



# Speaking up for Advocacy

## My life as an Advocate - the story so far!

According to the movie character Forrest Gump, life is like a box of chocolates - you never know what you're going to get. Well, my work as an Advocacy Officer seeking change with and on behalf of others is a lot like that. Sometimes my work is satisfying and fun, other times frustrating and very hard, but it is never dull and I like it!

Of the clients I have worked with to date, a number of them stand out for me. For example the case of the mother, who, on behalf of her child, has struggled for two and a half years to secure living accommodation specific to her daughter's needs. Her determination and strength have been reinforced by my listening ear, communication skills and resolve.

Then there's the non-instructed advocacy case, where basic human rights and ordinary life principles dictate my work. I ask the questions a reasonable person would ask on behalf of my client, Mary. This case has been interesting and sometimes difficult but nonetheless invaluable in creating important links with a range of services in the community and, most importantly, in the difference my work has made to Mary's life including finding out the name she responds to, family contact and on-going therapy programme.

My group advocacy work with the residents of a local nursing home to set up a Residents' Council has been thoroughly enjoyable. Who says committee meetings can't be fun! We regularly laughed together while changing the programme of activities at the nursing home to include baking days, pot planting and the recording of the residents' stories with the local transition year students. The Council was also featured on the regional radio station Mid West Radio at Christmas.

In order to persevere, particularly when cases take a toll, I seek support from others – my Manager, colleagues and external supervisor. They each bring different perspectives and qualities,



Clare O'Neill with Eithne Kenny, Chairperson of Residents Council, St Attracta's Nursing Home, Charlestown

which I greatly appreciate. Of course, I also rely on family, friends and myself. I recommend a 10km run and home-made chocolate cake to help see the light!

To conclude, we all need advocates from time to time and people with disabilities, many of whom remain so vulnerable in today's society, need advocates more. So for 2009 I'm going to try to remember the following quote to bring a smile!

*"If you think you're too small to have an impact, try going to sleep with a mosquito!"*

**Clare O'Neill**, Advocacy Officer, Mayo Advocacy Service.

## Standards in Advocacy

During the first stage of disability advocacy in Ireland time and energy went into defining advocacy and setting up projects. But now that the definitions are there and the initial projects set up, the question of quality arises? Are we running the best service possible? How do we measure something which can be intangible and may not result in a clear outcome?

- The *Advocacy Guidelines* published by CIB and revised in 2007 provide essential pointers in the quality area and are worth dipping into regularly.
- Action for Advocacy, a UK umbrella organisation provides useful information. Its standards -based on the principles in the Advocacy Charter - can be used as both a guide and a measure. Their website guide links policies, principles and codes of practice.

For example, under the principle, Clarity of Purpose, the *Action for Advocacy* document starts with the following:

“The advocacy scheme has clearly stated aims and objectives and can demonstrate how it meets the principles contained in the Advocacy Charter. Advocacy schemes will ensure that people they advocate for, service providers and funding agencies have information on the scope and limitations of the schemes’ role.”

Action for Advocacy has also introduced a three stage quality performance management system, consisting of self assessment, desktop assessment and site assessment.

You can find out more about quality standards on the website: <http://www.actionforadvocacy.org.uk/articleServlet?action=display&article=1123&articletype=8>

## Unpacking non-instructed advocacy

*“Non-instructed advocacy is.....taking affirmative action with or on behalf of a person who is unable to give a clear indication of their views or wishes in a specific situation. The non-instructed advocate seeks to uphold the person’s rights; ensure fair and equal treatment and access to services; and make certain that decisions are taken with due consideration for their unique preferences and perspectives.”*

(Henderson, 2006)

The essential difference between instructed and non-instructed advocacy lies in the presence or absence of “instructions” – in “normal” advocacy the advocate works to an agenda negotiated with the client. Henderson sees the role of the non instructed advocate as:

- Establishing an open, trusting relationship
- Finding what the service-user wants from the relationship
- Identifying goals and desired outcomes
- Gathering information on behalf of the service user
- Representing the person’s views, wishes and concerns to third parties
- Reviewing progress & goals in light of experience.

Non-instructed advocacy requires advocates to use a far greater level of judgement than instructed advocacy, which leaves them open to the criticism that they are following their own agenda. Seeking instruction from the service user should always be the starting point, but advocates must be willing to act even if no instruction is forthcoming. People who lack capacity have a right to independent support and representation.

There are four main approaches to non-instructed advocacy:

- **Human rights based**  
*If the advocate believes that the person’s basic human rights are being violated, he/she will intervene or seek legal redress on the person’s behalf.*
- **Person centred**  
*The advocate develops a relationship with the person, comes to understand their needs, wants and views and represents these to service or family.*
- **Watching brief**  
*This approach uses 8 quality of life domains as the basis for a framework of questions to service providers and decision makers on the person’s life.*
- **Witness observer approach**  
*The advocate observes and then reports back to the service instances of unacceptable behaviour or lack of interaction in services.*

Rick Henderson sees the non-instructed advocate as a cross between a watchdog and a negotiator – ready to bark at unacceptable behaviour, but also ready – and able – to negotiate a better deal for the person in question.

The full article can be found at: [http://www.aqvx59.dsl.pipex.com/What\\_is\\_non\\_instructed\\_advocacy.pdf](http://www.aqvx59.dsl.pipex.com/What_is_non_instructed_advocacy.pdf)

## Residential Staff and Advocacy: orientation day in Peamount Hospital

On 30th September CIB hosted a training day in advocacy in Peamount Education Centre, Newcastle Co. Dublin. It was designed for staff who work in four residential services - Peamount, Daughters of Charity Blanchardstown services and St Raphael's and Dara Services ( Celbridge). Advocates are now working with residents of these services, which means a certain amount of change for staff. The training was attended by staff, advocates and CIB personnel – with presentations on the experiences of the Community & Voluntary Advocacy programme to date, on non-instructed advocacy, on the role of the independent advocate. One presentation was given by a self advocate.

In the afternoon there was a workshop session with Dr Stephen Kealy from Moore Abbey, a residential service

which has had the services of an advocate for a couple of years. Real life dilemmas were discussed by the groups: these included the group home that didn't open because of a dispute; rights of service users to sexual relationships and simple complaints. One participant commented:

" The Residential Projects day, was very useful, in particular the discussions, which helped clarify the role of the steering group, and involved everyone, including service staff. The presentations helped identify issues and in particular the complexity of advocacy in a residential setting. Examples were presented by services and possible ways forward gave great ideas about where a service might go with advocacy."

## Advocacy projects come together across the regions.

Between September and November 2009 CIB hosted 5 regional networking days for those involved in Community & Volunteer sector advocacy projects. Advocates, managers and Steering Group members attended and many expressed satisfaction at the opportunity to get together and exchange experiences. Two events took place in Dublin, the others in Kilkenny, Charleville and Sligo. Presentations and workshops allowed for discussion and participant

input. "Good open forum" "increased insight into the complexities of advocacy work" "local networking working well" were among the favourable comments. Safeguarding independence and data protection were difficulties for some and participants were keen for CIB to set good practice standards and to make the networking days more accessible for Steering Group members with disabilities. Further occasions to network would be welcomed.

Participants at the CIB Regional networking day held in the Gresham hotel in October 2008.





The Citizens Information Board is the statutory body which supports the provision of information, advice and advocacy on the broad range of social and civil services to the public. It provides the Citizens Information website and supports the voluntary network of Citizens Information Services and the Citizens Information Phone Service.

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## 2008 Reports from C&V Advocacy Programme

Every six months projects in the Community & Voluntary Advocacy programme for people with disabilities report to the Citizens Information Board on their progress. These reports outline the sterling work being done by projects and advocates and their growing levels of experience and confidence. The table sets out the numbers of clients. Numbers have risen steadily from 734 in 2006 (13 projects) 1,322 in 2007 (27 projects), to 2,056 in 2008 (43 projects). Citizen advocate projects are not included.

The top five issues named by the projects were in the areas of Housing and Accommodation, Disability Services (or their lack), Independence, Personal Assistance issues and Social Welfare Entitlements. Other issues emerging from the cases include self advocacy support, access to professional services (often in the health area) and family issues. Older projects reported a growing acceptance and understanding of the advocate's role among service-providers.

### Case Numbers Annual Report 2008

Project Start up year	Totals	Average number of clients per project
2005	988	66
2006	698	54
2007	370	23
All (43)	2056	46
All 46 (incl Citizen Advocacy)	2087	

## Mapping Self Advocacy

*Self-advocacy is the act of speaking up for oneself. With the right support in terms of advice, information and encouragement, self-advocacy is something that many individuals can achieve. The term "advocacy" literally means standing with or speaking for someone, so self-advocacy is sometimes interpreted as being a contradiction in terms. In reality, self-advocacy is the process by which people are empowered to speak for themselves. (Goodbody, 2004, p.14).*

Self advocacy movements first began in Sweden and in the United States but are now well established in most European countries. Some people with intellectual disabilities now speak at conferences, train other self-advocates and staff and organise aspects of their own services and lives in ways that would have been considered impossible thirty years ago. Self-advocacy programmes are often linked to person-centred planning.

In 2008 the Citizens Information Board commissioned mapping research from Francesca Lundstrom in order to identify existing self-advocacy initiatives for people with intellectual disabilities and gaps in their spread.

From a survey of 87 services the report gives details of 43, a response rate of about 50%. Initiatives were categorised using a scale which starts with the presence of within-service

self-advocacy training for service users, takes in involvement in the service's representative groups and goes through to self advocates lobbying at local or national level.

Most of the issues arise in the accommodation, work or training areas. The most illuminating account was that of the service without walls (P.22), where the person's whole service is set up on advocacy principles and provided in very small clusters, several of which are integrated with other community groups (for example, a women's group). This integrated approach to provision allows for natural advocacy with the person negotiating the type and amount of desired support and the service facilitating the things they wish to do.

Overall the report gives an interesting sketch of the spread and depth of self advocacy initiatives in the intellectual disability field in Ireland. It seeks a new definition of self advocacy, and highlights inter-agency work. The need to involve staff and families in self advocacy initiatives is also seen as having high priority.

*Mapping Self Advocacy* can be downloaded from the CIB website [http://www.citizensinformationboard.ie/publications/social/downloads/SelfAdvocacyMapping\\_rpt\\_Oct2008.doc](http://www.citizensinformationboard.ie/publications/social/downloads/SelfAdvocacyMapping_rpt_Oct2008.doc) If you would like a hard copy please contact CIB at 6059000.