or perhaps the real question is... Why not?"***
>
> ***Speaking up for Advocacy (2009)***

For the person with disability, the engagement with the advocacy service can be a journey where the focus can be on one or more issues. The journey of engagement can be as important as the outcome and offers opportunities in varieties of ways. The service user may present with one or more issues. There are challenges for the person who may be unable to assert themselves or be heard in a meaningful way.

Case 8: Reengaging with life in the Community

A challenge for people with disabilities is to receive recognition that they have a right to make choices on any issue.

Orla is a middle-aged lady, with a mild intellectual disability, who has spent her life working in sheltered employment and isolated from mainstream living. Through the National Learning Network, Orla became involved with an advocate who has helped her to make life changing decisions. She is now employed in a family business, is taking courses of study, and takes part in disability networking and educational projects.

Through advocacy, people with disabilities can make choices that matter in their lives.

Through the support of the advocate, Orla's life has been transformed. The advocate helped Orla to contact her family, facilitated meetings between her and her family and helped her reintegrate. She now lives with her sister and is in contact with members of her family. Orla now sees herself as part of the general community where she partakes in social activities and contributes to society.

For others, the advocacy journey enables people with disabilities to make choices. The ability to make choices is fundamental to human rights and a right that can be overlooked.

Case 9: Making Choices

Challenges for people with disabilities are isolation within their community and not reaching their full potential.

Dorothy has cerebral palsy and lives in a residential home. The only food she really liked was pasta. She said that it took quite a long time for her concerns to be heard and even when they were, she was told that change was not possible. She offered to pay for the pasta if someone could cook it, but was told again that it was not possible, as the kitchen staff had too much to do in cooking for all the residents. In addition, Dorothy wished to live independently of the residential home and had been asking for this for three years.

The advocate worked with Dorothy to help her resolve the first issue and to make choices around independent living.

Dorothy now lives in a ground floor apartment in the community.

Through advocacy, there is opportunity to reengage with life in the community and contribute effectively.

In this case, two issues were presented - firstly, the issue of food choice and secondly, the issue of living independently. In considering both of these issues, there could be an initial view that the issue of food choice is simple and easily resolvable. However, considerable work was undertaken by the advocate on behalf of Dorothy to enable her to have food choice. The service provider argued that it was an industrial relations issue and unless the staff member agreed, there was nothing that the manager could do. The advocate in this instance spent a number of months negotiating with the manager to resolve this issue.

For Dorothy, resolving this issue was important. She felt that she was not listened to and she developed a high respect for the advocate. In an interview with Dorothy she said:

> *"People don't realise that I understand as much as I do... But (the advocate) from the very start knew that I did.... she doesn't know how good she is".*

From this, Dorothy trusted the advocate to help and support her in making her wishes clear that she should live independently. Both the advocate and Dorothy began negotiations and looking at suitable accommodation. Once ground-floor accommodation had been found, the advocate and Dorothy then engaged with different agencies to prepare the accommodation to suit Dorothy's needs. They then negotiated home help and support for an interim period, with a view to Dorothy using minimal support in the long-term.

Dorothy was nine years in care. From the outset she requested independent living and was not listened to. Through the support and skill of the advocate, Dorothy's wishes were realised.

Advocacy Issues

Service users presented with a variety of issues which were categorised into twelve main areas. In some cases, the user presented with a simple issue and moved to more complex issues as a trust developed with the advocate. In other cases, the service user presented with several issues.

The three main areas where service users had issues in accessing services were rights and entitlements, housing and employment/training. Very often, there was more than one issue and the advocate often worked with the service user on multiple issues.

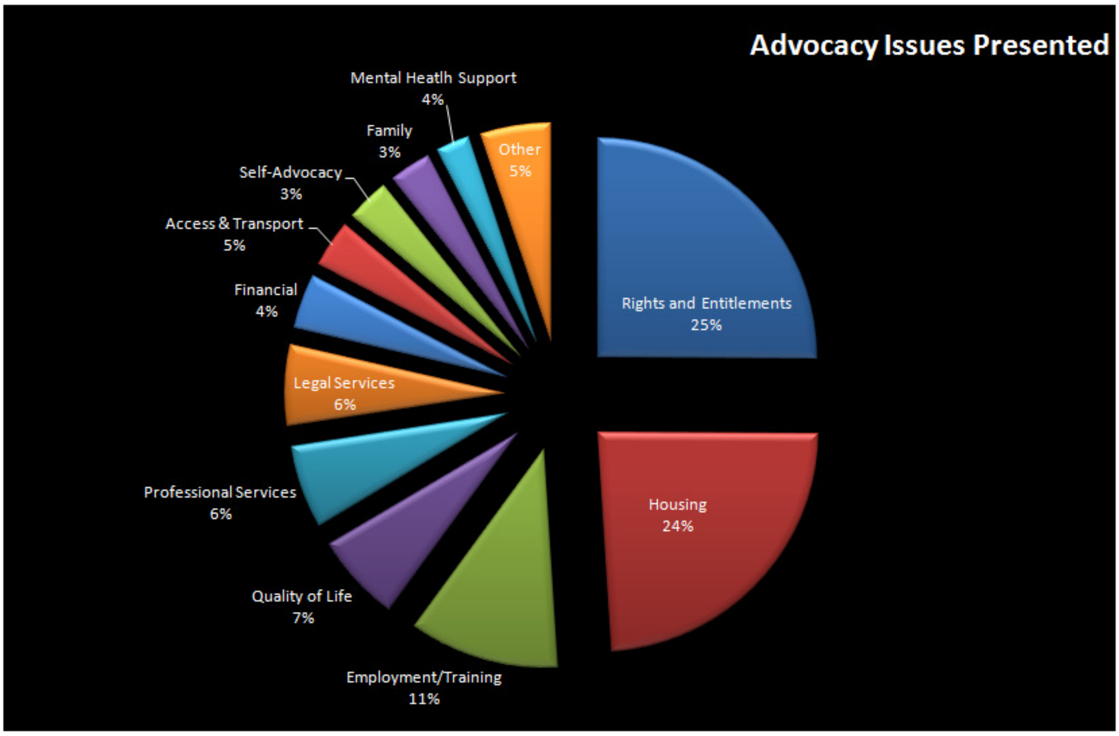


Figure 10: Advocacy Issues Presented

Rights and Entitlements

Rights and entitlements are the prerogative of all citizens, including people with disabilities who, in some cases, are entitled to additional benefits and supports – such as income, employment or other specific supports. Many service users interviewed spoke of the difficulties that they had in accessing these supports. In addition, 25% of cases reviewed in this evaluation related to rights and entitlements that the service user was endeavouring to obtain.

Case 10: Seeking Services

Martin, a homeless man, who walked with extreme difficulty and only with the help of a walking frame, spoke of two experiences he had. His frame was missing a seat and the evaluator asked him about it. He said that he was on a list for a new frame, but had been sent to four different places for the replacement. Each time he went to collect one, he was told he needed to go elsewhere. The final place was four miles from the city centre and he could not get there as public transport did not pass this office and he could not afford a taxi.

A challenge for people with disabilities is falling out of the Community Welfare safety net.

He told of a further incident where he went to the Community Welfare Officer and was told to leave his frame outside the door. He tried to explain that he could not walk without it, but was told that unless he left it outside he would not be dealt with. Martin left without seeking the assistance he needed as he could not walk unaided into the office. Martin sought the help of an advocate.

Through advocacy, dignity and respect can be restored to the service user.

The advocate held several meetings with Martin. Martin recounted the deep respect he had for the advocate and how he was treated with dignity. This was evidenced by her punctual time-keeping, her caring attitude and her ability to progress issues that were agreed between them. The outcome to this case was successful and Martin not only received the service he was entitled to, but subsequently worked with the advocate to acquire a place to live.

Housing

Housing was the second key advocacy issue for many service users. In the review of the inventory of cases, 23.9% of issues fell into this category. On closer examination of the cases, issues ranged from new housing to modifications of existing homes to suit the needs of users.

Case 11: More than a Roof

Mary is a traveller with mental health issues. She has six children, the eldest of whom has spina bifida. Mary's children are doing well in school and she is anxious to be rehoused in the settled community, as she does not want to live with other travellers. Mary was referred to the advocate by a member of the Travellers Development Group.

A challenge can be the dichotomy of views between service users and statutory agencies

Gardaí moved Mary's illegally parked caravan to the front of the house allocated to her by the local authority. Accessibility to the caravan is blocked by a large skip. Running water is available from an outside tap. The local authority

Advocacy can be a platform for generating creative possibilities wants Mary to sign for the house before she sees it. Mary is unwilling to live there because it is isolated.

The advocate liaised, on Mary's behalf, with the Traveller Liaison Officer in the local authority in trying to access housing for Mary. Efforts to obtain private rental housing have been unsuccessful to date. Council have no other house to offer.

This is a recently opened case, with complex issues. The advocacy plan agreed with Mary has a desired outcome where Mary will live with her children near the school.

Training and Education

Access to training is critical for people with disabilities to enable them to feel part of society. In this evaluation, lack of access to training demanded considerable work of advocates.

Case 12: Return to Training

This 30 year old with an intellectual disability, who lived in the community, was referred by the social worker. Michael was doing a course with the service provider. He was suspended from the service due an allegation of sexual abuse made against him from someone outside the service. The case was referred to the DPP and did not proceed.

The challenge is to enable a service user to become re-engaged with a system

Michael wishes to go back to the training programme, but the provider advised that the course was full. The social worker referred Michael to an advocate.

Advocacy validates the concerns of the service user

The advocate approached the service provider who said that Michael was suspended from the course. At a second meeting the service provider said that, in fact, he was discharged from the course. This case was opened in October 2007 and took 15 months to complete. Barriers that existed for Michael’s re-entry to the course included the service provider requesting a risk-assessment for Michael; questioning of the risk-assessment when submitted to the service provider; the service provider designing a different type of course for Michael; an application to the HSE for one to one supervision. In January 2009, through the considerable work of the advocate working on his behalf, Michael started a training programme.

This case illustrates the persistence of the advocate in working on behalf of the service user, her ability to clearly and logically work through the complex issues and to enable an outcome that is in the service user’s best interests.

Legal Issues

Six percent of cases were identified by advocates as primarily having a legal component. These were highly complex cases requiring independent legal advice. Several advocates requested that, notwithstanding the support available through the Coolock Law Centre, independent legal advice should be available to all advocates dealing with complex legal issues.

Case 13: A Ward of Court

Case Excerpt written by the Advocate:

> “*There was a dispute between the HSE and the Ward of Court office about who was to pay for (a service user’s) care. This resulted in no decision being made regarding discharge as long as the dispute was not resolved, as it included legal actions between the two institutions. I stressed my concerns that this dispute was harming the service user, (possibly leading to an infringement of) her human rights; i.e. the right to self-determination.*

The challenge is that people with disabilities can be invisible

> *My main concern was that there may be a conflict of interest with the “(Ward-of-Court) Committee” consisting of a Ward-of-Court solicitor, as the “Committee” is to act in the best interest of the service user. In this case the*

> *solicitor was also connected to a party in the dispute... One issue was that the Ward-of-Court solicitor did not visit the service user at all.*
>
> *I have stressed that I feel the solicitor cannot function as the service user's "Committee", and act on her behalf, without visiting her regularly to explore the service user's wishes. I also stressed I feel it is very important that the service user is informed about her situation, and that the solicitor explains she is a Ward of Court and therefore can't make certain decisions herself."*

Advocacy gives People with Disability a voice

The advocate in this case needed an understanding of Ward-of-Court issues, confidence to challenge conflicts of interests, competence in negotiation and communication skills to work effectively with all stakeholders.

3.5.3. The Complexity of Advocacy

The advocacy cases reviewed in this evaluation demonstrated various degrees of complexity. Complexity of a case could present in terms of risk involved to the service user, multiple issues presented by the service user or barriers preventing the service user obtaining their entitlements. These barriers could be lack of information, lack of confidence, over-complexity of the official process. The complexity of a case impacts on the advocate's work, the time spent on a case, the case-load that the advocate can carry and his/her need for specialist knowledge, support and supervision.

Three categories of cases emerged from this review across a spectrum of complexity:

- ***High Complex Cases –***
  - An advocacy case where there is a serious risk of harm to the service user's health, welfare or safety. These cases will often include a legal dimension.
- ***Complex Cases***
  - An advocacy case where there are complex issues preventing the individual obtaining their rights and entitlements for themselves.

- ***Low complex Cases***

  An advocacy case where the service user presents as requiring limited support on one issue or one aspect of an issue.

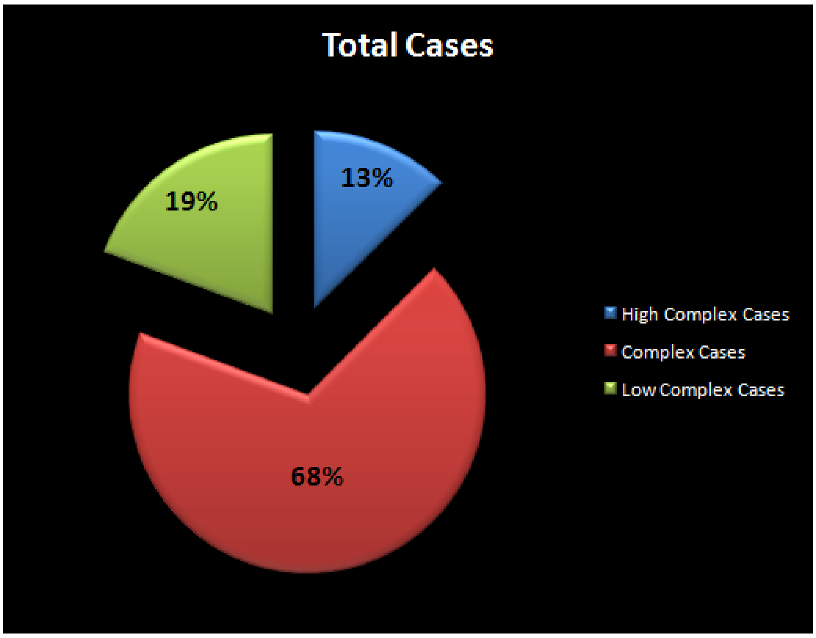


Figure 11: Spectrum of complexity of cases.

In *Developing an Advocacy Service for People with Disabilities (2004)*, it was envisaged that the Community and Voluntary Sector Programme would work with complex cases. This evaluation showed that the majority of cases were complex, tapering at each end of the spectrum to encompass some high complex cases and at the other end of the spectrum low complex cases.

In the analysis, the majority of cases were complex cases that fell into the category envisioned in the report as suitable to Strand 2 (Goodbody 2004). To understand the work of each level, a typical case-study is presented in each of the categories.

High Complex cases

Thirteen percent of cases were high complex cases, with some cases at the higher end that would have been envisaged as coming under the remit of the Personal Advocacy Service. High complex cases that were reviewed required considerable expertise and experience by the advocate in working through the case. Often the cases covered legal issues.

Case 14: High Complex Case – Two Jurisdictions

Janice and Fred are Irish social welfare pensioners who lived in England and bought a house in 1989 while resident there. After some years, they returned to Ireland and handed back their English house, agreeing to pay the mortgage shortfall eventually from an expected inheritance. Ten years later the mortgage company lodged a claim against Janice and Fred. A hearing was held by telephone conference and a judgment given to the mortgage company to include interest. Two years later Janice and Fred were given one month to appeal a high court order recognising the judgment. They were unable to sell their inherited land to pay the debt as it was leased under the REPS scheme until 2010.

In poor health, and on very low income, they needed support in accessing expert advice to enable them to negotiate an agreement around paying the debt without further escalation of interest. Janice's health was severely impacted by the stress of the situation adding to her existing depression. She had made 33 phone calls seeking assistance before finding the advocate. The advocate supported Janice and Fred in making a plan – "nobody could have done what she did for us" The advocate sought all the relevant information in relation to the legalities in both jurisdictions, and supported Janice through the telephone hearing. She worked with Janice's solicitor, whom Janice quoted as saying "I couldn't have done the work without the help of the advocate".

Pensioners, Mental Health issues, low income

Repossessed family home

Inheritance

Sale of land

UK judgement in favour of mortgage company.

Health deteriorates

Needs help to access expert advice

Advocate sought relevant information in two jurisdictions

Advocate supported service user in telephone hearing with UK Court

The advocate enabled Janice and Fred to avail of the services of the Voluntary Assistance Scheme (Bar Council) through liaising with relevant solicitors and barristers in preparing the appeal. She was dedicated to finding out what could be done. The case is ongoing and the advocate continues to assist Janice and Fred in resolving the complicated issues in relation to inheritance and sale of land.

High complex cases required time to work through the myriad of issues, understanding of those issues and liaising with professionals working through complex matters. Parallel to this structured and focused work, the advocate is also working with people with disabilities who are very vulnerable and fragile, whose health in these high complex cases may be deteriorating. Although not specifically recorded, an underlying pattern for the service user was their increasing capacity as they worked with the support of the advocate.

In the absence of considerable expertise and experience in specialised areas, there could be a risk to the service user. In one case, the advocate challenged medical personnel on the medication prescribed for a service user illustrating the very real danger of an advocate operating outside her area of competence. This highlights the need for on-going supervision.

Case 15: High Complex Case: "We live in a world of economics not people…"

> *Patrick has Multiple Sclerosis and is paralysed from the neck down and has some cognitive difficulties. Patrick is separated and has two children, who live in another European jurisdiction with his partner. Patrick has not seen his children for two years.*
>
> *Patrick was looked after by a member of his family, but he entered residential care as she could no longer care for him. Patrick is very unhappy in care and the recreational facilitator within the home referred Patrick to the advocate.*
>
> *Patrick's issues included finance; independent living; medical support and access to his children.*

> *Patrick's family was not in favour of his travelling to see his children. The advocate worked on his behalf and secured a trip to Europe for Patrick. This required protracted negotiations with management in the residential home.*

In interviews with the evaluator, Patrick said that he had to push very hard for an advocate as the residential home:

> "Doesn't like advocacy because it shows the weaknesses in their ability to meet the needs of the service user".

Referring to the advocate, he said:

> "The advocate has become a great partner in trying to fight for what I need."

He said the fight is for human dignity and he felt his disability is used against him.

> "They (the home) have stripped me of my dignity. I am rotting here."

Patrick felt that independent living would give him a quality of life he doesn't have.

> "Realistically, I think the bureaucracy is insurmountable."
>
> "We live in a world of economics, not people."

Patrick says that the advocate ensures his rights are upheld – rights that the Ombudsman feels he should have.

High complex cases take a toll on the advocate not only in time, but in personal engagement. For some of the highly complex cases with very vulnerable people who were socially isolated, there can be a high emotional impact on the advocate. External and/or internal supervision was seen as critical in the management of these cases.

Complex cases

Sixty eight percent of cases were complex cases. This is the central focus of this programme and where it is envisaged that most advocacy is needed. Complex cases covered a wide range of issues and had different foci of complexity. In some cases, the complexity emerged because the service user was vulnerable, in other cases, the complexity emerged because of the number of different agencies involved and in other cases, the complexity emerged from the issue itself. The intersection of the needs of the service user, the provision of the service provider and the range of issues increased the complexity of the work.

Case 16: Complex Case – Maybe I was hurting the people who hurt me....

Donal has just turned 60 years of age. When he was four, his aunt placed him in a residential institution. Donal has lived in two types of enviornments during the subsequent 56 years – in residential settings and as a homeless man. He is now confined to a wheelchair and has significant physical and verbal limitations and for 10 years has lived in an old people's home. During a period of homelessness, Donal assaulted his friend who died. Through his advocate, he composed a letter to the court – an excerpt as follows:

> *"......There have been so many bad things happen to me and when I hurt Martin, maybe I was hurting all the people who hurt me or maybe I was just a homeless drunk having another fight with my friend..........*
>
> *......I don't want to live that way ever again. I am being supported by an Advocate who is helping me look at my options, so I can help myself have a better future where I can be safe and not have to be the "Donal" that lived on the streets.*
>
> *.....I know I can't tell my friend I am sorry, but I hope that by making a better life for myself, I can show how sorry I am."*

Physical Disability

Inappropriate living

In 2009, Donal, with the help of his advocate, moved into his own home. Not being used to silence in the home, the advocate is assisting him in getting a dog.

This was a multiple issue case, where the advocate was supporting this man in independent living. The advocate has worked with the service user since May 2005. State agencies involved in the case include the local authority, An Garda Síochana, Court Services and Department of Health and Children. The advocate spent considerable time building up trust with the service user and then working on his behalf to ensure that he received the services he needed. The advocate expects that in five years, she may be working with the service user again to secure residential accommodation because of his deteriorating health.

Case 17: Complex Case: Unfair Dismissal

Stephen suffers from depression and was dismissed from his employment. He was out of work on sick leave and dismissed without notice. He felt that he was discriminated against on the grounds of his disability and insisted on an investigation. Over seventy hours of advocacy work went into this case which involved the advocate supporting Stephen in his efforts to bring this case for unfair dismissal to the Employment Appeals Tribunal. The advocate researched similar cases and decisions from the Employment Appeals Tribunal and supported Stephen in making his submission, in completing his statement of response to the other side's submission and represented him at the tribunal. Following an award to Stephen there was an appeal and the advocate supported Stephen as his case went to the Labour court.

Tasks of the Advocate

Support to bring an unfair dismissal case

Research

Support in submissions to Employment Appeals Tribunal

Representation at Tribunal

Low complex cases

Nineteen percent of cases were categorized as low complex cases. Low complex cases often fell into providing information for a person with disabilities.

Case 18: Low Complex Case

> *Mary is 24 years old, registered blind and moving into independent living. She sought an advocate to help her with applications for benefits package, living alone increase, fuel allowance and rent supplement. Mary had difficulty in reading the correspondence and forms.*

In this less complex case, the work to be done was straightforward. However, because of Mary's disability, the case took five months to complete. Low complex cases raise a serious question in relation to their inclusion in the advocacy case load. Mary's case may have been an appropriate case for an Information Officer in the local CIS. There is some evidence that in some CISs when a person with a disability comes for information to an information officer they are automatically referred to the advocate because of their disability. With a mainstreaming remit, this should not happen.

In a number of projects that presented with a significantly higher case return than the norm, the evaluation found that there were a significant number of information provision cases recorded as advocacy cases. In some instances the sending out of medical card applications was recorded as a case. Usually these cases were recorded as having been opened and closed on the same day.

Many advocates, however, were strong in their view that this work is a gateway for those with a disability to bring serious issues to the advocate.

A closer analysis of the cases presents interesting data, especially within the peripheral high and low complex cases.

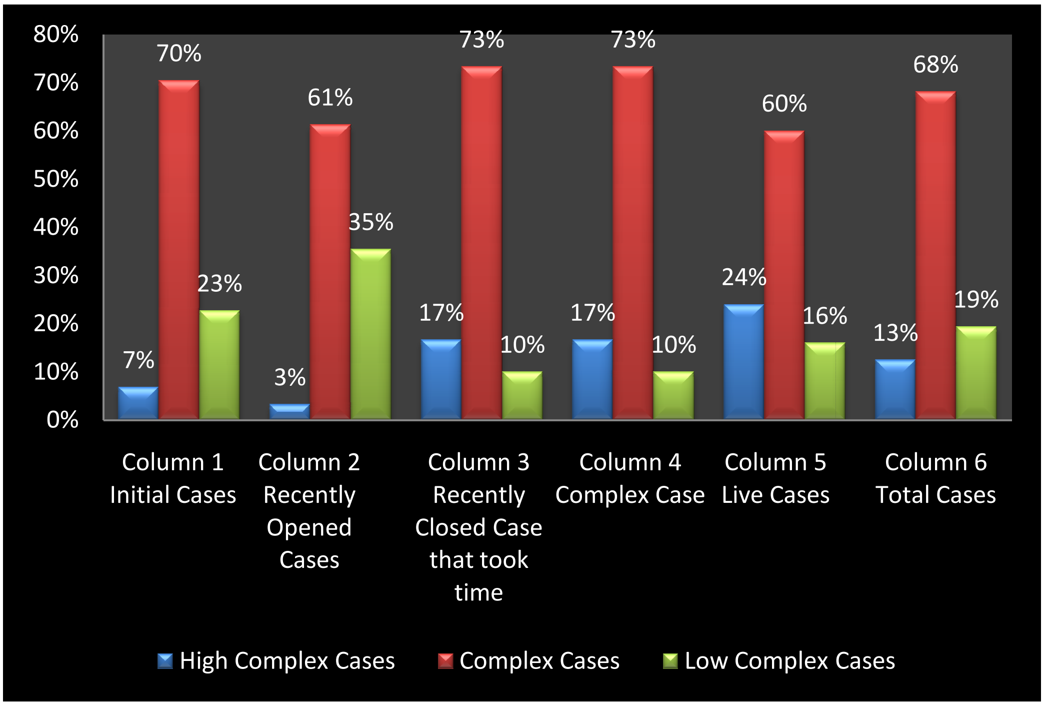
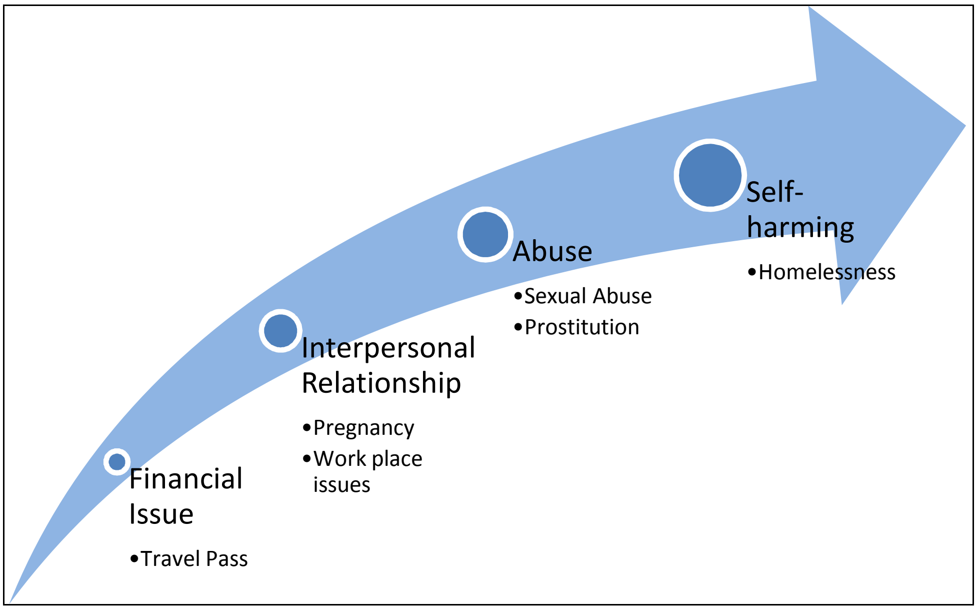


Figure 12: Distribution of Cases according to complexity

In the in-depth review of cases, data was analysed through different lenses. In the total number of cases analysed (Column 6), complex cases averaged 68%. Within a range of 8%, this is replicated, in each of the categories analysed.

An interesting pattern emerges when there is an examination of the relationship between each of the levels of complexity. In column 6, the low complex cases plateau at 19%. In the *Initial Cases* requested, (column 1), low complex cases represent 23% of cases analysed. However, in the *recently opened cases* (Column 2), low complex cases represent 35% of the cases. When data is analysed on *recently closed cases that took time* (Column 3)*,* this figure drops considerably to 10%, a figure that is also replicated in the *complex cases* (Column 4). Equally, the number of High Complex cases moves from 7% (Column 1) to 3% when recently opened (Column 2) to 17% when recently closed (Column 3) and when analysed as a complex case (Column 4). In the live cases analysed, high complex cases consisted of 24% of all cases (Column 5).

In one case reviewed, the service user first approached the advocate with an information issue. Over the next three years, the advocate has supported this service user in dealing with high complex issues.



Case 19: Low complex case that became a High Complex Case

This case above relates to a young woman who first made contact in November 2006. Ten issues have come to the advocate and each one grew in complexity, demonstrating the absolute vulnerability of the service user. The gateway of entry started when the service user sought the help of an advocate in accessing a travel pass – an apparently routine issue. Several months later the advocate was supporting complex issues at the upper end of complexity.

3.6. The Personal Advocacy Service

> ***An entire society can go into denial frequently and regularly over issues of gross injustice effecting the most voiceless and the most vulnerable.***
>
> ***Mary Rafftery – States of Fear, 2010***

In *Developing an Advocacy Service for People with Disabilities, (2004)*, it was envisaged that the first stage for the Citizens Information Board in implementing advocacy provision was to be the Community & Voluntary Sector Programme. Two years later, the Personal Advocacy Service (PAS) was to follow. The Citizens Information Act (2007) made provision for PAS in Sections 4 and 5. These sections have not yet been implemented. The distinctive aspect of advocacy under the PAS was the statutory powers given to advocates. The legislation envisaged that qualifying people with disabilities would be prioritised according to the seriousness of their case, non-availability of other advocacy services, and high level of risk of harm to the person's health, welfare or safety if he/she were not provided with the services that person was seeking to obtain.[22] The evaluators found a small number of cases that could have qualified for the Personal Advocacy Service and where the presence of statutory powers could have been crucial. In the absence of the implementation of the Personal Advocacy Service, there is no planned service to ensure the effective provision, delivery, co-ordination and review of the Personal Advocacy Service, as outlined within Section 5 of the Act to meet the needs of people with disabilities. Cases pertinent to a PAS are being dealt with, but without a planned service, are particularly time consuming. The needs of people with disabilities could best be served by a degree of integration between the proposed Personal Advocacy Service and the existing Community and Voluntary Programme.

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[22] S5(3)(a)(ii) Citizens Information Act 2007

3.6.1. Legislative Context – Citizens Information Act 2007

In 2007 the Citizens Information Act was passed. Section 4 amends the Comhairle Act 2000 with regard to an expansion of the role of the Citizens Information Board to advocacy for people with disabilities beyond its remit of mainstream information, advice and advocacy. In 2008, the implementation of PAS was placed on hold due to lack of government resources. As a result, the Sections of the Citizens Information Act (2007) relating to the Personal Advocacy Service have not been implemented to date.

The provisions of the PAS, as expressed under the legislation, stipulates that the Citizens Information Board provides, or arranges to provide, a personal advocacy service.[23] This provision is subject to public finance and whether the qualifying person can obtain advocacy services otherwise than under the Act.[24]

The legislation recognises the need for Personal Advocates to have relevant qualifications, experience and expertise[25]. The role of the personal advocate is to assist, support and represent the qualifying person with disability in the Assessment of Need process; in obtaining social service or services and to pursue a review, reference or appeal to a body other than a court.[26] The personal advocate is entitled to enter premises, access information, attend meetings and consultations, and identify relevant family members who may assist the person with a disability.[27]

The legislation envisages that the Citizens Information Board can decide how the Personal Advocacy Service would be made available to those who have a disability. Not all people with disability require the assistance of an advocate. For those who do, the vast majority will be assisted through mainstream information, advice and advocacy services and through the Community and Voluntary Programme Advocacy Service for people with disabilities. The legislation envisaged the PAS as targeting those who are

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[23] S4 (a) Citizens Information Act 2007

[24] Ibid.

[25] S5 Citizens Information Act 2007, amending the Principal Act under section 7A (2)

[26] S5 Citizens Information Act 2007, amending the Principal Act under section 7D

[27] Ibid.

most vulnerable particularly in relation to the proposed Assessment of Need and other formal complaint and review projects. This “most vulnerable” sector includes people with very significant levels of disability, those in residential centres, particularly those who are inappropriately accommodated, those who are socially isolated and those with limited communication skills.

The Citizens Information Act [2007] sets out criteria for a person to qualify for the Personal Advocacy Service[28]. These are

- The Person is not less than 18 years of age and in the opinion of the Director of Advocacy
    - Is, by reason of their disability, unable to obtain or has difficulty in obtaining a particular social service or services without the assistance or support of a personal advocate; and
    - There are reasonable grounds for believing that there is, in relation to the person, a risk of harm to his or her health, welfare or safety if he or she is not provided with the social service or services that he or she is seeking to obtain
- The Person is under 18 years of age and
    - his or her sole parent or guardian is a qualifying person

      or
    - He or she has a disability or in the opinion of the Director, there are reasonable grounds for believing that he or she has a disability, and in either case the circumstances are such that it would be unreasonable to expect a parent or guardian of the person to act on his or her behalf in obtaining a particular social service or services without the assistance or support of a personal advocate.

      And in the opinion of the Director there are reasonable grounds for believing that there is, in relation to the person, a risk of harm to his or her health, welfare or safety if he or she is not provided

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[28] S5 Citizens Information Act 2007, amending the Principal Act under section 7A (3)

with the social service or services that he or she is seeking to obtain.

The legislation also sets out the criteria to be considered when determining priority for cases within the Personal Advocacy Service[29]. These are:

- The needs of the qualifying person
- The degree of risk of harm to the health, welfare or safety of the qualifying person if they are not provided with the social service or services that they are seeking to obtain
- The benefits likely to accrue to qualifying persons if personal advocates are assigned to them.
- The availability to qualifying persons of other Advocacy Services

The legislation does not prescribe how the Personal Advocacy Service will be provided, but rather devolves this function to the Citizens Information Board.

In the absence of the implementation of the legislation, the availability of advocacy to some of the most vulnerable in society is not available. While it can be seen in the following cases that experienced advocates within the Community and Voluntary Sector are taking on PAS type cases, there is limited access of advocacy to many of the most vulnerable people with disability.

3.6.2. Legislative Provisions

The legislation is designed to provide an advocacy service for qualifying persons with disabilities prioritising those who are vulnerable.

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[29] S5 Citizens Information Act 2007, amending the Principal Act under section 7A (5)

3.6.3. Powers of the Personal Advocate

In advocating for those qualifying for PAS, the personal advocate would have certain rights under the legislation. A personal advocate assigned to a qualifying person under the Act would have the power to:

> *"enter any place where day care, residential care or training is provided for the person and make such inquiries in such place in relation to the person as he or she considers appropriate. A personal advocate, subject to the Data Protection Acts 1988 and 2003, could obtain from a statutory body or voluntary body any information relating to the person that the personal advocate considers necessary", and "attend and present the person at any meeting, consultation or discussion at which the interests of the person are being considered".*[30]

When evaluating the Community and Voluntary Sector Programme, the evaluation team considered, from the cases presented, whether advocates were able to enter residential settings, access information and/or attend meetings and consultations with service users, given that the provisions of the Personal Advocacy Service were absent.

Entering Premises

In reviewing the cases from the current *Advocacy Programme for People with Disabilities in the Community and Voluntary Sector*, the evaluation found a wide variation of access to premises – i.e. residential or day-care services. However, in all cases, access is dependent on the goodwill of the management of those premises.

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[30] Ibid 7 (d)

In one case, the advocate recorded that she had two residential homes within her area. One home was initially reluctant to give her permission to access the home, but when she began working with some of the residents, the service provider was more open to her presence and over a period of time, changed their policies and procedures to allow access. In the second residential home, the manager was clear that the advocate could not enter the premises to provide advocacy to residents.

In a second case, the advocate worked in a day care centre attached to a residential home. There were clear guidelines given to the advocate. She could provide advocacy for people with disabilities who lived in the community. However, those who resided in the home and attended the day care centre could not be provided with advocacy.

In a third case, the advocate reported providing advocacy for one resident in a home but being prevented by the manager from providing advocacy to another resident who requested it.

In a fourth case, a member of the public requested that the advocate would meet with a resident of a home, but the advocate was not given permission to meet that resident.

These instances create a major concern that in the absence of a right to enter premises by a personal advocate, there is a serious risk that those who are most vulnerable may be denied their right to advocacy.

Case 20: Afraid to object

> *A resident objected to the fact that his disability allowance was being used to fund services for other residents. This was successfully dealt with by an advocate. However, the advocate had concerns on behalf of other residents in relation to the institution's policy regarding residents' finances, but did not have the authority to act on behalf of others without a referral.*

This issue of victimisation was also raised with dependent service users fearful of victimisation if complaints were made. If PAS were implemented, the advocate would have greater rights to enter such institutions and to seek documentation on money holding and other practices.

There are a number of cases where it has taken considerable time to secure the service of an advocate.

> **Excerpt from a case note:** *I have had a few cases where access to a service user on a one to one basis has been denied at first, or I have been told that due to their serious mental health (difficulty), a formal interview with an advocate would not be in the best interests of the service user. Obviously, I've pushed these cases further, but it does make things more difficult and the advocate is often kept out of the loop re protocols etc. Whether this is a case of the staff forgetting or not, I could not say, but they definitely don't like the idea of the advocate interfering with strategies and the old chestnut of risk management is often used as an excuse.*

Attend meetings

The legislation would give the personal advocate the right to attend meetings and consultations with and on behalf of service users. This is a key function in ensuring that a service user's needs and wishes are heard and taken seriously and service users have commented on the favourable difference the advocate's presence made at a case conference. In the review of *Community and Voluntary Sector* cases, the evaluation team considered incidences where advocates attended or were denied attendance to meetings.

Case 21: I attended anyway

> **Advocate Report:** *I was asked by the service user to act as his independent Advocate in relation to the planned placement of his children, by the HSE, in*

> *long- term permanent foster arrangements against the wishes of both parents and with no consultation with the service user or his wife.*
>
> *Having contacted the HSE and requested that I be given permission to attend a "Care Planning Conference" on the children as the service users Advocate, I was informed by the HSE Social Worker that my attendance would only further complicate the case. However, without their approval I turned up to represent my service user at the conference.*
>
> *Since then, I have attended meetings with senior social workers and the family. They now discuss future dates of meetings with me.*
>
> *If I had not asserted myself and attended the Care Planning Conference, the service user would have been prevented from effectively using our advocacy service.*

In many cases, once the role of the advocate is clarified, the initial resistance is dissipated and can sometimes change to support. The fact that advocacy is a new service means that there is necessarily a period of negotiation while service providers, as well as users, become familiar with it. However, the advocate may spend more time in negotiating access and consequently more time on the advocacy case than if he/she had statutory powers available to assist should providers did not co-operate.

There were also instances where the advocate was denied attendance at meetings involving the service user. In some cases this was because there was a lack of awareness about the role of the advocate, but in others it appeared that access was denied because the advocate's attendance was not backed up by a statutory right.

Accessing Information

Access to information about the service user is important if the advocate's support is to be useful. While many advocates, with the consent of the service user, are given access to information (service user files, etc), in a number of situations access to this information was withheld. In one case, a family member sought to withhold information about alternative accommodation from the person with a disability. Without the advocate, he would not have known the options available to him.

Case 22: Non-instructed Advocacy

Martina is a 30 year old woman with a severe to profound intellectual disability. The advocate is working with her.

The advocate became aware that the HSE and the day service had serious concerns about Martina's safety and welfare and began non-instructed advocacy seeking to find out more about Martina and to advocate for her needs.

PAS would enable

the Advocate to access information without fear of intimidation in the best interests of the service user

The advocate gathered information in order to make a complaint about the interval between the first suspicions of abuse and the decision to remove Martina to residential care. She asked for information from the HSE about possible reporting of concerns to the Gardaí.

This case highlighted considerable concerns and possible conflicts of interest as Martina's placement in foster care has been overseen by the HSE since childhood. The service provider has taken independent legal advice and is currently making a submission to the Wards of Court office.

During the course of the case the HSE spoke of taking a complaint against the advocate but did not proceed with this. The advocate remains involved with Martina.

In this case, the service user was in foster care placement for more than 10 years. During this time, there was significant family neglect. Had the PAS legislation been enacted, the advocate would have had a right to access information including the service user's files, without the fear of intimidation and in the best interests of the service user.

> ***Excerpt from a case note:*** *I had one particular case where the service user was very vocal about what she wanted i.e. not to move out of her home. The multidisciplinary team and service provider took actions regardless and she was moved back home to her family. The psychiatrist made a call that this was in her best interests. There were also several meetings about what authority I had to view her clinical files. I think a case of this serious nature would benefit from having a PAS.*

3.6.4. Obtaining Services

The Citizens Information Act allows an advocate

> *"to assist, support and represent the person...in relation to an application, assessment and service statement....or to obtain a social service or services...and if the personal advocate considers it appropriate to do so, to pursue any right of review, reference or appeal to a body other than a court if the application for such service or services is refused".* [31]

The Right to an Assessment of Need (as set out in the Disability Act 2005) is at present postponed except for those under 5 years of age. When Assessment of Need comes on stream for all, requests for Personal Advocacy Services will inevitably grow. At present advocates in the Community and Voluntary Programme may assist people with disabilities at HSE assessments and reviews and at Social Welfare meetings. In this regard, the evaluation team considered areas that have arisen in the Community and Voluntary Sector Programme that are applicable to the PAS.

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[31] Ibid S7

Individual Needs vs. Family needs

Issues arise where service users' needs are seen as secondary to their family wishes and without access to an independent advocate they have little power to change their situations. This was a particular concern in one case where agencies including the HSE and Local Authorities had been involved with a family.

Case 23: Need for a Care Package

Maurice is a 37 year old man with significant physical disabilities. He communicates by means of a pathfinder system. Maurice lives in an isolated area, cared for by a family member. The HSE has been involved with his family for 20 years. Maurice was referred to an independent advocate for help in future planning after a training course. The family had experienced serious breakdown involving abuse issues, safety issues and Maurice's need for respite care. The HSE decided on continuation of homecare with some additional support. Twelve months later the advocate became involved again when Maurice disclosed emotional and physical abuse and the advocate – with Maurice's consent - then sought a new care package to meet Maurice's needs.

PAS would have identified

Right to a personal care package

Importance of independent advocate where an individual and family have had a long involvement with existing services

The service users needs and wishes that differed from those of his family.

In this case, the HSE social worker's focus appeared to be keeping the family together. However, that may not always be in the best interests of the person with a disability who, in this instance, needed an advocate to ensure his rights were safeguarded. Similar issues arise where service users' needs are seen as secondary to their family's wishes and unless they can access an advocate through a service provider, they have little power to change their situations.

Finding a suitable placement for a person with a significant disability involves a number of issues including the person's wishes, family preferences, past history of care, personal advocate availability, medical support required, costs etc. The option easiest for a Disability Manager to organise – care in a home – may not be the one most suited to the person and it is here that an independent advocate can be of major value.

Making a complaint

Service users can sometimes be fearful of approaching service providers in relation to complaints and difficulties and so need the ongoing support of an advocate. If the PAS service were available, residential homes would be more likely to engage systemically with the advocate and have formal complaints mechanisms in place.

Case 24: Making a complaint

Jennifer lives in a nursing home where she is fully dependent on her carers. Jennifer is in dispute with the nursing home over some aspects of her care and is being physically restrained and denied food of her choice. An advocate visiting a service user became concerned at Jennifer's treatment, but Jennifer refused to make a complaint for fear of further victimisation by staff. The advocate contacted a HSE manager and support services were put in place for Jennifer. The advocate was not in a position to follow up with other residents to query practices.

PAS would enable

an advocate to follow up with all residents to ensure that standards are being upheld.

Cases where a staff member in a residential institution asks an advocate to intervene on behalf of a service user are particularly challenging because of the difficulties such intervention can raise for the staff member. Families who are not happy with the service user's care may also be afraid to "*rock the boat*" PAS would establish the right for concerns to be raised about practices and for this to be followed up through advocacy.

Managing Challenging Behaviour

In the 2009 *Annual Report on the Community and Voluntary Sector Advocacy Programme for People with Disabilities*, concern was raised on two instances of where a challenging behaviour has led to withdrawal of rights. In one residential home, there was "a *culture of denying advocacy, social activities and other services in response to challenging behaviour."* In another a service user was denied home visits because of challenging behaviour before his return to the service.

In situations such as these, where rights are restricted due to a service user's behaviour, it is important that a statutory based advocacy service is available to the service user.

Support at official processes

Support from an advocate can be extremely important in the lives of many people with disabilities. Some advocates have very good standing with other professionals and this enables them to move on a case quickly and to receive the information required. Other advocates encounter many obstacles from bureaucratic structures. To rely solely on the goodwill and relationship between professionals and advocates to obtain services is not sufficient. Having statutory powers will enable the advocates to ensure that those with a disability are supported in formal processes and receive fair treatment.

Case 25: Rights and Entitlements

Jane has an intellectual disability and is the mother of a 10 year old daughter, also with an intellectual disability, who is in foster care. Jane's ultimate hope is that her daughter will return to live with her full time. She has had access to her daugher but her daughter is now refusing to see her. The HSE are investigating abuse allegations from the past and Jane has needed support

PAS would ensure

Advocate establishes and protects Jane's right to participate in the HSE child protection process and the decisions being made around her daughter.

Advocate has actively supported Jane in negotiations around appropriate access arrangements.

The voice of parents with an intellectual in accessing this information about her daughter and in being recognised as a decision-maker in her future. She has been supported by the advocate at case conferences and now has more understanding of the reasons and dilemmas of access in this difficult sensitive and disturbing case.

Case 26: Ward of Court – compensation fund

John had an accident in childhood leaving him with a mild intellectual disability and is a wheelchair user. John lives in care with little contact with his family. A large compensation fund is available for him, which is in trust until he is 18. His wish is to access his compensation and establish independent living. His service provider has serious concerns that his family of origin are now reappearing in his life and that his compensation fund may be in danger if he has total access to it. The service provider wishes to make John a ward of court and his advocate has serious concerns around the restrictiveness of such legislation for John in the future. There are a number of different possibilities that could be explored to address all the concerns.

PAS would enable

John's advocate deals with the conflicting needs and concerns of those involved in John's life and the different legal options available to ensure that John is empowered to live independently while protected for the future.

Case 27: Ward of Court Issues – Inheritance.

Two sisters – Mary (who has a mild intellectual disabiltiy) and Ann (who has a moderate intellectual disablity – have a brother James. Their mother died without making a will and James took over the administration of the estate. The sisters should have benefited equally from the

PAS would enable

Advocate to address issues of intestacy, wills, ownership of the family home on behalf of the two sisters, ensuring that their rights are preserved.

estate. Mary was unable to advocate on behalf of herself and her sister (in full time residential care.) James, her brother, has taken over registered ownership of the family home.

Court and Court issues can be an extremely challenging for most people. For the most vulnerable in our society, the support of an advocate is critical, not to take over the legal role but to explain to the service user what is going on and explain his or her wishes to the lawyers involved. Where the court is unaware of the role of the advocate and denies access in *in-camera* proceedings, the service user can be left extremely isolated. A PAS advocate with statutory powers would be less easy to dismiss in these circumstances.

3.7. Social Policy

> ***People who are satisfied with their lives and have choices and opportunities are more likely to be creative, productive and healthy, and bring benefits to the overall well-being of society.***
>
> ***NESC 2009:1:22***

Through the evaluation of cases and interviews with service users, advocates and other stakeholders, the role of the Citizens Information Board in the development of social policy was apparent.

When a social policy issue presents itself, it normally does so when a number of cases on similar themes present themselves. Two examples of some social policy issues that have been identified within the *Programme of Advocacy for People with Disabilities in the Community and Voluntary Sector* are:

Case 28: Inappropriate use of nursing home

Due to the lack of appropriate respite facilities, some adults with an intellectual disability are being placed in nursing homes. Examples from the casework included:

- A brother and sister, both with intellectual disabilities, needed respite care because of medical crises in the lives of the carers' family and extended family. The only service available was nursing home care. They spent 5 and 15 months respectively in nursing home care. The brother was in his forties and had no medical issues.
- A fifty year old man with moderate intellectual disability and no medical needs is currently living in a nursing home with his mother who is in her late eighties.

The advocate's intervention in these cases is to seek appropriate accommodation for the service users. As part of the work, the advocate found a commonality between the cases and referred the issues to be considered by the Citizens Information Board as a Social Policy issue.

Case 29: legislation and financial abuse

Due to a lack of appropriate legislation, some people with intellectual disability are vulnerable to financial abuse.

The service user has a moderate intellectual disability and lives in full time residential care. Following the death of her father, the service user has a civil service dependant's pension that amounts to more than €600 each month. This pension is lodged into an account in the name of the service user and her brother. However, the service user only receives on average €200 per month. The advocate has calculated that more than €10,000 of the pension that has been paid into the account in the past 7 years has not been received by the service user. The "built-in safety check" is not working as it should. Each month the service user's brother signs a document for the administrator of the pension scheme giving assurance that the money is being used for the service user's needs and that she continues to live with him. The service user's GP co-signs a document once a year for the administrator of the pension scheme also giving assurances that the pension monies are being used for the service user's needs.

How the issue is progressed

Advocate highlights the issues with the Management Steering Committee

The steering committee begin discussions with the Local Health Officer

There are many similar examples of cases that require social policy interventions in favour of those in society who are most vulnerable. Access to issues and case studies is critical in the presentation of social policy concerns in order to effect change at a macro level.

The *Programme of Advocacy for People with Disabilities in the Community and Voluntary Sector* has its focus on representative advocacy, where advocates provide a personal individualised service to people with disability and the advocate speaks up on behalf of the individual. On the frontline, advocates have in-depth awareness of the ways in which national social policies and structures are being implemented and experienced by vulnerable people and this is a critical resource in national policy development.

The agreed protocol for highlighting issues within the programme is through upward feedback, coming from the advocate, lead agencies, steering groups so that the Citizens Information Board can present evidence-based examples to Government in order to seek change.

The majority of advocates use this mechanism to raise social policy issues. In this evaluation, however, there was evidence that some advocates make individual policy submissions. This raises a concern that individual advocates could become focused on public policy advocacy and move away from the individual needs of the person with disabilities. In addition, the time spent on developing policy submissions takes from the available time to advocate on service users' behalf.

The Citizens Information Board's main social policy aim is to increase capacity amongst Citizens Information Services and advocacy projects in order to create better access for people with disabilities and get feedback on issues arising. Where there is strong evidence, based on real cases detailing the effects of access or lack of it to services or to rights and entitlements, the steering committee or the Citizens Information Board when informed, engages with the relevant policy makers.

4. EVALUATION OF FINDINGS – PROGRAMME STRUCTURE

4.1. Programme Structures

The Makeup of the Programme: Project Structures

In accordance with the recommendations provided by the Citizens Information Board in the *Advocacy Project Resource Pack*[32], each project has established a structure that has a lead agency taking responsibility for the employment and management of the advocate within the project. The lead agency receives funding and has legal responsibility for the operation of the project. Each lead agency appoints a line manager to manage the advocate on a day to day basis. In each project, a steering group is formed that takes responsibility for the planning and review of the project. This steering group is made up of a number of organisations including:

- Project staff, project director and line manager;
- Citizens Information Board representative;
- Representatives from relevant external statutory and voluntary agencies, such as the HSE, local authority, FÁS, Department of Social and Family Affairs, Area Partnerships and Citizens Information Services;
- Family and friends representative groups;
- Local relevant service providers, including residential institutions;
- Service users, potential service user groups and disabled people's representative organisations.

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[32] Revised September 2008

There are currently forty six projects in operation located in twenty three counties:

LEAD AGENCY	No of Projects	PROJECTS
Centres for Independent Living	5	Blanchardstown, Carlow, Greater Dublin, Galway, West Limerick
Citizens Information Services	16	Ballyfermot, Co. Clare, Clondalkin (2), Co. Leitrim, Co. Longford, Co. Mayo, Co. Offaly, Co. Westmeath (2), Cork City Centre, North Kildare, Co. Roscommon, Co. Sligo, Tallaght, Co. Waterford.
County Partnerships and Integrated Development Companies	5	Blanchardstown, Bray, Ballyhoura, Monaghan, North & East Kerry
Disability Organisations	20	Clare, Cork (4), Donegal, Dublin (8), Galway, Meath, Monaghan, Tipperary, Wexford, Waterford.

Table 1: Lead Agencies and Projects

Profile of Projects

-
- Nine of the projects operate within a residential setting; twenty three in a community setting and the remaining fourteen work in both.
- Twenty projects are cross-disability serving all types of disability, two are non-specific involving more than one but not all disability types and twenty four projects are specific disability projects focusing on one disability type.

All Disability Types	20 Projects
Intellectual, Physical and Sensory	2 projects
Intellectual	13 Projects
Physical and Sensory	4 Projects
Mental Health	4 Projects
Dementia	1 Project
Asperger Syndrome	1 Project
MS & Neurological	1 Project

Table 2: Classification of Projects by Disability Type

4.2. The Programme Review

During its life span, the Programme has touched a significant number of service users, disability organisations, residential institutions, agencies, service providers, volunteers, public, carers and community representatives. The projects cover a significant geographical area and contain a substantial body of knowledge and experience. In evaluating programme structures several critical questions were considered:

- Is the ***independence*** of an advocate influenced in any way by the structural arrangement of the project within which they advocate?
- Is the ***quality and level of service*** offered by the advocate in any way impacted negatively or prevented as a result of the structural arrangement of the project within which they advocate?
- Does the structure of the projects and the programme enable the advocate to deliver ever ***increasing value*** to their service users while also enabling all stakeholders to gain the maximum possible value through their involvement and investment of time?
- Is ***collaboration and partnership*** enabled through the project and programme structures as a way of providing a better outcome for service users?

- Does the ***level of diversity*** that exists in project steering groups enable ***optimum solutions*** to be found for service users?
- Do structures support or prevent the project from delivering the desired outcome?
- Is the structural arrangement of projects in any way preventing advocates from **reaching the most vulnerable**?
- Is the service user's right to be at the centre of ***determining their future*** being limited in any way by the structures of the projects and the programme?
- Is there an alternative ***structure*** that would better support the programme into the future?

The eight projects that were considered included projects at differing stages of development. Each had a steering group in place with varying numbers of members from all stakeholder groups. Each of the considered projects had commenced advocacy, having dealt with a number of cases and the sample consists of both residential and community-based projects including both citizen advocacy and representative advocacy.

A number of observations were made in the areas of focus following the evaluation team's visits to projects. The findings are discussed relative to seven domain areas;

1. *Strategy and Purpose*
2. *Reach*
3. *Integration and Cohesion*
4. *Collaboration and Partnership*
5. *Independence*
6. *Steering Group Practices*
7. *Project Practices*

4.2.1. Strategy and Purpose

In the early part of the programme in 2004/05, following the plan set out in *Developing an Advocacy Service for People with Disabilities* (2004), the Citizens Information Board began the task of establishing the second strand of the recommended programme. This involved creating strategy, structures, policies and approaches in partnership with the disability sector. The approach taken was an iterative one where learning from the first group of projects was used in the development of the next. Even with this learning, the task presented a number of challenges:

Lead Agency Role

- The diversity of organisations that became involved in the programme as lead agencies attracted a wide range of interest and expertise and provided access to people with a range of disabilities in an array of settings. Many of the organisations that took on the lead role acted as employer and provided administrative support and accommodation for an advocate working within a service, thus taking on responsibilities with no immediate gain for the organisation involved.
- The diversity of employer organisations meant that advocates worked in a range of settings with a wide variation in remuneration and conditions and standards across the programme. A sustainable programme needs to develop in a situation where policies and procedures, remuneration and conditions, advocacy practice, supervision and support, training and professional development are at a consistently high standard across the country.

Steering Group Role

- At the outset, many steering groups were unclear of their role, the role of the advocate and how the project was to operate. While the Citizens Information Board supported the initiative, lack of resources and previous experience ensured this was going to be a learning process for all involved. Many projects spent significant amounts of time in 'forming' mode before engaging with service users. This included the setup of steering groups, recruitment, policy writing, establishing facilities among others. This time spent was considered by many steering group members to be excessive with some projects waiting up to six months before seeing a service user. Other steering groups expressed appreciation of the significant learning over the period and the projects held a level of allegiance from stakeholders as a result.

- *"Host organisations that don't have a history of case work or disability may be at a disadvantage for the success of the programme"*

- *"The advocate spent six months writing before seeing any service users but the process was excellent in building an understanding of what advocacy is about"*

- Due to a lack of experience and competence in advocacy among many members a number of project steering groups reported that they looked to take direction on their role from the advocate who was more experienced. This included areas such as the appropriate advocate case-load, the boundaries of confidentiality and the types of operational practices that were appropriate in engaging with service providers.

  There is both reasonableness and risk associated with this approach. It is sensible for the advocates, in conjunction with guidelines provided by the Citizens Information Board, to play a significant role in the development of the service, its approach, its policies and its boundaries. However, there are risks in affording so much control over direction and policies to a single advocate, as it may result in a level of separation between the advocate, line manager and the steering group. Independence and confidentiality are two areas where members of steering groups are unclear as to how far the advocate could or should go when safeguarding them. Many steering group members have suggested that the approach taken by the advocate is leading to situations where the steering group is not always clear on what the advocate is doing or achieving.

- *"I am not sure sometimes whether we are a steering or consultative group. Is the action instructed by Steering or decided by advocate?"*

- *"We're lucky we have an excellent advocate who is experienced and points us in the right direction"*

- *"We have a view of what the advocate is doing through the discussion we have at steering on anonymised cases but it is limited"*

- Lack of clarity on what the advocate is doing or explicitly achieving, is also resulting in steering groups either questioning their value or finding difficulty in expressing their value to the project, other than in simple and generic ways such as

  - "We're providing support for the advocate", or

  - "We're providing advice to the advocate."

  This questioning in a number of cases stems from the changing in the life cycle of the project, from a start-up project that is maturing into a project that has bedded down. Much of the work involved in setting the project up transitions to a more operational mode. Each of the projects selected is at a different level of development in this regard.

- Other steering groups have sought to develop a working relationship among stakeholders, particularly with service providers. As a result, recurring issues have been acted on directly by the relevant service provider either at the meeting or indirectly through advising the advocate on how best to act on the issue in that stakeholder's organisation. This approach is considered by many to have a better chance of yielding results and to be very effective in creating change for service users.

  - *"I find the best way to get the steering group involved is to bring them through cases; it works really well"*

- ➢ *"I have a repeating service user issues list. It is the most vigorously discussed topic at steering."*

The degree to which this approach is adopted within projects is based on several factors. These include the ability and willingness of stakeholders to discuss their organisations' issues openly, while respecting the confidentiality of the service user and service provider staff in any particular situation. Equally, the level of engagement that the advocate creates through careful planning and preparation of cases or themes, safeguards the confidentiality of service users and facilitates focused issue-based discussion at steering meetings.

There are varying practices being used across the projects, from the advocate discussing only a limited number of case examples or critical themes to cases being discussed regularly in detail. There is no standard method used but the time spent reviewing cases that have been anonymised is the most valued by steering group members

- ➢ *"While a number of cases involve members of steering, they are happy to listen to them and try to action them".*

- ➢ *"I have had some cases that involved a member of steering directly; I was not sure on how much detail I could go into even when anonymised".*

- ➢ *"Independence is being confused with not sharing information"*

Steering Group Membership

- Many steering groups have expressed difficulty in attracting and maintaining membership. This is connected to two key issues. Firstly, a number of service providers, especially those in key state agencies, such as the HSE and county councils, are not responding due to the perception that they are being invited to a meeting of complaint, where issues will be raised and passed over for action. Secondly, maintaining ongoing interest and value for members is a continuing challenge. Steering groups work well when the members are engaged in real case issues, where they have the opportunity to advise or act and where those members can effect real change for people with disabilities and seeing the results of their effort. Having the right decision-makers on steering groups is critical.

- Many community based steering groups expressed a particular difficulty in attracting a representative from local authorities. Certain steering groups, however, did attract representatives and this made a difference to how the local authority responded to cases involving those with disabilities.

  In one particular relationship the local authority representative spoke about how, having worked with the advocate, they now appreciated the different approach that was required when responding to people with disabilities. The advocate in this case was trusted by the local authority representative to give a reliable account of the service user's needs and he felt that this would not be possible from many other services due to potential conflicts of interest in areas such as *'whose budget should pay for a solution'* or *'disagreement over who was responsible for resolving the issue'*.

  - *"Housing is a particular issue; we cannot get anyone to represent housing at steering; we are in touch constantly and get no response"*

  - *"The HSE were reluctant to join in order to avoid complaint. However, they did and it's been good for us all"*

  - *"We work with the advocate. We used to be clinically stamping and sending back forms if not filled out correctly; then we went on house visits with the advocate and saw the social issues. We trust the advocate now as someone who gives us the real picture, the facts. Now we get the cases that have most need highlighted to us, (those) that may be in the middle of the bundle. We have a budget and we need to get it to the neediest. The value: I saw it first hand, I went out to see before work was done and after it was done. I'm not in* *that job anymore, I don't know what they do now." Local Authority Steering Member*

To see the issue from beginning to end was central in creating solutions for people with disabilities in community settings. The trusting relationship that had developed between the local authority representative and the advocate as an independent representative of the service user led to a positive result for the service user and the local authority who were confident that the need was genuine and that fulfilling that need was a good investment of their resources.

Personal Advocacy Service

- A need for the Personal Advocacy Service (PAS) has been expressed but not in every project examined. Some projects felt that PAS was necessary and others did not. Those that saw a need for PAS had a range of reasons including:
    - Using PAS to gain access to closed or difficult-to-access institutions;
    - To push for change with service providers who placed barriers in their way;
    - 'Getting a seat at the service providers' table' to ensure they co-operated;
    - Using PAS to access the most vulnerable, and
    - Act on their behalf when there was risk of serious harm or neglect for a particular service user.

The reasons offered above demonstrate that statutory powers, while important in serious cases, are not routinely required and need to be used judiciously as over-insistence on their use could damage ground already gained with service providers and managers. In most cases co-operation is the key to progressing issues for people with disabilities who use services. The vast majority of steering members, advocates and line managers were clear about this.

- *"There is a need for PAS, for very difficult cases"*

- *"Do not bring in the legal side in mainstream advocacy. There is a need for PAS but it must be tightly controlled"*

- *"Legislative powers for project advocates across the board, no! Escalation path to PAS in the Citizens Information Board, yes!"*

Citizens Information Board Role

- The expertise and experience of the Citizens Information Board is hugely valued by the stakeholders. However, some steering groups are unclear on how to get the most out of it. Some are also unclear why the Citizens Information Board has not taken a more strategic leadership position even though they recognise that the programme is still in pilot phase. At present, there is a strategy in place for the pilot phase that has included the delivery and support of 46 projects through collaboration with disability groups and service providers. The Citizens Information Board area executives play a role on the steering group of each project. This involves communication between projects and programme; governance; reporting; practice support; advice and interventions where necessary, to ensure each project stays within its overall remit. Each Citizens Information Board area executive sits on between two and three project steering groups.
    - *"There is a reticence in the Citizens Information Board to take leadership, leaving local services to try and lead."*
    - *"The Citizens Information Board's role is to monitor pilot projects, champion independence and governance. They take a stand here."*
    - *"Without the Citizens Information Board we would not have the national picture. We'd be isolated. Through the Citizens Information*

Board's involvement at steering we have access to experiences of other projects and are aware of other work being done"

4.2.2. Reach

The programmes' ability to reach people with disabilities, particularly those who are most vulnerable, has improved over the duration of the pilot. This is as a result of project learning and a change of strategy. 2007 saw a targeting of 'broader county-wide projects' in counties where no advocate was then employed and negotiation with a number of residential services to allow access to an independent advocate. This enabled the programme to cover 23 counties as well as specific residential institutions. In the beginning demand was uncertain and resources limited and both the Citizens Information Board and the project managers had concerns that advocates could be overstretched.

- Projects reported that they had assisted people whom they considered extremely vulnerable. However, steering members from each project suggested that they had no real way of being certain that they were reaching the most vulnerable. The reasons for this varied. They included difficulty in identifying and locating vulnerable people; limited capacity to extend service to a wider group of people with disabilities; restriction on seeking vulnerable people with disabilities due to the anticipation of increased complexity of cases and the impact it would have on their ability to deliver the service in the absence of the Personal Advocacy Service (PAS).
- There is a variation among advocates and other stakeholders as to what represents a complex case, particularly when it is linked to the definition of "those most vulnerable". This group is not well defined in the first instance. The description of "vulnerable" has, for example, been used to describe a person who was persistently being affected by a recurring but relatively simple issue such as not being able to decide when they could wash themselves, as compared to a person who was hidden away, profoundly disabled with *"no contact from anyone in their lives other than those who are paid to be there."*
- In the early part of the pilot certain projects led by service providers and disability organisations confined their advocacy project to specific groups.

Usually, this was for those for whom they provided a service. As a result, this excluded other people with disabilities. The original pilot contracts asked projects to specify the particular group that they would target, with some projects believing that the type of advocacy expertise required would differ between groups (for example people with mental health difficulties or with severe intellectual disabilities). In the later part of the pilot cross-disability projects were favoured in order to provide wider coverage.

- Geographic boundaries are enforced in a number of the evaluated projects where a person with a disability from another county or external to the institution will not be served by the project. There are a number of examples where day service users could not be seen by the advocate in particular institutions, while residents could. In all cases, varying opinions on the validity and appropriateness of these approaches were offered by advocates.

  - *"First thing I do when I meet a service user: I check if they are within the county and my geography*."

Over the period of the pilot, a number of projects have expanded their footprint, by either removing restrictions that the host organisation had originally put in place, by taking service users with a wider range of disabilities, by expanding into new geographies or by including local residential centres while continuing to provide advocacy in the community.

  - *"Local knowledge and representation is key to extending reach"*

- A number of projects have been successful in cross referring between disability organisations, CIS's, health workers, local authorities, family and friends and other service providers. Examples of this include situations where representatives have been assigned a role within a disability organisation, service provider or institution to connect service users of those organisations with the advocate.

  - *"Demand was slow to take off, now there is a substantial waiting list."*

  - *"The best promotion is a satisfied customer."*

  - *"We have somewhere to refer to now. We have now got our own dedicated resource that co-ordinates the referral of our members into the advocacy project"*

- Advocates and disability organisations strongly promote the need to facilitate appropriate access for people with disabilities to the advocate in a manner sensitive to their needs. Demand for services has increased where a range of locations and confidential access has been assured. The provision of professional advocates gives confidence to many of the disability organisations, service providers and their service users, that concerns will be handled responsibly and professionally.

  - *"The fact that the advocate offers a range of locations to meet makes all the difference for my members in terms of using the service; confidential, sensitive and individual"*

  - *"Being based in the CIS, it is good to have a network of offices in the county and also do home visits"*

- Some advocates are spending time and effort on issues that could be dealt with by mainstream services. It may be difficult to determine what can be mainstreamed. A simple request for information could be extremely difficult for someone with an intellectual disability or could hide a more serious issue which might emerge when trust had been built up between advocate and service user. In situations where the advocate is close to, or housed in, a mainstream service such as a CIS, there is evidence that service users are availing of these services thus benefiting both and leading to greater efficiency. This also frees up the advocate in the disability programme to seek out the more vulnerable who cannot self-refer and empowers people with disabilities who are more confident and capable of using mainstream services.

  - *"We refer people from project to CIS and vice versa. It works well"*

  - *"Need to mainstream more"*

  - *"To be referred from a CIS to another location for access to advocacy and information is not right just because they have a disability"*

- The promotion and 'selling' of advocacy and its benefits is critical to the success of a project whether in a residential setting or community. Establishing the connection between the medical professionals, the disability organisations, the service providers and service users is central to accessing service users and increasing referral. All advocates spend a significant amount of effort in educating, promoting and communicating their role and their services. These efforts have met with varying success as recognition of any new profession tends to be slow.

  - *"I ran an open information day in the HSE for staff on role of advocacy, policy and the project in general; the doors have been open ever since"*

  - *"We are not flying the flag fully as we could not deal with the demand that would come as a result"*

  - *"As a major service provider, I work with many people who are not aware of the advocacy service such as the Gardaí and FÁS"*

4.2.3. Integration and Cohesion

There is evidence that the advocates are enabling change to occur:

- among staff in residential institutions, among medical personnel both in residential and community settings and in local authorities' approach to provision of services for people with disabilities, and
- in how health services are being delivered by health service providers.

Examples of this include:

1. An advocate's involvement led to a local authority allowing a person with disabilities to see and assess a local authority house as fit for their needs, in advance of accepting it. This new approach ensures that any modifications that need to be made can be completed in advance, avoiding the need for displacement and delay during subsequent works. This was successful for both the service user and the local authority.
2. Staff in a number of residential institutions have expressed directly, that they welcome the advocate, as the advocate provides a valuable feedback loop that ordinarily would not exist or be listened to.

Staff in local authorities described the advocate as the only person independent of the local authority and the HSE that can give an honest portrayal of the service user's needs without any concern that internal issues such as protecting budgets might limit the end result for the service user.

Advocacy as the Lynchpin

> ➢ *"The advocate was the only one who was in a position to pull together all the views of the service user, medical personnel, family and service providers to find a solution and a way forward"*

The relationships work because those who need to account for value for money, now have a working relationship with an advocate, who can assure them of an individual's genuine need and can be trusted to do so without any bias or influence from any service provider. This is a level of reach that previously was not being achieved. Another example of this increased reach is where the HSE contacted an advocate about a service user who was in inappropriate accommodation. Because the service user had both an intellectual disability and a mental health issue there was little agreement on where responsibility for his accommodation lay. Because the advocate was considered the neutral professional, she was able to organise a series of meetings between those previously involved in trying to get a resolution including local clergy, politicians, HSE, the county council, family and friends and medical professionals. Through the facilitated meetings a resolution was found. In the opinion of the HSE, this would not have happened without the advocate who was:

- *"Independent and capable of joined up thinking, as the advocate was the only one who held all of the concerns on behalf of the service user".*

This experience has already led to changes in the way that various service providers and concerned parties are responding to the needs of those with disabilities in that particular area.

- *"The advocate gets everyone together. As a major service provider, we could not achieve that. They are the honest broker between health workers, councils, family and friends speaking for the person with disabilities. They don't have the influences we have and they can't/don't pass the buck around"*

This element of the advocate's role is key to providing integrated services to the individual person with a disability at local level.

- *"There is a huge advantage in bringing the work of the project outside of the disability sector, putting it at the centre of the community. Integration of this work with other mainstream services and work, broadens it out and reaches other service users"*

The pilot showed that funding specific projects across a range of host organisations, not only brought these organisations and other stakeholders closer together, but that the future lies in a national approach if people with disabilities, who are most vulnerable are to be reached.

4.2.4. Collaboration and Partnership

The value of 'Collaboration and Partnership' has been experienced by all those interviewed in the course of the review of the programme. This new-found collaboration and partnership has resulted in improvement in the lives of people with disabilities. This change can be as simple as being able to get to an event because transport, previously lacking, can now be provided by another organisation represented on the advocacy project steering group; or as significant as several service providers setting up or reconfiguring internal functions to become a monitor of services focused on improvement. Service providers in a number of projects are now coming together, through the advocate, to generate an outcome for service users. Advocates are trusted by all involved to carry out this role, leading to greater collaboration and partnership between service providers and stakeholders.

- *"Service providers see the benefit when the advocate is involved; they come with the groundwork done which helps everyone."*

- In designing the programme, the Citizens Information Board decided to draw on the expertise in the sector through bringing together a wide range of service users, service providers, disability organisations, agencies and others. In doing this, there was considerable learning achieved by the different partners within the stakeholder group. Stakeholders now have a greater understanding of the benefits of advocacy and the structure of the pilot stage is now ready for a new direction. With collaboration and partnership, stakeholders share a commitment to satisfying concerns of service users and stakeholders.

- *"We did think about stitching into the CIS but worried they wouldn't reach and that they didn't know enough about the disability sector; hence we decided to go with the project approach with diverse steering groups"*

- *"In order to get into more residential institutions, we will need more experienced advocates; partnership and getting in is the key"*

- Many service providers are using the advocate to change areas of their service provision without going through their own management structures and processes. This is done for a range of reasons including the slow pace of change or their inability to communicate issues to peers or superiors within their own organisation.

  - *"The service provider is fighting for change in their own organisation; they need advocates to create change from the inside; can't knock on the door from the outside and expect to be let in"*

- A significant amount of collaboration between organisations has developed from their involvement in the projects. Organisations are sharing resources, facilitating service access, finding ways to connect service users into the community and collaborating to produce better solutions for service users. The comments of those interviewed, however, reflect different experiences in different projects, and a lack of collaboration and partnership still exists in some areas.

  - *"As one of the disability organisations, I now provide services from my organisation into the pot to help. This never happened before; my job now is to network with everyone"*

  - *"Advisory group is the guarantor of the disability advocacy project; the people they invite on, ensure disability is to the forefront."*

> ➢ *"The disability sector is very territorial. This project broke that down"*

> ➢ *"There is real value from major disability organisations being on steering: knowledge is great"*

- Service provider stakeholders for a number of projects suggested that advocates must not 'burn bridges' while carrying out their role. Advocates may feel they are forced to tread a fine line to ensure a level of positive response from those who control the service or the access to it. There is also a risk that advocates may not take enough account of the concerns of service providers as they advocate. The definition of what advocacy is, the role of independence and the boundaries that are created become ever more important. Independence cannot result in exclusion nor can the need to collaborate lead to a compromise where service users' wishes are not represented.

> ➢ *"Sustained relationships between all involved must be at the centre; any move towards more independence should take this into consideration; cannot be adverse to the service providers"*

4.2.5. Independence

A critical question that must be answered when considering the role of independence is whether the advocate is in any way influenced or impacted in their ability to represent or speak for a service user. The structural arrangements within which the advocate is placed can challenge his/her independence. The evaluation identified independence as a particular issue, where the advocate is employed by a service provider.

> ➢ *"As a user of the advocacy service, I felt that the advocate was not independent, and was being treated as part of the host organisation."*

- Independence is being safeguarded by steering groups through policy and practice developed using previous experience, the adoption of considered best practice and ongoing learning. The importance of independence is articulated by all. In the main it is described by many stakeholders, particularly those involved in service provision, as having never or rarely become an issue and where it has, it was managed and resolved.
  - *"Our lead agency is a major service provider so we always have to manage the boundaries and nuances."*
  - *"We do provide service provision, so I suppose there is the potential to threaten independence, but there are always levels of dependence within independence. Honesty to service user is important."*

Independence, its definition and its role in the delivery of advocacy services is complex. The independence of the advocate and their ability to operate without fear of inappropriate influence is dependent not only on their own principles, competencies and ethics, but also on the independence of decision making and advice within their steering group and line management. There are examples where steering members who had been involved in a case were asked, and agreed to leave the steering group meeting for that part of the discussion to avoid a conflict of interest.

There are other examples where steering group members were not asked to leave even though it was clear that confidentiality might be breached and, potentially, the independence of the steering group's decision-making compromised.

- *"A major service provider was not asked to leave when a case that they were involved with was brought to steering, yet another steering member was asked to leave in a separate yet similar situation."*

  - *"As a major service provider, I needed to ensure I was not entering into a conflict of interest; as it was advisory I decided it was ok."*

  - *"There is no ambiguity between my role as a major service provider and the role of the advocate, I feel they are independent and we work well together. It's more productive all around."*

  - *"We use steering for their expertise but it can be difficult while trying to maintain confidentiality."*

- In the projects where the 'employing host organisation' is also a major service provider to service users, there was a striking lack of examples where interventions by the steering group or the line manager had been necessary to clear the way or resolve a blockage for the advocate with the 'employing service provider'. There was also little evidence that these interventions were sought by the advocate. This suggests that, in certain instances, as previously discussed, collaboration has crossed the line and become an unspoken arrangement where a balance is being struck or the potential for tension is being avoided. Where this is happening, the independence of the advocate is being compromised. One tries to reach agreement while not necessarily settling for it. Collaborating does not mean agreeing on everything. It centres on working with others towards a shared outcome. Healthy tension is necessary to push out the boundaries of what is acceptable and possible.

  - *"Watch out for the service provider who might say no, if we become too independent. They might ban all external services"*

  - *"As a major service provider, the advocate is the standard bearer. Somebody has to do it"*

- In engaging with service users, independence was not usually expressed as an issue. In some consultations with service users, their satisfaction came from the fact that someone was taking an interest in them and seeking their opinion on their needs. Independence issues may only surface in the interaction between advocate and provider, with the service user remaining unaware of them.

- It has been suggested that the boards of some lead agencies are influencing the direction of projects through their staff member who holds the position of line manager for the advocacy project.
    - ➢ *"The steering committee is consulted but then the lead agency does their own thing. What are we doing here?"*

  In some cases the need to consult with the lead agency board before certain decisions are taken is made explicit by the line manager at steering group meetings. This is felt by some steering group members to be impacting on the role of the steering group and in other cases the influence is less direct but exists nonetheless. Concerns expressed in this area point at the need to clarify respective roles in projects where this is considered to be an issue.

    - ➢ *"There was a conflict, the chair was also a service provider"*

    - ➢ *"The chair of steering should not be affiliated with any group or organisation that has interests in using advocacy service as there would be a conflict of interest and services may be pulled in that direction"*

    - ➢ *"We separate our advocate from any conflict through providing separate room, with own filing cabinet and through our policies and procedures <u>but they form part of our team</u>………"*

- Independence having been described by many steering members as not, or rarely, an issue has, however, been articulated as <u>a potential issue</u> by many advocates and some stakeholders during our consultations. In each instance where the host organisation is engaged in the provision of services to service users, the majority of steering members agreed that the <u>potential</u> for conflict of interest exists. If the independence of the advocate is to be totally safeguarded for the sake of service users, many of whom are vulnerable, then the potential for conflict of interest alone is enough to warrant change. The expressions of concern from steering group members including representatives of the host organisations further suggests a need for change.

An agreed definition of independence and its function is required and will be important in determining the action that must be taken to preserve it. Independence is often spoken of in terms of 'the degree of independence'. This, in fact, suggests that there are issues in relation to the meaning of independence, the potential for conflict of interest, and its relevance to the provision of advocacy that are not fully understood.

- *"Our view of conflict of interest is evolving but overall it needs to be addressed as the potential for conflict exists."*

- *"As an advocate, I cannot carry an organisation's goals with me and remain independent, but how independent is independent?"*

- *"Advocate really keeps it independent but in fact, when you think about it, they cannot really."*

- *"Independence a real issue, I didn't want to rock the service provider boat"*

4.2.6. Steering Group Practices

Each of the projects has policies and procedures in place. These policies underpin the practice of this new profession of advocacy and are updated continually. All the evluated projects spent their early development period drafting and implementing policies and procedures to define how the project would operate, how service users would be engaged, protected and served. Advocates were employed, steering groups were formed and advocacy commenced.

- The policies are considered by many steering group members to be necessary and are a useful mechanism for building an understanding of the role of advocacy, its remit and the desired outcomes, standards, protocols ensuring service user protection. However, the majority felt the process took too long, feeling that it could have been achieved much sooner through sharing between projects or policy being handed down by the Citizens Information Board to all projects allowing advocacy to begin earlier.

  - *"Policies and procedures, why would we want to write again what has already been written"*

  - *"As a member of steering, I am not sure that I know enough about advocacy or disability; a comprehensive induction would have been good"*

- In a small sample of the evaluated projects it was suggested that policies are being used by the advocate to draw a line between themselves, line managers, and other stakeholders including steering groups. A number of stakeholders were of the opinion that the advocate is too removed from steering, justifying this stance on grounds of confidentiality/independence. This raises a potential risk and threat to a number of areas including quality of service, service user protection and good governance.

  - *"Good governance makes you accountable to someone; may be a liability if something went wrong"*

- The definition and measurement of success at steering group levels is varied and in many cases not easily quantified. Steering groups are lacking any real measures of the impact that the service is having other than through the limited number of case studies that are presented to them. This differs slightly in the context of residential services, as in many of these cases, the director of services or similar, attends and testifies with confidence that the advocate is achieving their goals. This in itself is possibly flawed as the potential exists for a managed relationship. While the explicit relationship is achieving successes, any managed agreement may be placing limits on what can or cannot be challenged and achieved. It is important to note that change requires partners who are committed to an outcome achieved through collaboration rather than competition.

  - ➢ *“We cannot really see what the advocates achieve because of confidentiality, but we get the numbers and get some idea from that. It’s not like information services, it takes time and time is progress.”*

  - ➢ *“Measure of success: meetings well attended, commitment when there. Live cases are the missing piece.”*

- The lines between social work, mediation and advocacy were appreciated by the majority of steering group members although many admitted that these lines had become blurred at times in practice. Few had concerns about it. Many expressed their understanding that the advocate is there to speak for, or assist the service user to articulate their needs and concerns. However, there were a number of examples where advocates were using mediation skills to gain agreement between service providers, family members and service users, or where social workers in both residential and community settings voiced their concerns regarding overlap of roles.

  - ➢ *“Lines between advocacy, mediation and social work or approach to development of advocacy may be left untouched by external supervision and not appreciated by the line managers.”*

- Steering groups are in many cases failing to get service users or others with disabilities involved. Supports may not be adequate in terms of preparing service users prior to joining, so that any concerns or difficulties they may have in relation to participating are alleviated. It has been suggested that service users experience anxiety around the formality of the meetings and the level of engagement between professionals. Many similar difficulties occur in attracting and preparing people from the community and target groups to any advisory or governance role. There is a need to first gain commitment and then to prepare the person for their role.

   - *"No user on steering group"*

   - *"Users of various services would be better informed, attracted and supported to join steering groups if they were inducted and trained properly up front"*

   - *"As a service user of advocacy, steering group was top heavy with too many statutory agencies. The steering group need more from voluntary organisations and users."*

- The role of the chairperson of the steering group is key. Independence, knowledge of advocacy and disability and an ability to attract and maintain a diverse attendance at steering groups are critical elements to the success or otherwise of a project.

   - *"The role of chair is to get diversity among steering group members and get them to turn up"*

   - *"If CIB were the chair, then we would have the same standard, build expertise and sustainability."*

- Steering meetings are taking place in projects, about every six weeks with a leaning towards less frequent meetings. This is indicative of either a maturing of the project and a consequent lesser need or struggle by steering members to see the value in investing more time. A mix of both exists across the evaluated projects.

   - *"We meet every month but are moving to every two months. There is not as much to do now."*

   - *"Did a job description, job interview of seven or eight candidates; the advisory group was heavily involved and the outcome was excellent."*

  - *"Members stopped coming because they were not getting a lot out of it. It was fine in the set-up phase but as time went on it changed."*

  - *"On the fringes, responsible yet no power."*

- Steering groups are a place where strong networks can be built. If they are to be effective they must be built at all levels, from the officer in the housing department to the county manager; from the mental health nurse to the HSE regional director of services; from disability organisations to the parents and friends; the service user to the advocate. The members of the steering group are afforded the opportunity to hear direct feedback on their services and to experience it first-hand in some cases. This is producing positive change where it is working well. The value of the steering group comes from its ability to produce action and create positive change. The key is having the decision makers involved.

  - *"As a service user of advocacy, I believe there should be working groups; CIS, MABS, Advocacy under regional steering committees that have their bosses sitting on them."*

  - *"There is a large number of people on steering from outside the organisation, this is a positive and can push things through. If we could widen further, it would be better."*

  - *"The diversity in the steering group membership provides us with independence as well as access and influence with service providers."*

- Given that the Citizens Information Board was instrumental in designing and supporting formal third level qualifications in advocacy, the more experienced advocates felt that this should have informed the recruitment policies of the projects. When the projects were started, the advocacy qualification was not available and other third level qualifications (or equivalents) were accepted. As it is a distance learning qualification many advocates have studied for it while working. In the future, an employing agency may insist that prospective advocates have such a specific qualification.

- *"We need to know what kind of people do we need, what standard should they hold. We need a proper advocate placement programme."*

4.2.7. Project Practices

Practices have been developed locally for each project. They generally follow a similar pattern on the lines of the guidelines laid down by the Citizens Information Board. There is a variation in the outcomes, reflecting competency of the advocate and line manager, level of direct operational involvement of the line manager in the delivery of advocacy and the level of monitoring and ongoing development of the service quality and efficiency. The steering groups also play a role here but mainly it involves the line manager and the advocate. The role of line manager and advocate and the working practices between them are core ingredients in an effective project. The success of a project is currently heavily reliant on individual relationships.

- In the main, weekly meetings/discussions are taking place between line managers and advocates although the content of these meetings varies significantly based on agreed local practice and the competency levels of both. The meetings vary in significance for the line manager and the advocate in the context of supporting the delivery of the advocacy service. The advocate/line manager relationship impacts on the efficiency and quality of the service, and the outcomes achieved for service users. A positive example is where a line manager, independent of any service provision, qualified and experienced in advocacy is spending two hours per week, reviewing case-load and case-work in confidence, with the advocate. The line manager is providing support, supervision, coaching, development and back up where necessary, all of which leads to better outcomes for service users. A different example is where the line manager lacks knowledge of both advocacy and disability and has less frequent interaction with the advocate. The line management interaction relates mainly to administrative issues and leaving the advocate is largely operating in isolation. In the evaluation a wide variation in the advocate/line manager relationship has been identified.

- ➢ *"We meet every week, review cases, going through the urgent and priority cases"*
- ➢ *"We meet informally each week, more formal every quarter."*
- ➢ *"The line manager is not aware of the detail of my cases."*
- ➢ *"Meet with line manager for 1½ hours per week; new cases, case development, resourcing, safety, policies, performance, quality."*

- In some instances, there is evidence of an over-reliance on individual relationships. Access to residential centres can be determined by the good will of individuals. Where changes in personnel have taken place in projects, the dynamic has also changed and in some places significantly. There are examples of how a change of advocate within a project led to a change in how the steering group played its role, due to differences in the new advocate's interpretation of what constituted independence and confidentiality. A further illustration of over-reliance on individual relationships is where a number of service providers, who were also the employers of the advocate, made changes in senior personnel. Previously unwritten agreements or understandings on access, protocol or approach were no longer of relevance and had to be reinvented. This directly relates to the independence of the advocate and the need to have explicit agreements between all involved.

- ➢ *"Nobody interferes with my work as an advocate but if I had a different service provider/ line manager, it might be a different story"*

- ➢ *"As an advocate, I see myself also as a trainer for other service providers, working with them; they call me, they're coming around to us, heading towards the same goals."*

- The evaluation found that, in general, policies are implemented which cover all aspects of engaging with service users, including preparation in advance of contact, initial meeting, ongoing work, follow-up and closure. There is variation in the administrative processes used and there are varying degrees of implementation across the evluated projects.
  - ➢ *"We meet the service user upfront, we prep beforehand and then ensure follow up is managed to closure."*

  - ➢ *"Guidelines and resource pack from CIB is very good"*

- Expectations are that, where possible, mainstreaming should happen, but evidence suggests that it is sporadic. Where it does happen, it increases the overall capacity of the advocate while also enhancing the service user's ability to get things resolved themselves, through more direct and ongoing involvement with mainstream services.
- Not all referrals may be screened by the referrer to ascertain whether they should use mainstream services. People with disabilities are also able to refer themselves. Some advocates have expressed reluctance to redirect a referral put forward by a steering group member – which shows a possible conflict of interest.
- In most projects, advocates are operating alone and are isolated as a consequence. This presents many challenges which impact upon the consistency of advocacy services across the programme. For the advocate it raises issues of morale, ongoing competency development, supervision, the need to build peer relationships; holiday or sickness cover; advocate-service user compatibility; availability of specialist expertise when necessary; and as such impacts on the advocate's capacity to deliver value.
- Some projects have software facilities available to them that assist in the management of case work. In response to this need, the Citizens Information Board developed an electronic case management system during 2009, to support the work of all advocates in the programme, provide for easy and consistent reporting and help projects comply with data protection legislation.

- *"More training is required, especially in facilitation and empowerment."*

Peer support meetings occur in a number of regions and are hugely valued by advocates. These fora provide opportunities for advocates to raise concerns and to discuss challenges and issues they may have. Not all advocates attend these sessions all of the time, as they sometimes feel that they take time from service users or may be viewed as doing so by line management. Most advocates are members of the Irish Association of Advocates which was established in 2007 as a representative organisation for advocates in Ireland.

- *"We need to find some way for our advocate to link in with other advocates; they are very isolated"*

- *"I can't get out to peer support - conscious of time spent out of the office away from service users"*

- The link between residential service users and the community is weak but it is strengthening in some areas. Many projects are working to enable residential service users to connect to and become part of the community, through:
  - Re-housing programmes;
  - Citizen advocate and service user relationships that are being developed over long periods;
  - External organised group events;
  - CIS hosted service visits, and
  - Independent user forums organised by the advocates and others, where people with disabilities can come together to discuss their interests.

These initiatives can help to support people long-term in the mainstream after a representative advocacy case is closed, placing service users at the centre of the development of the service.

- *"Have successfully created a network outside of the institution for residents, extended into the community that is now drawing in many people with disabilities from all corners of the community; it is their forum, nobody but them, it has grown hugely."*

- The facility to engage in external supervision exists in the majority of the evaluated projects but its uptake varies. For those advocates who engage in external supervision, it is regarded as an important part of their development and service delivery process. However, external supervision does not always appear to concentrate on specific case needs or on the actual supervision of service quality for the project. For some advocates, external supervision replaces their line management case supervision. This brings its own challenges in relation to day-to-day service delivery.
  - *"External supervision is great but can't be the only way we monitor quality of service provision by the advocate"*
  - *"We need to ensure we do not burn out the advocate, cases are complex and leave their impact; external supervision or peer support would help."*

4.2.8. Value

The evaluation team is very clear that advocacy for people with disabilities is delivering significant value and is changing people's lives in a real way. This is attested to by the hundreds of people who are investing their time and resources in the programme. Need is need. A service user who is in need does not differentiate between services or providers easily. This is the space filled by the advocate, who connects '*the dots*' between services to offer a single solution to service users and this is hugely valued.

- *"There is a difference between advocacy offered by the CIS and the project; both are valuable but the contacts the project advocate holds with major service providers and agencies is the key. There is a morass of red tape to get to your entitlements, they know the way through." Service user*

- *"People with disabilities will know what they lost if this programme ends." Service user*

- *"I hope they never withdraw this service, the gains are huge. We've taken people off the scrapheap, given them a feeling of dignity, the problem of a lifetime is sorted." HSE representative.*

5. OVERALL CONCLUSIONS FROM FINDINGS

The evaluation of the *Programme of Advocacy Services for People with Disabilities in the Community and Voluntary Sector* scrutinized advocacy from a number of different perspectives, through analysis of cases, document review, structural reviews and discussions with representatives of all stakeholder groups. The conclusions from the findings are set out as follows.

Service Users' Experience of Advocacy

- Advocacy for people with disability is delivering significant value and is changing people's lives in a real way. Service users consistently recorded the effectiveness of achieving outcomes with the help of the advocate. Advocacy brought a significant improvement in the lives of people who are vulnerable, marginalised, hidden, ignored or overlooked and has been a transformative experience for those using the service. Advocates' impact on the lives of service users was considerable. The advocate focused on what the service user needed and supported them in asserting their rights.
- Advocates and steering groups in the main are close to service users and listen effectively to their needs However, the service user's right to be at the centre of designing and developing the service is limited by their lack of involvement in some projects.

The development of the Programme

- The flexibility of the pilot programme has contributed significantly to the spread and infiltration of advocacy. The programme's ability to reach people with disabilities particularly those who are most vulnerable has improved over the duration of the pilot programme.

Collaboration and Partnership

- Collaboration and partnership is being enabled through the projects and programme structures as a way of providing a better outcome for service users, but in some cases collaboration is being confused with getting agreement without tension. This is driven by some structural arrangements where the host organisation is also the service provider, potentially making it more difficult to address contentious issues.

Cases

- Advocacy cases can be categorized as high complex; complex and low complex cases. Some high complex cases fall within the legislative definition of the Personal Advocacy Service. Most cases are complex cases. Low complex cases often develop into complex cases.

- The qualifications, experience and professionalism of the advocate enables the programme to offer the high level of service required by the complexity of the cases presented.

The Advocate

- The present structure of the working environment within which the Advocate operates is not optimum to the ongoing development of the service, the quality of advocacy and the value delivered for the financial investment made.
- The quality and level of service offered by the advocate is impacted actually and potentially, by working arrangements established within structures where the host organisation is also involved in the provision of services.
- The independence of the advocate is or has the potential to be influenced in projects where the host organisation is involved in the direct provision of services to the target service users.
- The advocate is delivering ever increasing value to their service users while also working with all stakeholders to maximise the possible value for them through their involvement and investment of time. Some advocates are isolated, with little professional monitoring and coaching and have little opportunity to ensure consistency of service across the programme.

- The relationship between the advocate, line manager and steering committee is key to the delivery of advocacy in the programme. There is a wide variation of practice in terms of supervision (both internal and external), case management, support, and expectations.

The Projects

- The local nature of the projects and increased collaboration are having a positive effect on reaching more people with disabilities and ultimately more who are extremely vulnerable. However, the individual approach to projects; the lack of peer support and the lack of shared standards in both quality and productivity are in some cases preventing advocates from reaching the most vulnerable. There is currently no shared agreement to identify the most vulnerable and ensure that they are being reached.

Steering Groups

- The level of diversity that exists in project steering groups does enable optimum solutions to be found for service users. There are, however, missing decision-making stakeholders from key service providers, agencies and service users, which is limiting the value that can be delivered.

- There are shortcomings in the value and role of steering group involvement, the measurement of success as projects have matured, and the level of value that can be delivered on a sustained basis by individual projects with single advocates and large steering groups.

Personal Advocacy Service

- Some cases undertaken by experienced advocates would have come under the remit of the Personal Advocacy Service. In the absence of statutory powers, there are considerable delays in offering advocacy to those most in need.

- Advocates are experiencing difficulty in gaining access to some residential settings. In the absence of this access, it is difficult to determine need.

- Based on the evidence of the need in residential settings where advocates do have access, it can be taken that there are vulnerable people in residential settings who are not given the opportunity to access advocacy.

- In some residential settings, advocates were given permission to work on behalf of some service users and denied permission to work on behalf of others.

- In the absence of the powers of the Personal Advocacy Service and in certain circumstances, advocates are excluded by some service providers from representing and/or supporting service users.

- Advocates can be denied access to information pertinent to their work with service users.

- Some advocates are excluded from meetings and consultations including medical consultations; court proceedings, legal consultations, care planning conferences

The Need to Restructure the Programme

The evaluation team are convinced through the evaluation of the pilot programme, that significant value is being added, by all involved; service providers, advocates, agencies, disability organisations among many others. Service users' lives have been truly improved. This has taken place because many different organisations and individuals have collaborated to make it happen. However, the findings in this section point to the need to find a new programme structure.

To take it to the next level and deliver increased value, with the same or fewer resources, requires change. The implementation of a new model of representative advocacy, informed by collaboration and partnership, should be positive for all concerned. The recommended changes will impact positively on the needs and interests of service users, stakeholders and advocates in line with government policy.

6. THE FUTURE DESIGN OF ADVOCACY

6.1. Introduction

The findings of the evaluation point clearly to the fact that the advocacy programme has had a hugely positive impact on the lives of people with disabilities. Our findings show that project staff, their steering groups, their hosts and their supporters in the Citizens Information Board and the Department of Social and Family Affairs have been hugely successful in not only establishing forty six projects, covering twenty three counties but in delivering real change for people with disabilities that otherwise would not have happened. The case studies provided in this report testify to this. Huge learning has occurred during the pilot phase that has come through hard work and through trial and error. This learning must now be used to strengthen the advocacy programme, deliver increased value to its service users, ensure it delivers better value for money while upholding the principles that have delivered its success to date.

Several conclusions have been presented that point to the need for change which if addressed will significantly enhance the ability of the advocacy programme to deliver on its aims. They include the need to;

- Enhance and protect the ***independence*** of the advocate to represent people with disabilities.

- Improve the ***quality, capacity and level*** of advocacy response to a point where the service is capable of developing and sustaining itself and is not limited by structural arrangements.

- Demonstrate and communicate the ***worth and value*** generated for the money invested and the time given by all involved in the provision of advocacy.

- Maximise the ***collaboration and partnership*** between all stakeholders which is central to the success of the advocates' work with service users.

- Increase the ***level of diversity*** among those advising on or working to improve the situation for people with disabilities who use the advocacy service, as it has a direct impact on the quality of the solutions found.

- Build ***capability and confidence*** that the most vulnerable are being reached.

- Ensure that the voice of the ***service user is at the centre*** informing the ongoing design of the advocacy service.

The project approach has succeeded in delivering value. A different response is needed, however, if the enhancements are to be achieved and if a consistent, quality service is to be offered on a more equitable basis to a greater number of service users. This response has to take account of present stakeholders, whose input is crucial to building on what has been achieved. The concerns of each must be taken into account, as to alienate or ignore any one, will lead to a poorer outcome for the service user. The future approach must be consistent with Central Government Strategy and with what the users of advocacy perceive as their needs.

6.2. Future Advocacy Service

An advocacy service needs first to have a clear sense of its role and boundaries, and must have the capacity to respond to cases covering a range of complexity, including those of service users who are not in a position to articulate their wishes (e.g. non-instructed advocacy). Occasionally, with cases that do not respond to collaborative working or where an abuse of rights has occurred, the service may require the backing of statutory powers.

The service user's perspective is critical. The important feature of advocacy is the fact that someone is acting and following through on the service user's wishes. The background structures are of less interest to them but are crucial to the delivery of a seamless service. While some service users can voice their concerns, there are others who are not in a position to easily articulate their wishes. It is crucial that any service is capable a provision that covers the range of complexity of cases and also has the ability to understand and listen to those who do not have a voice and respond accordingly.

National Advocacy Service

The evaluation team recommends the bringing together of the experience and learning from all stakeholders into a 'single service' with the ability to provide improved advocacy services to people who need them, regardless of location, disability type, or level of vulnerability.

Pivotal Role of the Citizens Information Board

The architecture shows the Citizens Information Board as the funder, supporter and holder of the Advocacy provision at a statutory level on behalf of government, delivering advocacy across the full range of complexity, requiring the enactment of the Personal Advocacy Service (PAS). The three strand approach, as defined by the *Developing an Advocacy Service for People with Disabilities* (2004), will be transformed into a single arc providing advocacy to people with disabilities according to need. The statutory responsibilities envisaged in the Act would be vested in the Director of Advocacy within the Citizens Information Board.

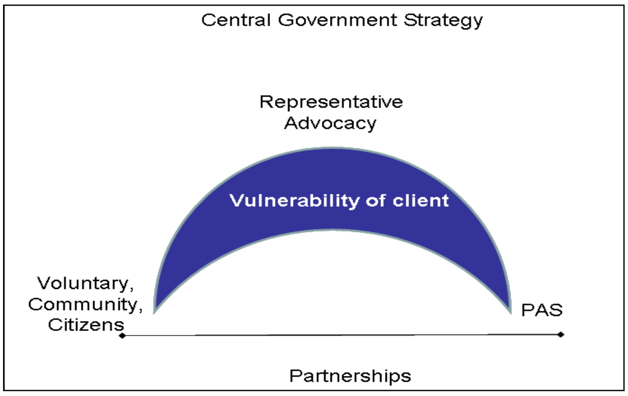

Figure 13: Figure National Advocacy Service

The Implementation of the Personal Advocacy Service

The implementation of the Personal Advocacy Service (PAS) and its integration into the current service is critical to the development of the National Service. Not only has it a function under its legislative provisions, but also there is a consequential effect for the rest of advocacy provision. It will have a direct impact on three critical areas. These are the legal Arena, policy development and individual service level.

The majority of high complex cases will fall under the remit of representative advocates. For those who cannot exercise their right to advocacy through this mechanism and who fall under the legislative criteria, the implementation of PAS will ensure their representation.

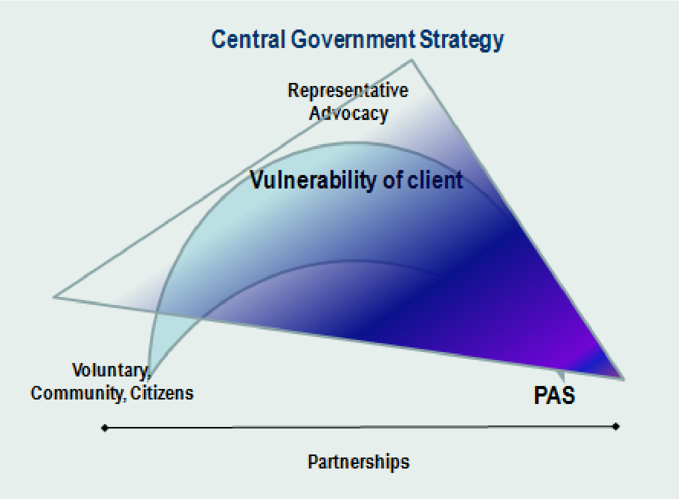

Figure 14: Model of Legislative and Consequential Effect of the implementation of the Personal Advocacy Service.

In the legal area, the powers of PAS will ensure that those with a disability who are most vulnerable will have the support of an advocate even where their cases end up in the formal legal system. In the policy arena, PAS will ensure that systemic issues will be dealt with at the correct level, ensuring that those who are most vulnerable are protected. Enacting the legislation fully will increase awareness of the role of independent advocacy, and its role in safeguarding disabled people's rights and enabling their fuller participation in society. At the individual service level, PAS will provide non-instructed advocacy to those who are most vulnerable; ensure that people with disabilities are able to take complaints against statutory and voluntary bodies. The PAS should make advocacy better known and allow all people with a disability to exercise their right to use an advocate.

In addition, the implementation of the personal advocacy service will have a consequential impact on other areas in the delivery of advocacy. Under the new structure, where PAS has been implemented, advocates working on cases will have a smoother access to information and the ability to represent people with disabilities in a variety of situations where they may not now be accepted.

The authority of PAS will inform practice within the entire sector. Initially, it is the authority that will initiate action on behalf of the service user and consequently, in time, it will inform best practice. Once PAS is in place, there is an expectation that service providers will be more likely to provide the opportunity to vulnerable people with disabilities to engage with advocates on the ground, without the advocates needing to use statutory powers. It will also smooth necessary access for advocates to service users' files.

Design Principles

A national service that can truly function as a seamless service for both service users and stakeholders, requires a structure that is capable of responding, adapting and growing as the need changes over time. The national service, those who work in it, those who are served by it and those who support it, require clarity on the services to be offered, goals to be achieved, effective measurement of outcomes, management of performance and an efficient way of operating that will ensure its success.

It is clear from the cases reviewed, and consultation with all stakeholders, that there is overwhelming support for the continuation of advocacy work. It is also clear that it can only be sustained through a single approach, where advocates are no longer isolated, vulnerable service users are reached, service quality is improved and value is assured. Forty six separate projects cannot achieve this. A national approach is now required.

The evaluation team recommends that the following service principles are adopted as a starting point in moving the advocacy service from a project-based structure, towards a national service with consistent standards that will be fit for purpose beyond 2010.

- ***People with Disabilities at the Centre***: where people with disabilities will be at the centre of service provision as user, advocate or provider.

- ***Professional Development, Professional Delivery***: where each staff member, paid or volunteer will achieve a minimum standard of competency in their role, will be assessed on an ongoing basis and will be led by a competent authority in their area to deliver a confident, professional, independent and satisfying service to all service users.

- ***One Team, One Service***: where advocates will offer nationally a consistent, quality-assured, valued service, that is accessible to all people with disabilities and actively seeks out those who are most vulnerable regardless of disability type.

- ***Work with, Work for***: where Advocates will actively work to create and develop partnerships between disability organisations, service providers, service users, community and other stakeholders so that all get value from their involvement.

- ***Share the Success***: where the value of the investment and the benefit that it brings, will be communicated openly while safeguarding confidentiality.

The evaluation team believes that in adopting these principles, the future advocacy service will address many of the challenges raised regarding the current configuration such as the advocate's independence, gaps in provision, inappropriate management, undue influence of service providers, disparate working conditions and standards and advocate's isolation. Furthermore, in order to effectively and efficiently deliver the required change in a consistent manner with consistent outcomes, the service must be managed through a national structure but organised and delivered locally.

National Organisation

A national structure requires a national organisation to be established or identified, which at the very least, offers a consistency of approach within which the advocacy service can be delivered. The national organisation model would be supported and influenced by national and regional advisory groups, similar to the current steering group role on each project, but with increased focus on action and change in support of the advocate's work. The national organisation would act as the employer and would be governed by a board structure. All services would be delivered locally through regional and local structures, sometimes in the same locations as at present.

Figure 15: National Organisation

Options Considered for the Role of National Organisation

An entity that would employ the advocates, develop the services in a unified manner and bring together a range of appropriate stakeholders is envisaged. A number of possibilities of the kinds of organisations that would be suitable to take up the role of the single 'national organisation' were considered.

Initially, a new independent entity was examined. This would be established to employ the advocates and develop the services in a unified manner. Feedback from Government representatives suggests that in the current economic climate and given integration and cohesion strategies at national and local level, this structure would not be feasible.

The evaluation team then considered the possibility of an existing organisation taking up the mantle. A number of criteria needed to be considered;

- Independence from service provision for people with disabilities.
- Knowledge of disability, advocacy and target service users.
- Degree of change in core business from taking on this service.
- Scale of the organisation, its governance arrangements and its capacity to take on the service.
- National footprint and locations served by the organisation.
- Bias towards any stakeholder grouping.
- Organisation's standing with stakeholder groupings.
- Facilities and supports offered by the organisation without the need for significant investment.
- Economies of scale and efficiencies to be gained.
- Constraints of current economic climate.
- Relationship of organisation's existing services to the proposed advocacy service.
- Ability to bring people with disabilities into the mainstream.
- Fit with Central Government Strategy.

While several organisations – such as the Centres for Independent Living (CIL), People with Disabilities in Ireland (PWDI), Inclusion Ireland, Disability Federation of Ireland (DFI) etc. - met a number of the criteria, only one organisation stood out as being independently capable of supporting the delivery of the advocacy service nationally, without requiring significant change, while also addressing most of the concerns raised throughout the evaluation.

The Citizens Information Service (CIS) network, long established, with an existing infrastructure offering information, advice and advocacy services, matched many of the criteria outlined. The CIS is a network of 42 independent organisations with their own boards of management, resourced and overseen by the Citizens Information Board. It operates a service in over 250 locations across the country. This is without counting the locations that advocates already operate from and, with agreement, may continue to do so. The CIS structure can, therefore, increase the number of potential locations for the advocates while affording a level of mainstream contact not offered by any other organisation. A number of CISs have already been lead agencies in the existing advocacy projects. The CIS network which, under the direction of the Citizens Information Board has undergone significant modernisation, represents an existing vehicle to offer advocacy as a service locally while still having national cohesiveness. Most CISs also have ongoing close relationships with local community groups and parallel advice organisations such as the Money Advice and Budgeting Service (MABS) and the Free Legal Aid Centres (FLAC) and subscribe to the community ethos which is evident in the existing projects. The recommended advisory groups, discussed below, will take up any shortfall in knowledge or experience in the disability area.

While there are many important facets to the delivery of a national advocacy service, a key one is the need for the service to be delivered and remain local, easily available to those who need it. Under no circumstances should a structural change place distance between the advocate and the service users unless explicitly intended for their benefit. The evaluators believe that Citizen Information Services(CIS) offer an extremely 'good fit' for a national organisation that is delivering value to citizens locally and already involving many local stakeholders.

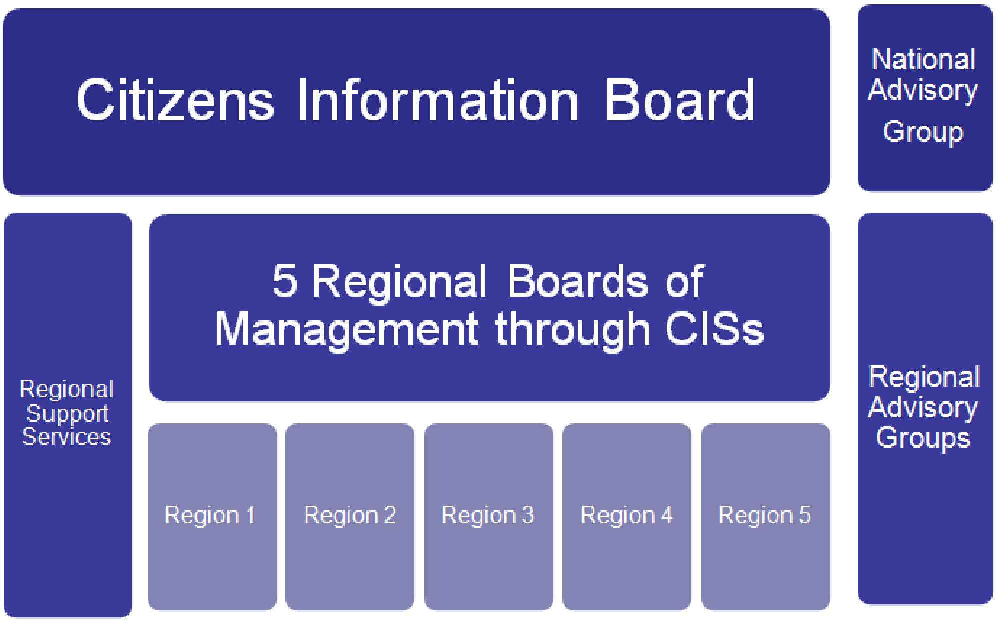

Figure 16: Structure of National Advocacy Organisation

The recommended design (see diagram above) proposes seeking agreement from five established CIS boards of management who would take up the responsibility for delivering advocacy for people with disabilities locally within a region, while integrated with the other regions to form a national advocacy service and structure under the Citizens Information Board. They will each have responsibility for a local advocacy service comprising a team of advocates, a manager and an administrator, which will be separate from the information service. They will be advised and partnered by regional and national advisory groups. They may also be supported by local fora as necessary if directed by the regional advisory group.

Advocates will be organised and supported regionally. They will be team based and form part of a national team providing advocacy services.

Implementing Design Principles

Under the new recommended structure, the interactions and future operating conditions of the advocacy service can be described best using the principles outlined previously;

1. ***People with Disabilities at the Centre***

    - People with disabilities will participate in the design and development of the future of the advocacy service through an ongoing consultation process and direct participation on regional and national advisory groups.
    - The national advocacy service will have an equal opportunities employment policy and will welcome applications from people with disabilities to become advocates, recognising the value of their experience and offering reasonable accommodation where required. All advocates will be assessed and trained to a standard to be determined by the Citizens Information Board.

2. ***Professional Development, Professional Delivery***

    - The advocacy service will mainly offer representative advocacy but it will also assist people to speak up for themselves and will incorporate a volunteer model through employment of a citizen advocacy co-ordinator who will recruit and train volunteers to partner individual people with disabilities who are residents of institutions.

- Advocacy managers, who are experienced in advocacy, disability and management, will focus on organising the service throughout their region, deciding on priorities, promoting the service and linking with relevant local organisations; and also on competency development, performance management, support and case-supervision. They will drive continuous improvement in service quality, outcomes and value for money achieved.
- Advocates' level of competence will be assessed on recruitment. A competency standard and ongoing assessment will be put in place. Continuing professional development will be a requirement.
- Each regional service will organise its deployment of advocates and some advocates may specialise in particular areas. As far as possible, services will respond to demand and advocates with specific skills will be leveraged across geographies, disability types and settings as required. Demand for services and skills will drive the allocation and location of resources.
- External supervision will be a part of ongoing practice. However the main concentration for setting and monitoring of practices and outcomes will rest within the organisation.
- Services will be promoted, cross referral measured and actioned. Reach will be improved through increasing the diversity among stakeholders, the involvement of regional and national advisory groups, leading to an enhanced profile for advocacy and increased access.

3. One Team, One Service

- A national service will seek to make advocacy available to all people with disabilities on the most equitable basis possible.
- A single organisation of advocates, regionally based in five selected Citizens Information Services, responsible for the delivery and development of advocacy services across their region.

- Five Citizen Information Service (CIS) Boards acting as employer, responsible for a line management reporting structure, governance, service development and deployment of strategy.
- The Citizens Information Board (CIB) responsible for governance, development and deployment of strategy, training, support services, quality service standards and value.
- PAS established and put into effect through the appointment of a PAS Director in the Citizens Information Board. PAS will act as the escalation path for the advocates and 'the advocacy organisation' where statutory powers are required and all other avenues have been exhausted. The advocacy service required under PAS will be provided by a designated group of regionally based, highly qualified and experienced senior advocates, within the Advocacy Service, under the direction of the PAS Director in the Citizens Information Board.
- The Citizens Information Board's Director of PAS and Advocacy will sit on the national advisory group alongside selected senior personnel from disability organisations, family and friends groups, academia, service providers, people with disabilities, community and business leaders at a national level. Their purpose will be to develop national policy, national strategy, deployment of strategy, measurement of its success and ongoing development.
- Advisory Groups established at a regional level which may, in turn, consolidate, maintain or discontinue the current steering group structures at local level. The Advisory Groups will become 'partnerships for action' rather than being concerned with providing guidance to advocates. These groups will be resourced regionally with influence from the national advisory group. Equally the regional advisory groups will influence the membership and focus of any local fora that they decide should exist.
- Advisory groups will be composed of senior regional and local stakeholder groups across disability organisations, service providers, service users, carer groups, business, community and residential groups, ensuring diversity, collaboration and partnership. They will advise the advocacy manager and advocates for the purpose of effecting change.

4. Work with, Work for

- Advocacy will be delivered locally across the defined regions.
- Advocates will continue to work in community and residential settings through agreement with service providers. Emphasis is on offering choice, access and quality of facilities through complementary arrangements with other organisations. The regional advocacy teams will seek access to residential institutions not previously served and actively seek out and offer services to isolated people with disabilities in their communities.
- Advocates will work independently on behalf of service users liaising with service providers and statutory services in their service users' interests. They will engage with local fora or groups established in a locality either by regional advisory groups for the purpose of supporting advocacy or by any other group with interests in serving people with disabilities.
- Co-operative working and agreed solutions will be sought wherever possible but advocates will ensure service users' rights are respected.
- Social policy feedback will be captured and acted upon through an agreed pathway.

5. Share the Success

- Success will be shared, taking account of confidentiality and sensitivities, in a way that increases the capacity and capability within society to improve the lives of those with disabilities.
- Outcomes, issues and performance will be communicated and reported to effect change in practice and policy where necessary.

Implementing Structure and Organisation

In considering the organisational and structural aspects of the future National Advocacy Service the following components should be considered:

1. Advocacy operating model
2. Governance
3. Strategy development and deployment

1. Advocacy Operating Model

The basic operating model addresses the needs of service users, the needs of those working in the service and the needs of the stakeholders supporting or funding the service. A team-based approach is proposed that will operate within a region delivering services locally where they are needed. Five regions are proposed in line with current regional structures within the Citizens Information Board. This number is not prescriptive and the number of regions may be defined in accordance with the current review of regional structures within the Citizens Information Board. These are:

- Region 1: Dublin City, Fingal, Meath, Louth, Cavan, Monaghan
- Region 2: Dublin South, Longford, Westmeath, Offaly, Laois, Kildare
- Region 3: Dun Laoghaire/Rathdown, Wexford, Carlow, Tipperary South, Tipperary North, Kilkenny, Wicklow, Waterford
- Region 4: Cork, Kerry, Limerick Clare
- Region 5: Galway, Donegal, Mayo, Sligo, Roscommon, Leitrim

Regional Team

Each region will have a team of advocates. It is recommended that each region will have senior advocates, advocates and a citizen advocacy co-ordinator. The team will be led by an advocacy manager. Each team will have one administrator.

The citizen advocacy co-ordinator, advocates, senior advocates and advocacy manager will satisfy minimum experience and qualification requirements that will be set out as part of ongoing competency development and succession planning. Depending on the position, it will include experience and qualifications in management, disability and advocacy.

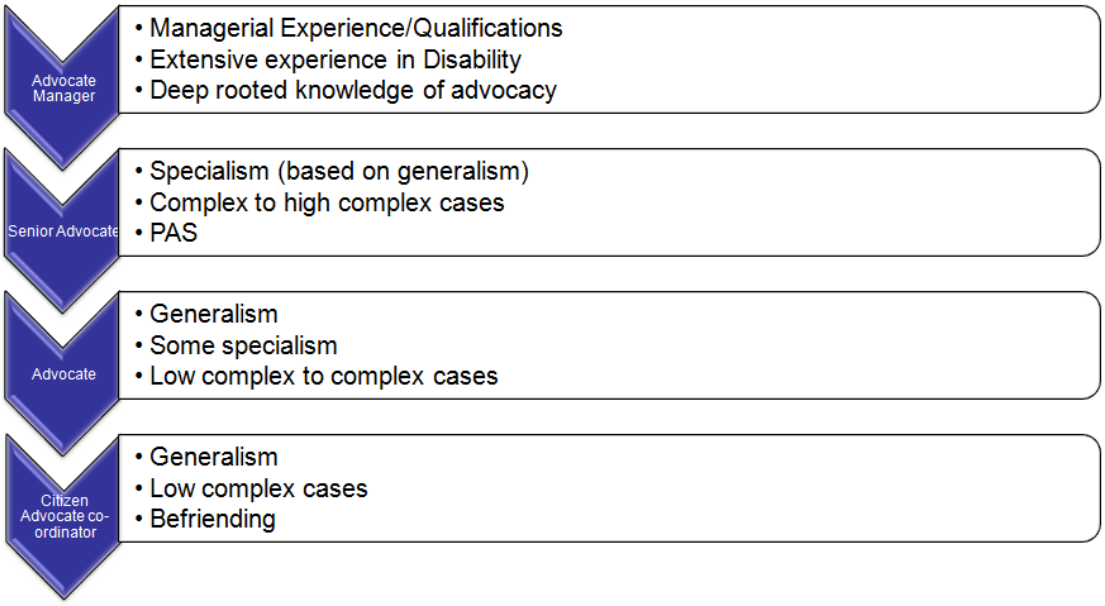

Figure 17: Advocacy Operating Model

The ***advocacy manager*** will be responsible for the overall success of the advocacy service within a region. S/he will have significant experience in managing all aspects of performance including efficiency, effectiveness and quality. S/he shall be involved in developing standards at a national level and implementing them at a regional and local level. S/he will require significant experience in advocacy and disability. S/he will work closely with the Director of the Personal Advocacy Service and Advocates to identify PAS cases and will allocate these to Senior Advocates, depending on their availability and their degree of expertise in the relevant field. S/he will be responsible for the supervision and mentoring of the team. S/he will also review cases with advocates in the team and assist with difficult cases.

The ***senior advocates*** will be responsible for the delivery of advocacy services for complex cases to the most vulnerable service users and those who come within the remit of the Personal Advocacy Service (PAS). It is highly likely they will have a specialism that has grown from providing advocacy services over a number of years and may be called upon to take specific cases within their region or from another region. They will have a mentoring and coaching role within their advocate team.

The ***advocate*** will operate in the provision of representative advocacy services generally. They may have certain specialisms that can be called upon within their region.

The ***citizen advocacy co-ordinator*** will identify, recruit and train volunteers to engage with long term residents in institutions. S/he will connect with residential institutions in the team's catchment area and negotiate access on behalf of the trained volunteers. S/he will support the volunteers in terms of meeting and debriefing and taking back issues that arise for residents and will advocate where appropriate.

Advocacy Support Services and Structures

Each advocate interacts with a service user, while being supported by an advocacy manager, peers, external supervision and a professional network. This model ensures that advocates are no longer isolated; standards are set and maintained through peer support, management structures and ongoing professional development.

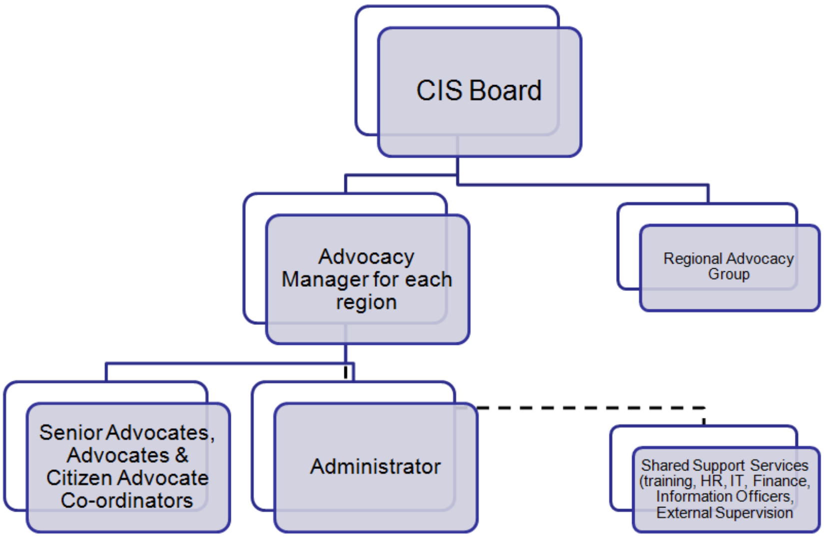

Figure 18: Regional Advocacy Structure

Advocates will be supported by a number of regional and national support services provided through the CIS network and the Citizen Information Board. The CIS network will support the advocacy teams with their expertise in information provision, governance and facilities located in selected CIS's, provide support in information communications technology (ICT)[33], human resources, financial Services, public relations, communication and promotional work.

Advocates will also work closely with the proposed advocacy support worker in the CIS network to ensure that people with disabilities who need information, advice and advocacy are provided with the service that best supports their needs and that those with the capacity to self-advocate are supported to use mainstream services in their local community.

2. Governance

The National Advocacy Service headed up by the Citizens Information Board will be established regionally through selected CISs. Its general direction will come from existing structures within the Citizens Information Board (both central and regional), but it will be managed at local level through the board of the selected CIS which will have responsibility for governance.

CIS Boards with responsibility for the Regional Advocacy Service

The board of each selected CIS will take on responsibility for the delivery of advocacy services within a defined region. Each selected CIS board will take on the governance and employer responsibility for the advocacy team. Advocacy, however, will remain a dedicated service in its own right with the advocacy manager reporting directly to the CIS board. The CIS board will report on its Advocacy Service in the same way that it reports on its other services.

Regional and National Advisory Groups

The regional board and the regional advocacy team will be supported by an advisory group set up to ensure the critical elements of successful advocacy provision are maintained i.e. independence protected, diversity among stakeholders created, service

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[33] Information and Communication Technology Support

users reached, access achieved, outcomes achieved, change implemented and value delivered. The advisory groups will be created at both national and regional level. At regional level, they will be linked to the CIS boards through having a member of each regional advisory group join each selected CIS board (or having a member of the CIS board sit on the regional advisory group). The five regional advisory groups will be linked to the national advisory group through regional representation.

The evaluation team strongly recommend that the membership of the regional advisory groups be formed from a cross section of existing project steering groups as well as regional representatives of stakeholder groups to ensure the best mix of experience and influence. The value added by these steering groups must be respected and retained with local groups continuing in a voluntary capacity if that is desired. The ultimate design of any local forum will rest with the regional advisory group, the advocacy managers, the Citizens Information Board and members of the current steering groups. It has proved important to have access to local service providers through their membership of project steering groups. It is recommended that if these groups are to remain, their focus should turn to local interventions in progressing issues for the advocates on behalf of their service users.

The advisory groups at both national and regional levels will be made up of as many stakeholder groups as possible and should include representatives from:

Carers, Family and Friends	**Community Development Projects (CDPs) & Family Resource Centres (FRCs)**	**Local Community Organisations**
City and County Councils	**Disability Organisations**	**Money Advice and Budgeting Service (MABs)**
Citizen Information Service (CISs)	**Health Service Executive**	**Residential Institutions**
Community and Business Leaders	**Legal Services**	**Service Users**

Table 3: Stakeholders of the Advisory Groups

The most important element of establishing advisory groups both nationally and regionally is that key government departments and agencies are in attendance alongside disability organisations, service providers and service users. The Citizens Information Board will play a critical role in the advisory groups. The chairperson's role is central to a successful advisory group and should be held by a person entirely independent of any direct service provision but with a knowledge of disability, advocacy and service provision.

An important function of advisory groups is to participate in the development of national and regional strategy and become 'partnerships for action' where advocacy teams are promoted, facilitated, given access and channels for escalating and resolving issues through the collaboration and partnership entered into by all the stakeholders.

3. Strategy Development and Deployment.

The strategy to develop advocacy services across the country through a series of different pilots has been hugely successful. However, a new strategy is required. The new strategy now needs to be developed directly from the service users' needs as articulated by them, by the advocates, by the advisory groups, the chosen CIS's and finally the national advisory group which is connected to Central Government Strategy in its design.

Within a period of three to five years the strategy needs to consider:

a. what outcomes it aims to achieve,

b. where it will focus the efforts of the Advocacy Service,

c. the capability and capacity it wishes to build over that period and,

d. the value it will deliver for all stakeholders involved.

Larger questions of where a National Advocacy Service will be placed in the rollout of Central Government Strategy as well as its role in Public Sector Transformation need to be considered. Advocacy's direct link with public services offers significant insights into the effectiveness or otherwise of mainstream public services and has the potential to influence policy on public sector transformation. In the future the advocacy service must consider its role in changing behaviours, perceptions, building new connections and relationships between all those who impact on, or are impacted by disability. Over 9% of the population (CSO Census 2006) fall into this sector without including all those connected with or working for this group of citizens.

The National Advocacy Service, under the Citizens Information Board, will require an operating definition of how it will conduct its work; the standards by which its outcomes will be measured, and a measurement system that will evaluate its success. The national advocacy service needs to add a number of key components to this;

- **Reach:** To define and establish what constitutes someone who is vulnerable, how they should be identified and reached by the advocacy service and how such service users should be prioritised while maintaining open access.
- **Independence**: To define and establish the role of independence in the delivery of advocacy so that the service users can be assured that their wishes will be respected and their interests and rights safeguarded.
- **Diversity, Collaboration and Partnership**: To define and establish how diversity, collaboration and partnership will be maintained within advisory groups and how wider collaborative relationships can be facilitated at local and national level contributing to the richness of services for service users.
- **Performance: Efficiency, Effectiveness and Quality**; To define and establish how best practice will be maintained to guarantee standards of performance and quality in the delivery of services and how outcomes will be measured to determine the effectiveness of the service.

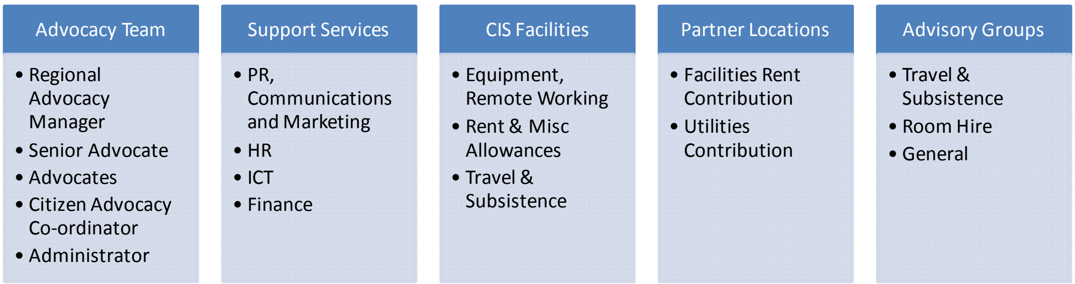
While the advisory groups, nationally and regionally operate in an advisory capacity, they do have an active role to play, being central to the development and deployment of strategy. It is envisaged that the Citizens Information Board will work with the national advisory group and will take on the national perspective and will focus on the role and fit of the advocacy service for people with disabilities with Central Government Strategy, local cohesion strategy and public sector transformation.

Each regional advisory group will play a strong role in the agreement of working practices and approaches; focus of work; policy areas requiring change; and intervention in the community or residential settings to enable vulnerable people to be reached. Those who are in a position to make lives better for people with disabilities are in many cases represented on current project steering groups and their representation on the proposed regional advisory groups should continue.

6.3. Finances

Outline Budget

A number of elements need to be considered when estimating whether the new model will fit within the existing budgets. The budget has been estimated within five components; the advocacy team, the support services required, CIS facility costs, allowances for third party partner locations where advocates may work, and the costs associated with the advisory group meetings.

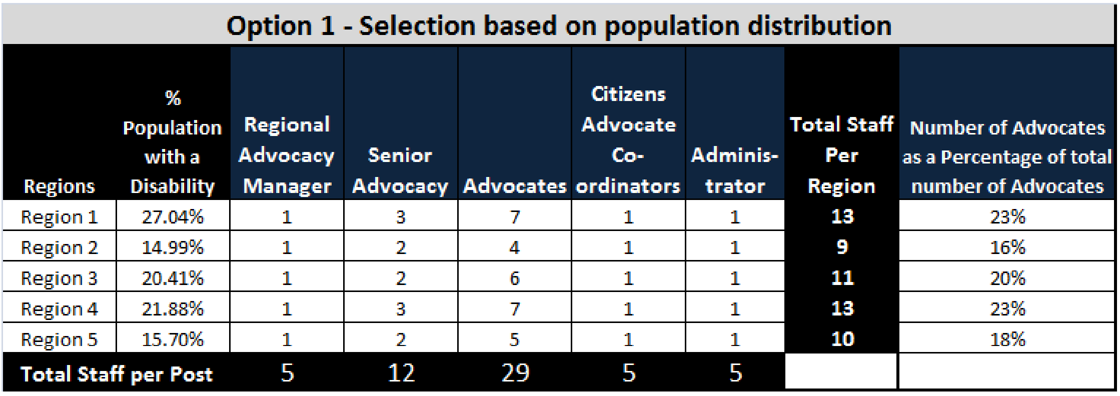


Advocacy Team	Support Services	CIS Facilities	Partner Locations	Advisory Groups
• Regional Advocacy Manager • Senior Advocate • Advocates • Citizen Advocacy Co-ordinator • Administrator	• PR, Communications and Marketing • HR • ICT • Finance	• Equipment, Remote Working • Rent & Misc Allowances • Travel & Subsistence	• Facilities Rent Contribution • Utilities Contribution	• Travel & Subsistence • Room Hire • General

Figure 19: Advocacy Cost Zones

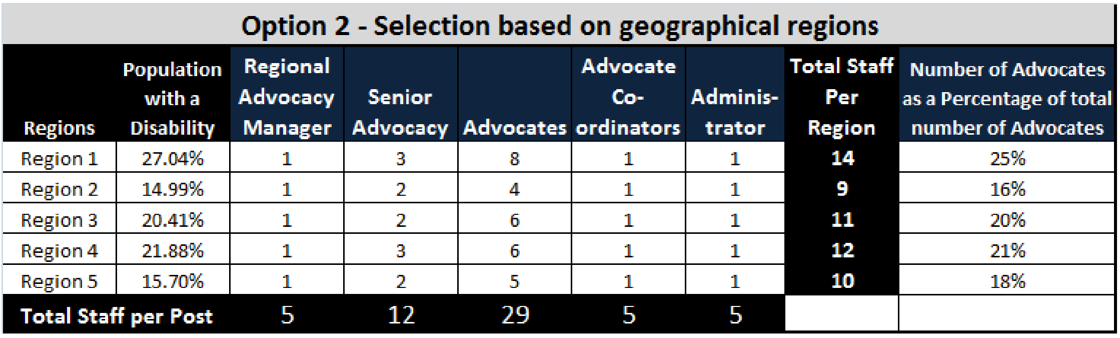
Human Resources

Depending on the size of a region, the numbers of advocates and senior advocates will vary. Two options were considered by the evaluation team.



Option 1 - Selection based on population distribution

Regions	% Population with a Disability	Regional Advocacy Manager	Senior Advocacy	Advocates	Citizens Advocate Co-ordinators	Adminis-trator	Total Staff Per Region	Number of Advocates as a Percentage of total number of Advocates
Region 1	27.04%	1	3	7	1	1	**13**	23%
Region 2	14.99%	1	2	4	1	1	**9**	16%
Region 3	20.41%	1	2	6	1	1	**11**	20%
Region 4	21.88%	1	3	7	1	1	**13**	23%
Region 5	15.70%	1	2	5	1	1	**10**	18%
Total Staff per Post		5	12	29	5	5		



Option 2 - Selection based on geographical regions

Regions	Population with a Disability	Regional Advocacy Manager	Senior Advocacy	Advocates	Advocate Co-ordinators	Adminis-trator	Total Staff Per Region	Number of Advocates as a Percentage of total number of Advocates
Region 1	27.04%	1	3	8	1	1	**14**	25%
Region 2	14.99%	1	2	4	1	1	**9**	16%
Region 3	20.41%	1	2	6	1	1	**11**	20%
Region 4	21.88%	1	3	6	1	1	**12**	21%
Region 5	15.70%	1	2	5	1	1	**10**	18%
Total Staff per Post		5	12	29	5	5		

Table 4: Options in allocation of Staff in different regions

In considering both of these options, the second option was closer to the percentage population of people with disability. However, the evaluation team gave consideration to the geographical spread of Region 4 and therefore recommend Option 1. This recommendation may change, on implementation of the programme and vary according to regional needs.

The total operating budget of the current pilot programme is €3,112,300. The projected annual financial requirement for the National Advocacy Service is €2,863,693. Table 7 sets out the summary of estimated costs across categories.

The National Service will require some additional financial and staffing resources.

- Projected set up costs are: €133,162.

- None of the projected costings have considered possible internal positions within the Citizens Information Board, such as Director of PAS and administrative support.
- With the projected annual financial requirement for the national advocacy service at €2,863,693, the costs will be within the current budget. of €3,112,300

PR & Advertising	€	30,000
Salary Costs	€	2,466,431
Administrative Costs for Advocates & Managers	€	38,862
ICT	€	12,900
Travel & Subsistence	€	153,000
Location	€	150,000
Advisory Group Expenses	€	12,500
Total	€	2,863,693

Table 5:Summary of Expense

7. CONCLUSION

The relevance and impact of the *Programme of Advocacy for People with Disabilities in the Community and Voluntary* sector is significant.

Vulnerable people, who have used the advocacy service, have consistently attested to how their lives have been changed and how they have developed skills and been empowered by their experience of advocacy. The relationship between the advocate and the service user is one founded on respect and dignity. The strength of these relationships supported by other stakeholders contributes significantly to the impact of this change for people with disabilities.

The implementation of the programme was fluid in its development. The Citizens Information Board's vision in rolling out the pilot programme in the way in which it did, offered the best combination of partnership, rapid infiltration of service and effective use of resources. Conversely, the development of the programme through forty six independent projects resulted in an overlap of administrative work. Because of the nature of the forty six independent projects, people were excluded from the service because of the geographical and service boundaries of the projects.

The partnership between the Citizens Information Board and the service providers through the development of the projects and the development of steering groups increased understanding and effectiveness amongst many stakeholders around the needs of vulnerable people and how each play a role in the support of people with disabilities.

As the programme developed the increased awareness of advocacy and its societal benefits grew, leading to an increase in understanding and acceptance of the advocate's role and demand for the service.

From its inception, independence of the advocate was critical in ensuring that the advocate could work in the best interests of the service user without conflict of interests. Many advocates expressed isolation in their work because of their employment as the sole advocate within the project. While they received support from line managers, steering groups and the Advocacy Association, their routine work was carried out in isolation with no advocate colleague to liaise with. This created major difficulties if an advocate took holidays, was sick or on maternity leave.

The issues that service users have presented during the pilot Programme have been varied, with the majority of the cases being complex, leading to successful outcomes. Without the implementation of the Personal Advocacy Service, the most vulnerable people with the most complex issues may never access advocacy. Many of the residential services who became involved in the pilot phase did so because of their desire to improve the lives for their residents, giving them a voice and more choices in their everyday lives. Those services which did not seek to be involved or refused access to an advocate may need to be approached with the legislative powers of the PAS.

In moving into its next phase of development, the Citizens Information Board will continue to be one of the key providers of representative advocacy in Ireland. It is imperative it retain its significance within this arena. Having a national identity and renewed programme structure will enable it to build on the strength of the pilot programme.

Should the recommendations of this report be implemented, the revised national structure of advocacy will consolidate representative advocacy provision for people with disabilities, to ensure greater reach and the use of scarce resources to their optimum.

The continued annual funding of this programme will support the new structures. The whole-of-life benefit of this funding, however, goes much further than the maintenance of the programme. It supports the State’s social policy initiatives and the National Disability Strategy. It supports the State’s stated aim in partnership agreements to give people with disabilities a voice and help them “to lead full and independent lives, to participate in work and in society and to maximise their potential". It supports the public service in meeting their obligations to people with disabilities as articulated in *Improving the Delivery of Quality Public Service*, which states that public service providers need to adopt a '*case management approach*' to service delivery, whereby the needs of the service user are assessed; the services and supports required to address these needs are identified; and the services are secured. The use of an *'advocate'* who can '*cut through the bureaucracy*' and help people '*navigate the system'* to help them draw down the range of services they require is essential". It supports the continued development of integrated services at national level and cohesion at local level. Most importantly it supports and empowers individuals with disability to be heard effectively when they may otherwise not be.

Considerable advances in legislation, social policy and programmes have been made to include people with disabilities. However, despite these advances, some people with disabilities in Ireland still experience extreme marginalisation in terms of health, housing, employment and social participation.

The findings of this evaluation and the recommendations made therein, offer an opportunity to build upon the dedication of the many stakeholders who contributed to the development of the pilot programme and to move forward in partnership to implement a National Advocacy Service that will best meet and support the needs of those who are most vulnerable.

8. APPENDIX 1 – ADVOCACY PROJECTS

No.	Project	Location	Spread	Advocacy Reach	Disability Type	Residential/ Community	Steering Group Type
1	Acquired Brain Injury Advocacy Association (BRI)	Dublin	Dun Laoghaire and National Rehabilatation Hospital	Specific Disability	Intellectual	Both	CIS Led
2	Ballyfermot Advocacy Service	Dublin	Ballyfermot area, and to those resident in Cara Cheshire home	Cross Disability	All	Both	CIS Led
3	Ballyhoura Development Ltd	Limerick	East and South Limerick/North East Cork region.	Non Specific Disability	Intellectual, Physical & Sensory	Community	Partnership Led
4	Blanchardstown Area Partnership / Daughters of Charity Navan Rd	Dublin	Daughters of Charity Services Dublin	Specific Disability	Intellectual	Residential	Partnership Led
5	Bray Partnership Limited	Wicklow	Bray	Non Specific Disability	Intellectual	Both	Partnership Led
6	Brothers of Charity (Limerick Citzien Advocacy)	Limerick	Limerick	Specific Disability	Intellectual	Residential	Service Provider Led
7	Cheshire Ireland	Dublin	Cara, Richmond and Barrett	Specific Disability	Physical & Sensory	Residential	Service Provider Led
8	Clare Independent Advocacy Service	Clare	Clare	Specific Disability	Intellectual	Both	CIS Led
9	Clondalkin CIS/ Peamount Hospital Disability Advocacy Service	Dublin	Peamount Hospital	Specific Disability	Intellectual	Residential	CIS Led
10	Clondalkin Disability Advocacy Project	Dublin	Clondalkin	Cross Disability	All	Community	CIS Led
11	Co Leitrim Citizens Information Service	Leitrim	Leitrim	Cross Disability	All	Community	CIS Led
12	Co Mayo CIS and Partners	Mayo	Mayo	Cross Disability	All	Both	CIS Led
13	Cork Advocacy Service Social and Health Education Project (SHEP), Cork	Cork	Cork & Kerry	Cross Disability	All	Community	Service Provider Led
14	Cork City South CIS (ECAS / Enable Cheshire Advocacy Service)	Cork	Cork Area	Specific Disability	Physical & Sensory	Residential	CIS Led
15	County Monaghan Partnership	Monaghan	Monaghan	Cross Disability	All	Community	Partnership Led
16	Cumas Advocacy Service	Carlow	Carlow & Kilkenny	Cross Disability	All	Both	CIL Led
17	DATA, Irish Wheelchair Association	Cork	North Cork, Mallow & Fermoy	Cross Disability	All	Community	Service Provider Led
18	Dementia Rights Advocacy Service - (Alzheimer Society)	Dublin	North County Dublin and City	Specific Disability	Alzheimer	Both	Soceity Led
19	Disability Advocacy Service	Dublin	Dublin 15	Cross Disability	All	Community	CIL Led
20	Disability Equality Specialist Support Agency (DESSA)	Waterford	Waterford	Cross Disability	All	Community	Soceity Led
21	Disabled People of Clare	Clare	Clare	Cross Disability	All	Community	CIL Led
22	Donegal Physical & Sensory Disability Consortium	Donegal	Donegal	Specific Disability	Physical & Sensory	Community	Soceity Led
23	Dublin Leader Advocacy Service (DLAS)	Dublin	Dublin City and County	Specific Disability	Physical & Sensory	Both	CIL Led
24	Eastern Vocational Enterprises (EVE) Ltd & TUISCINT	Dublin	Dublin	Specific Disability	Aspergers	Community	Service Provider Led
25	Galway Advocacy Service	Galway	Galway	Cross Disability	All	Community	CIL Led
26	Inclusion Ireland - Moore Abbey Monasterevin & St Joseph's Disability Service, St Ita's Portrane	Dublin	Moore Abbey Monasterevin & St Joseph's Disability Service, St	Specific Disability	Intellectual	Residential	Soceity Led
27	Inclusion Ireland & Regional Behavioural Support Service (RBSS)	Monaghan	HSE North East	Specific Disability	Intellectual	Residential	Soceity Led
28	Irish Wheelchair Association	Wexford	Wexford	Cross Disability	All	Community	Soceity Led
29	Longford Advocacy for People with Disabilities (LAPD)	Longford	Longford	Cross Disability	All	Community	CIS Led
30	Midway (Meath Intellectual Disability Work Advocacy You Ltd)	Meath	Meath	Specific Disability	Intellectual, Physical & Sensory	Community	Partnership Led
31	MS Ireland	Monaghan	Northe East	Specific Disability	MS & Neurological	Both	Soceity Led
32	National Learning Network (NLN)	Dublin	Dublin	Cross Disability	All	Community	Service Provider Led
33	North Kildare CIS / St Raphaels and Dara Residential Services	Dublin	Cellbridge	Specific Disability	Intellectual	Residential	CIS Led
34	Offaly Disability Advocacy Service (ODAS)	Offaly	Offaly	Cross Disability	All	Community	CIS Led
35	People with Disabilities Ireland	Westmeath	Westmeath	Specific Disability	Intellectual	Residential	CIS Led (PWDI)
36	Roscommon Advocacy Network	Roscommon	Roscommon	Cross Disability	All	Community	CIS Led
37	Schizophrenia Ireland -Ar nGlor Advocacy Service	Dublin, Galway, Kilkenny, Cork	Dublin	Specific Disability	Mental Health	Community	Soceity Led
38	Sliabh Luachra Advocacy Service for People with Intellectual Disabilities	Kerry	Kerry	Specific Disability	Intellectual	Community	Partnership Led
39	Sligo Interagency Disability Group (Our Voice)	Sligo	Sligo	Specific Disability	Intellectual	Both	CIS Led
40	STEER Ireland	Donegal	Donegal	Specific Disability	Mental Health	Both	Partnership Led
41	Tallaght Disability Advocacy Service	Dublin	St. John of God, Menni Services, Central Remedial	Cross Disability	All	Both	CIS Led
42	Tipperary Advocacy Service	Tipperary	Tipperary	Cross Disability	All	Community	Soceity Led
43	Waterford Advocacy Project	Waterford	Brothers of Charity Clients	Specific Disability	Intellectual	Both	CIS Led
44	West Limerick Independent Living (Limerick Advocacy Service)	Limerick	Limerick City and County	Cross Disability	All	Community	CIL Led
45	Westmeath Mental Health Advocacy Network	Westmeath	Westmeath	Specific Disability	Mental Health	Community	CIS Led
46	Youghal Advocacy Project, Co Cork	Cork	Raphael's Residential Service	Specific Disability	Mental Health	Residential	Soceity Led

9. APPENDIX 2 – POPULATION IN EACH OF THE REGIONS

Region 1			
	Total Population	Population with disability	Percentage of population with disability
Dublin City	506,211	56,420	11.10%
Fingal	239,992	17,215	7.20%
Meath	162,831	12,076	7.40%
Louth	111,267	10,414	9.40%
Cavan	64,003	5,435	8.50%
Monaghan	55,997	4,921	9.30%
Totals	**1,140,301**	**106,481**	27.04%
Region 2			
Dublin South	246,935	21,203	8.60%
Longford	34,391	3,285	9.60%
Westmeath	79,346	7,451	9.40%
Offaly	70,868	6,230	8.80%
Laois	67,059	5,872	8.80%
Kildare	186,335	14,986	8.00%
Totals	**684,934**	**59,027**	14.99%
Region 3			
Dun Laoghaire/ Rathdown	194,038	18,092	9.30%
Wexford	131,749	12,681	9.60%
Carlow	50,349	4,739	9.40%
Tipperary South	83,221	8,791	10.60%
Tipperary North	66,023	6,307	9.60%
Kilkenny	87,558	7,941	9.10%
Wicklow	126,194	11,576	9.20%
Waterford	107,961	10,224	9.50%
Totals	**847,093**	**80,351**	20.41%
Region 4			
Cork	481,295	44,762	9.30%
Kerry	139,835	13,186	9.40%
Limerick	184,055	18,226	9.90%
Clare	110,950	9,923	8.90%
Totals	**916,135**	**86,097**	21.86%
Region 5			
Galway	231,670	19,883	8.60%
Donegal	147,264	14,981	10.20%
Mayo	123,839	12,114	9.80%
Sligo	60,894	6,183	10.20%
Roscommon	58,768	5,746	9.80%
Leitrim	28,950	2,916	10.10%
Totals	**651,385**	**61,823**	15.70%

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