

Speaking up for Advocacy



Julianne Gillen, National Association for Deaf People;
Patrick O'Leary, Equality Authority; Helen Lahert, CIB

Level Playing field in Croke Park!

This is a special edition of Speaking up for Advocacy to celebrate the Citizens Information Board conference in the Croke Park Conference Centre. Advocacy: levelling the playing field took place on 27th April and brought together speakers from abroad, agency staff, lecturers from Sligo Institute of Technology, disability activists, and people from the new advocacy projects. The final speaker was a self advocate from Galway. The conference gave a real sense of the direction of advocacy in Ireland.

CONFERENCE

Current developments within the Citizens Information Board

Leonie Lunny, Chief Executive Officer of the Citizens Information Board (CIB) (formerly Comhairle) spoke of the CIB's new advocacy services. They aim to ensure that every person – whatever their degree of disability – will have their road to services smoothed, with an advisor to assist them to participate as fully as possible in all areas of Irish society – whether they just need information so they can advocate for themselves, or whether they need a trained person to undertake the job for them. In addition to its mainstream information, advice and advocacy channels, the CIB will be responsible for three strands of disability advocacy as set out in the Goodbody report which was commissioned in preparation for the Citizens Information Act 2007.

The first strand is the **Personal Advocacy Service (PAS)** – a new departure for the CIB as it will provide a direct advocacy service to the public. It is envisaged that this service will deal mainly with serious complaints and appeals. The aim is to

have a director, support workers, two senior and ten other advocates who will be recruited on a phased basis. Initially the service will be accommodated in the Citizens Information Board premises in Dublin. The second disability advocacy strand is the Community and Voluntary Programme for people with disabilities. The programme is currently funding 30 projects nationwide and will be expanded further this year. These are the main experiences emerging from the programme:

- The importance of independence for advocate and project.
- A consciousness of ethical issues – in terms of conflicts of interest and prioritising a client's best interests.
- The enthusiastic response of the sector and the degree of cooperation between different organisations in setting up a new service.
- The need to support self advocacy initiatives.
- The importance of working with service providers, as negotiated solutions tend to work best.

- The need for flexibility on client groups – so that the service can adjust to specific demands. The segmentation of present services for people with disabilities can lead to uneven spread of service.
- Practical problems for projects in terms of having only one advocate in each project.

The final strand recommended was a Community Visitors Programme for people in residential care. CIB will undertake a feasibility study on this programme in the light of other developments in the area.



Swantje Köbsell, University of Bremen; Neil Bateman; Tony McQuinn; CIB

CONFERENCE

The Importance of Advocacy in terms of Equality and Human Rights for People with Disabilities: Experiences from Germany

The keynote speaker was Swantje Köbsell a disability rights activist from the University of Bremen in Germany.

Swantje Köbsell, spoke about the history of the disability rights movement in Germany from the Nazi era when up to 300,000 disabled people were killed in the camps through the "cripples groups" movement in the 1970s and the Frankfurt Judgement in 1980. This judgement awarded damages to a woman because she had to bear the sight of severely disabled people while on holiday and caused a storm of protest, which strengthened the fledgling German Disability Rights Movement.

However it was not until the unification of East and West in 1994 when the German Constitution was amended, that the disability movement achieved the insertion of the sentence: "No person shall be disfavoured because of disability." The Federal Act on the Equalization of Disabled Persons came into force in May 2002 and

the civil anti-discrimination law in 2006 – after much debate, because certain political powers opposed the inclusion of disabled people. Swantje named personal assistance, deinstitutionalisation, a barrier free environment, inclusive education and personal and political advocacy as the areas where progress has been made but improvements are still needed.

In 1996 the national disabled women's network was founded, highlighting the connection between eugenics, genetic counselling, and selective abortion in relation to disabled people.

Under German law disabled people are entitled to a means tested allowance. However, costs for living outside an institution must not be higher than in an "adequate" institution. So disabled people who need a lot of assistance live under the constant threat of institutionalisation or have to make do with less assistance than they actually need. The "Personal Budget" model will be introduced throughout Germany in 2008 "changing the person with a

disability from alms recipient to customer".

In Germany there is now one federal ombudsperson for disability, as well as one for each federal state. They work towards equal and self-determined living conditions for disabled people and facilitate the implementation of the respective Acts on the Equalisation of Disabled Persons. They can also be approached about individual cases of discrimination or breach of law.

Swantje concluded by saying; *"In Germany, disabled person's advocacy has achieved a lot in recent years. Our organisations are well established and acknowledged; we have been central to the often-mentioned paradigm shift in German disability politics from welfare to self-determination and participation. Nevertheless, some of these achievements are endangered and in other areas still much has to be achieved; so we have to monitor closely what is being discussed and planned to make sure that our interests are taken into consideration".*

Certificate in Contemporary Living at the National Institute for Intellectual Disability (NIID), Trinity College Dublin



NIID Students, Trinity College Dublin, Certificate Course in Contemporary Living 2005-2007

This is an exciting programme for people with intellectual disability, which the National Institute for Intellectual Disability (NIID) at Trinity College, Dublin have run on a pilot basis. NIID is committed to promoting the full inclusion of people with intellectual disability through

- Developing lifelong education and learning programmes.
- Undertaking inclusive research and creating a network of researchers.
- Influencing disability policy and practice.

This Certificate in Contemporary Living is one example of an innovative response to the needs of people with intellectual disability. It is a two year, full-time programme which is made up of ten modules, eight mandatory, (English and Communication, Mathematics and Financial Management, Information Technology, Personal Effectiveness,

Inclusive Studies and Research, Career Development, International Awareness and Social Science) and two optional, from the following: Drama and Dance, Art and Design, Music and Creative Arts Appreciation and/or Performance. These modules allow the students to participate in a range of subjects that cover the disciplines of the arts, social sciences, career planning and development. Each module engages students in a series of workshops, lecture presentations, tutorials as well as self directed learning activities. The Special Topic module offers individual students an opportunity to research a topic of interest under the guidance of a tutor. The students plan and present the topic themselves.

Partnership with agencies, Trinity staff and students

Currently 18 students from the following service agencies are undertaking the

course: Carmona Services, St John of God; Moore Abbey, Monasterevin; Stewarts Hospital; Sunbeam House Services and Festina Lente Foundation. Staff from the agencies work in partnership with the staff of the Institute and of Trinity and of course with students. Departments such as, Occupational Therapy, Clinical Speech and Language and Nursing and Midwifery are involved. A mentor programme – set up with the Trinity Societies and Students Union is an integral part of the programme. Each student is matched with a mentor with whom they enjoy social activities on the Trinity Campus. At present the Certificate programme is being evaluated.

For further information please contact Molly O'Keeffe, Programme Co-ordinator, mookeeffe@tcd.ie, tel. 896 3875 or Dr. Patricia O'Brien, Director, obrienp3@tcd.ie, tel. 896 3879.

The Advocacy Facts of Life

Eleanor Edmonds presents some gems of experience

1 Nobody understands you. Deal with it.

You will spend a lot of time explaining what advocacy is, to lots of different people. Keep it simple. Make sure your explanation is accessible to the person you're talking to. Be prepared to recap – again and again and again!

2 Making it up as you go along? Fine.

Understand there is no one answer as to how to do advocacy, though there are lots of useful guidelines. Accept the fog and design your own set of headlights: agree your policies and procedures with management from the start.

3 What comes out must have gone in. (Or, it's not all about you!)

Always focus first on listening to the client (or follow your non instructed advocacy policy). Be like a broken record in referring everything back to your client.

4 Not everyone will be thrilled to see you coming.

Give them every opportunity to see you in a positive way. Ideally, meet service providers before an issue arises. Spend time building trust with clients.

Where conflict arises, stay focussed. Keep checking back with your client and your service policies – if you're on track there, it doesn't matter what anybody else thinks.

5 Fairies have magic wands. Advocates don't.

Try to manage expectations: your own and others. Accept you won't achieve everything you would like to achieve for the client. Know your boundaries. Make sure to notice and record what you do achieve. Where results are disappointing, try to identify why. Is it within your control? Does someone else need to know?

6 Advocates need support too.

Get your supports in place early. Figure out what's reasonable and realistic to expect from management, colleagues and peers. Give serious consideration to asking for external supervision. Remember your clients can be a source of support too – enjoy a hug and a kind word when you get it.

7 Sometimes, it works.

Celebrate your victories. Remember that while you often won't be able to achieve the client's desired outcome, you have done your job if you have improved the process. Try to note all the outcomes – big and small, "hard" and "soft". When all else fails, remember that finding out what doesn't work is useful too!

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Getting Involved in Community

Peter Kearns is a trainer and teaches the Higher Certificate in Advocacy Studies course in Sligo

Galway's Tuam is the centre for a partnership initiative entitled MENTORING WEST. A pool of disabled people will be trained as community based mentors for disabled people west of the Shannon. Citizens Information Board (CIB) is funding this pilot advocacy project with partners DESSA (Disability Equality Special Support Agency) and Forum of People with Disabilities (FPD). The mentors will work with designated disabled individuals (mentees) who are already taking an active part in disability equality programmes such as MAKING CHOICES or STEP FORWARD.

These programmes have been developed by DESSA/FPD and disability equality trainer Peter Kearns over the past three years. The MENTORING WEST programme is the third rung in an 8-step progression towards full mainstream participation in local community life.

These disabled mentors will oversee effective social model led mentoring processes with individuals who are starting to access their local Family Resource Centre (FRC) or Community Development Programme (CDP). The mentors will explore community development based advocacy options with their designated mentees. The disabled mentees are currently taking part in facilitation work alongside the programme facilitators Peter Kearns (Forum)

Martin Rogan is Assistant National Director for Mental Health, Health Service Executive (HSE)

Martin Rogan made an engaging presentation on advocacy which challenged all those present to dust off their assumptions – about presentations as well as advocacy. He identified issues of power between service provider and user which mean that staff cannot be totally successful as advocates. Services and advocates should be aware of these power imbalances- and in this context the service-user's image of the doctor was quite illuminating, showing that although staff and service users walk the same corridors, the experience is very different.

Martin emphasised the need for training – for advocates, service users and staff and described the facilitation advocacy training which had taken place in DCU in cooperation with the Irish Advocacy Network (IAN). The implementation of the Mental Health Act 2001 has changed the framework for the mental health sector, given added safeguards to involuntarily detained patients and provided a supervisory structure for services. A side effect

had been the provision of training to 5,500 staff in preparation for the tribunals.

The effective mental health service depends on partnership with the expert skilled and mandated service-user. Services need to be of high quality and the individual must contribute much more aggressively to their own treatment. The setting up of the National Service User Executive should help here. Martin reminded us that information was the fuel of all advocacy. In most cases there was no need for "best interests" buffers. Services had to respond to documented need in a way that respected the person with the mental health difficulty. His map of Ireland demonstrated how black spots for poor mental health are similar to those for other forms of deprivation.

Advocacy and self advocacy are not really new – we have just repackaged something that existed in another form. Martin gave us several examples of ancient advocates and self advocacy accounts that had fallen on deaf ears – the one from seventeenth century Bedlam – "They called me mad, I called them mad, Damn them, they



Martin Rogan,
Health Services Executive

outvoted me," – to Jack Nicholson's character in *One Flew over the Cuckoo's Nest*. He also reminded us that there is no high wall between those labelled mentally ill and those who haven't been – yet.

Martin's apt graphic for the level playing field demonstrated how "level" can lie in the eye of the beholder.

and Eileen Carroll (DESSA). They assist local disability groups with developing aims and objectives and action plans.

MENTORING WEST will offer a real local choice to mentees beyond the borders of the disability sector, which often entails individuals being bussed out of their immediate communities. Self-advocacy, capacity to achieve personal life goals within a rights-based model, liaison with their local community development centre will be the main elements.

The project will provide a pool of trained disabled mentors. It is envisaged that the mentors will also work alongside FCR/CDP staff to promote self-advocacy lifestyle goals within a rights based community development model.

"The community development sector offers a home for our rights based wishes, because it already has a tradition of equality and inclusion, plus a proven track record with other marginalised groups".

The many CDP/FRCs west of the Shannon who have enthusiastically recognised the benefits of having access to disabled mentors will have direct contact with disabled people and a greater understanding of disability advocacy processes. The project will be assessed by CIB for its effectiveness as a contribution to self-advocacy capacity of disabled individuals and their communities.

New Citizen Advocacy Service in Cheshire Dublin

Citizen advocacy is when one person makes a long-term commitment to the rights of another who finds him/herself devalued, disadvantaged, or socially excluded.

Citizen advocates play a vital role in facilitating access for the individual to a whole range of information, representation, and natural supports. This person-centred approach helps to empower people in their individual choices as to how they lead their lives.

Cheshire Ireland provides a range of supported accommodation services to people with physical disabilities and is committed to providing quality, person-centred services. With the continued support of the Citizen Information Board, Cheshire Ireland is now embarking on a project, which will involve the provision of a citizen advocacy

service for persons living in Cheshire Ireland residential services in the Dublin area.

The advocacy service will provide well-oriented, trained volunteers to support people living in these services to speak up, express their desires, choices, needs, and exercise their rights. A citizen advocacy co-ordinator is responsible for the planning, implementation and management of this new and exciting advocacy initiative.

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CONFERENCE Equality and Advocacy

Patrick O'Leary is in the Research and Communications Department of the Equality Authority

Patrick O'Leary outlined the role of The Equality Authority which was established to promote equality and combat discrimination across nine grounds which include disability. Casework under the Equality legislation has thrown up the following issues

- Significant levels of gender discrimination in terms of sexual harassment, promotion, equal pay and pregnancy related discrimination.
- Discrimination against migrant workers in terms of dismissal, equal pay and excessive working hours.
- Lack of reasonable accommodation for employees with disabilities.
- Workplace harassment on the race, disability, sexual orientation, age and Traveller grounds.
- Unequal practices by schools.
- Significant discrimination in the provision of public services.
- Significant discrimination in housing in particular on the race and Traveller grounds.

The Equality Authority's vision of equality takes in empowerment, representation, recognition of diversity, redistribution of wealth and jobs, respect and the areas of caring and solidarity. Patrick sees advocacy as a tool in ensuring the effective implementation of equality legislation and the achievement of equality objectives. He quoted a CSO survey which showed that many marginalised people and groups are less likely to obtain services they are

entitled to, less likely to have their voices heard or be involved in the decisions affecting their lives. In an equality context advocacy was about:

- Providing information on rights under the legislation.
- Building a culture of compliance with legislation.
- Providing assistance to those who wish to make a claim.

Patrick quoted a case that had been successfully taken by a Traveller couple with assistance. He highlighted the importance of a support infrastructure to ensure rights are implemented and the greater accessibility of the tribunal structure. Funding, the availability of a skilled and experienced advocate and the establishment of advocacy networks are essential here.

Patrick finished by praising the Citizens Information Board for resourcing advocacy projects in close co-operation with the voluntary sector. He looked forward to an ongoing partnership which would further improve services and access for marginalised groups.



Davin Roche, CIB; Majella Mulkeen, Sligo IT;
Teresa McCourt, Westmeath Citizens Information Service



CONFERENCE

Chris Glennon, Chairman CIB; Neil Bateman, Welfare Rights Consultant; Leonie Lunny, CEO CIB

Experience from the UK – Neil Bateman: trainer, author and advisor

Neil Bateman has 30 years experience of welfare rights and advocacy work. He is a trainer and advisor and author of the popular text book "Advocacy Skills for Health and Social Care Professionals".

Neil started with definitions and their lack. There is no agreed definition of advocacy in England and some definitions are complex and possibly artificial. Advocacy is essentially about "acting on behalf of, giving voice to and securing rights".

The lack of agreed definition may stem from the huge range of advocacy projects that operate in England. These projects cover issues from general legal entitlements to more specialised work focusing on the quality of social and health care. Indeed there is an unhelpful split between the older Citizens Advice Bureau type organisations and the newer dedicated advocacy organisations.

Competition between schemes for resources is an issue. But among the 800 advocacy schemes, there have been many success stories pushing back the boundaries of the welfare state and righting wrongs. Advocacy services have helped ensure that service

user involvement is now the norm in service delivery.

In discussing the challenges facing advocacy, Neil posed the question – is government funding a poisoned chalice? Some of the challenges include funding evaporating and the associated monitoring and bureaucracy. Unless advocates are clear from the outset and possible conflicts of interest are addressed, there is a danger advocates may self-censor their activities.

Neil quoted a Czech expression: *"the policeman in your head is more powerful than the policeman in the street."* Furthermore projects may take a wrong direction in an effort to chase statutory funding.

Neil spoke of the challenges for social workers and nurses being advocates. There is a careful line to tread between helping someone make a decision and helping them to enact that decision. Having a dual responsibility can hinder one or both roles.

Advocates need a range of legal and advocacy skills and knowledge. This does not mean being a qualified solicitor

or barrister, but it does mean that advocates need a good knowledge of the legal and administrative issues relevant to a particular case e.g. social welfare, equality legislation. Advocacy skills include interviewing and communication skills, self-management, putting a structure on advocacy and advocacy cases, negotiation and persuasion skills.

Neil concluded with thoughts on: *"What I would do if I was starting from scratch..."*

- Make sure advocates know what they do and don't do.
- Provide a "professional" service while not making it hard to use.
- Establish a legal duty to have publicly funded, independent advice and advocacy services.
- Use the evidence about what works and how to ensure equality of access to advice and advocacy services.
- Keep rights simple.

w www.neilbateman.co.uk

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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What Does Advocacy Mean To Me? *Marie Wolfe*

CONFERENCE

Marie Wolfe spoke as a service user. Since encountering self advocacy ten years ago her life has changed completely and she now has choices and opportunities she would never have thought possible.

She used to live in a group home with five other people, which felt like a mini institution because all the important decisions were made by somebody else - for instance, she shared a room with someone she had never met before moving to the house. Today she lives in her own rented apartment; staff visit her once or twice a week and she can call them whenever she likes; she has charge of her own medication and can go and come as she pleases.

She compared the changes in her life to the social and medical models of disability. The first focuses on individual strengths, interests, and abilities and most of all on people's rights. The second emphasises care, what people can't do and takes decisions for them. Luckily the Social Model is making changes as people with disabilities in Ireland have become strong and now claim independent lives with friends, a home of their own, suitable work and fair pay. They need support from staff to do these things in the best way for them - but not control.

Marie knows she is lucky because Advocacy has let her have her cake and eat it - and given her the confidence to speak up - as at the Conference. But many other people with disabilities could do this too, if people really listened - "Nothing About Us



Josephine Flaherty & Marie Wolfe, Galway Advocacy Service & Brothers of Charity; Chris Glennon, CIB

Without Us". Even people with severe disabilities have their own likes and dislikes. Everyone should be given the chance and the training to live their own lives in a responsible manner.

Service users should be involved in planning services and choosing staff. In Galway a service-user group has met with HSE Managers and other top bosses who have been surprised at their ability to explain their wishes and at their understanding of management and resource problems. More meetings like these could bring about changes which would take account of everybody's interest.

Advocacy is needed to help build people's self-esteem and let them know that they are respected, have rights, and are entitled to make choices.

It's important to move people out of institutions. Marie said that she thought that in the past she was disabled more by the situation she was in than by her learning disability.

Irish Association of Advocates

The IAA is a new, peer-led organisation, which has been established to support and promote the work of advocates in Ireland. The IAA is committed to a leadership role in the ongoing development of advocacy services in Ireland and to providing support to advocates. The association meets regularly to discuss issues of common interest. The IAA hopes to:

- Represent and lobby on behalf of advocates on matters of policy and practice
- Develop a code of practice incorporating the highest standards of ethical behaviour, competence and practice

- Offer peer support and share best practice
- Promote the IAA as the representative body for advocates

If you work in the area of advocacy, in whatever discipline, and are interested in joining or finding out more, please contact the group:

Gerald Mac Cann (North East Region): 087 2650552

Jim Winters (Dublin Region): 087 6884947

Martina Kilgallon (Western Region): 087 9980152

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