



# Speaking up for Advocacy

## Inclusion Award for Citizen Advocate!

**At Inclusion Ireland's conference in Killarney Máiríde Woods of CIB accepted the Advocacy Award on behalf of Citizen Advocate Ronan Murphy. Ronan is a volunteer with Cheshire Citizen Advocacy Project which is funded by the Citizens Information Board under the Community and Voluntary Sector Advocacy Programme. In citizen advocacy a person with a disability is matched with a non-disabled volunteer and both are supported to build a long-term relationship.**

Ronan's experience with his advocacy partner, Dara Overson shows how life-enhancing this relationship can be for both partners. He writes: "For me, a citizen advocate is simply an ordinary

person who supports somebody else to help them reach their potential. Citizen advocates really are independent which means that they can work in the interests of the person with whom they are matched...

I am very lucky Dara allowed me to become part of his life to witness him achieving so much. My partner Sonja and daughter Laurie have welcomed him in as part of our gang. As I've watched, Dara has become more confident in his own ability, and more determined to speak up for himself. I've also learned a lot about good music, about Don Baker and about guitars. If I ever need some honest advice or just want a friend to stick up for me, I can always rely on Dara. He is my best advocate."



Dara Overson and  
Ronan Murphy in Paris.

## Advocacy Standards Group

As advocacy becomes more established, quality standards to support delivery of a consistently excellent service become increasingly important. Quality of advocacy services depends on the people who deliver the service and the supports they have available to them. The *Advocacy Guidelines provided by CIB was an initial step in this direction*. An Advocacy Standards Group with representation

from CIB, Citizens Information Services, Advocates and NDA has been set up. A first meeting looked at work done in other countries: Scottish Independent Advocacy, Action for Advocacy UK and PQASSO (the quality assurance system not the painter!). The aim of the Advocacy Standards Group is to produce standards to support best practice and underpin quality service delivery.

## Round Table Evaluation Report

At meetings in Carrick on Shannon, Dublin and Cork, Roundtable presented the findings of their evaluation of the pilot Community and Voluntary Sector Advocacy Programme for people with disabilities. All projects and associated CIB staff were invited. The evaluators praised the work done under the Programme. On the basis of their research and consultation, they recommend that a National Advocacy Service be set up on a regional basis with advocates organised in teams, each with

an advocacy manager, senior advocates, advocates, citizen advocacy co-ordinator and administrator. In each region, the team will be employed by and report to a Citizens Information Service board. Discussions will now take place between the CIB board and the Department of Social Protection and it is hoped that the Department will sanction a roll-out of the new Advocacy Programme from January 2011. The full Annual report with case studies is available from CIB.

## CIB has a new Board

New members were appointed to the Board of CIB in April 2010. The new Chair is Sylva Langford who formerly worked in the public service including periods serving at a senior level in the Department of Health and Children and in the Department of Justice, Equality & Law Reform. Sylva was previously a member of the National

Disability Authority. Newcomers Noeline Blackwell, Stuart Stamp, Josephine Henry, Pat Fitzpatrick, Michael McGuane, John Sheehy and Sandra Ronayne join existing Board members Daragh O'Connor, Michael Nugent, Patricia Walshe, Martin Naughton, Laurie Cearr, Michael Healy Rae and Margaret Zheng.

## Highlights from the CIB funded Advocacy Programme in 2009.

During 2009 the 46 projects provided an advocacy service to 2,601 clients - an increase of 22% over the 2008 figure. 2009 reports refer to the increasing complexity of cases, to the need for support with specific expertise, and the vulnerability of people with severe and profound disabilities who may not have the capacity to consent or direct. Twenty nine of the 46 projects provided different levels of service to people with disabilities in residential institutions.

In 2009, as in previous years housing and accommodation issues dominated featuring in 21% of cases. Many cases involved people

with disabilities inappropriately housed in general hospitals, nursing homes or psychiatric hospitals because they could not access suitable accommodation, adequate Personal Assistance hours or care packages to support them to live independently. In one case a 60 year old man with physical disabilities who had spent 40 years in an institution secured rented accommodation and a personal assistance package with the help of the advocate. He now has his own GP, control of his money and links with the local community.

The full Annual report with case studies is available from CIB.

## Explaining Asperger Syndrome

Asperger Syndrome, (AS), is a condition which results in differences in the way information is processed due, apparently, to differences in the brain. This results in social and communication difficulties, rigid and concrete thinking patterns and a limited range of interests. It shares some of the characteristics of autism though there are qualitative differences, with AS usually seen as at the "high" or "mild" end of the autistic spectrum. AS was only confirmed as a distinct Autistic Spectrum condition in the early 1990's so we are still learning how it affects children and adults.

### How AS Affects People

Firstly it is important to point out that AS is NOT a disease, health problem or something to be cured. It is a life-long condition that people are born with. With good supports, people with AS can lead fulfilling lives, attend mainstream schools and have successful careers. People with AS have normal intelligence with some having above average abilities in specific areas, though others may struggle with some subjects. AS is a social learning difficulty that usually affects the way people relate to others, how they interact, communicate, cope with stress, and how they interpret social situations. It is sometimes described as "social dyslexia". An understanding of

the condition on the part of education providers and employers can greatly improve an individual's chances of living a happy and successful life.

People with AS will experience varying degrees of difficulty in the following areas:

**Social Interaction:** they may seem exceptionally quiet, be seen as loners and self-focused, or else be overly eager in imposing themselves on others. They may have a difficulty with sharing, turn-taking or having an interest in the other's preferences.

**Communication:** they may have unusual language characteristics, e.g. be overly formal, have an unusual tone of voice, interpret things literally, and not understand subtle non-verbal communication cues. Some can be helped by visual or written prompts to improve their understanding of what's expected from them.

**Imagination:** they may be very rigid thinkers and rely a lot on 'sameness' and routines. Change can sometimes cause them distress.

With thanks to the ASAS project and Jim Comiskey!

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## First Date with Data Protection – getting to know the 8 principles.

Manual data, automated data, relevant filing system, data controller, data processor, 8 principles...what does it all mean? The Data Protection Acts 1988 and 2003 are part of the legislative environment which determines our relationship with our information and other people's information and where we can and can't use it. They outline the individual's rights when their information is processed as well as the responsibilities of those persons or organisations who process it. Let's start with the first principle.

**Obtain and process the information fairly:** Tell the person who you are working for, why you are collecting the information, where it will be stored and how it is processed.

- Tell the person who will have access to their information.
- Tell the person whether replies to questions asked are obligatory and the consequences of not replying.
- Tell the person they have the right to access all information held about them at any stage and have it rectified if it is inaccurate. Makes sense eh?

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## 'Advocreate' - Celbridge and Peamount go creative!

Celbridge Advocacy Project and Peamount Advocacy Service brought over 'Advocreate', a UK based Advocacy Company to provide a three day self- advocacy training course with twenty four service users from three services; Dara Residential Services, St. Raphael's and Peamount.

The aim of the course was to develop self-advocacy skills. One day was tailored towards the needs of twelve adults with a mild / moderate learning disability, the second day focused on another twelve adults with a more moderate / severe learning disability. For those with higher support needs, an interactive story illustrated the ideas around making choices, the importance of decision making and communication skills.

The training was full of fun and energy –with vocal and physical warm ups, drama, story-telling, role play and collaborative group work. Voice and body language are so important in speaking up, as are non-verbal ways of communicating such

as facial expression, gestures, body language, signs and symbols. The group examined positive and negative ways of saying 'Yes' and 'No' and enacted various scenarios to learn appropriate and effective ways of speaking up and making oneself heard and understood. They shared stories and personal experiences about times when they needed an advocate or when they felt advocacy could have helped them.

The participants enjoyed the training and gave great feed-back – suggesting that everyone stay in touch. Both Projects felt that this training was value for money and could be regularly delivered to similar groups. The "Advocreate" team should be back in Celbridge in December or early January.

Rachel Bergin

Workshop packages for your group.  
<http://www.advocreate.com/workshops.php>

## Getting There – bus train and chair!

Advocates have contributed significantly to a number of CIB policy reports and submissions. A recently published example is; *Getting There: Transport and Access to Social Services*. In March, Clare Citizens Information Service held a briefing session for local organisations in Ennis, Co Clare. At the event The Mayor of Clare, Councillor Tony Mulcahy congratulated everyone involved in researching and compiling the report. He was particularly impressed that the document clearly outlined a series of proposals to address the issues identified. He said: *"While it is often far too easy to point out the existence of a problem it is not always that easy to identify likely solutions. What is most notable is that these solutions put members of the local community at the centre of how services should be delivered."*



Pictured from left: Michael Browne, Report Author, Greg Duff, Independent Advocate, Dermot Hayes Network Support Officer, People with Disabilities Ireland, Paul Woulfe Clare CIS and Nicky Mc Mahon Manager Clare Accessible Transport