

Speaking up for Advocacy

Deirdre Carroll steps down as CEO of Inclusion Ireland after 11 years

At the Inclusion Ireland Conference in Wexford Deirdre Carroll expressed her pride in the organisation's achievements in the 50 years since its establishment. Inclusion Ireland has, she said, been a shining light, campaigning on the real issues for people with a disability when it was neither popular nor interesting to do so. She named its main achievements as

- Taking up the plight of people with an intellectual disability in psychiatric hospitals and other large institutions;
- Calling for independent inspection and standards of all services for people with disabilities;
- Highlighting the long waiting-lists for services;
- Leading the fight for rights-based disability legislation, including modern capacity legislation;
- Questioning the lack of transparency and accountability in the provision of services;
- Pioneering independent advocacy to ensure the voice of people with disabilities is heard;
- Continually asking where the person with the disability fits.

She mentioned the first report of the Comptroller & Auditor General on the not-for-profit disability sector and the need for greater person-centredness and more individual control of funding. Referring to the difficulties of the present period of austerity she said, quoting Milton Friedman – that only crisis produces real change.



The basic function of bodies like *Inclusion Ireland* is to develop alternatives to existing policies, to keep them alive and available until the politically impossible becomes the politically inevitable." She thanked all those she had worked with over the years. Her chief regret was not to have seen the start of HIQA inspections in disability services.

Fintan Sheerin, the acting head of the National Institute for Intellectual Disability, spoke of the need to move on from over-reliance on professionals, perpetual modelling, oppression and dependency, charity and fear of risk. Seamus Greene spoke of his family's search for a home-and-away housing option that would suit his daughter while Emily Walsh and Rachael Kelly recounted how the Step-in model of service works – it involves a building local support for nine people with disability using their resources and a community living volunteer.

Presentations can be perused in more depth at <http://www.inclusionireland.ie/AGM2012.asp>

On Being a Senior Advocate - Christina Conroy

I would describe my role as senior advocate as stimulating, exciting, diverse, frustrating at times, yet often satisfying. No two days are ever the same. It is a unique and fulfilling job with a variety of environments and the opportunity to make a difference in the lives of vulnerable people with a disability. Being on the side of the person needing advocacy and ensuring that the right people get to hear that person's voice are vital.

Each case where you represent a person's needs or wishes is very specific, providing you with the opportunity to learn on the job and develop new skills. Often an arising issue that must be prioritised means your plan for the day can go out the window. The core elements of my job include supporting advocates in the team, case-work, promotion, presentation and development of the advocacy service; and assisting the regional manager as required. Synonymous to the role is flexibility, the ability to respond at short notice to unforeseen events and adaptability to meet the needs of the team and the service. Being part of a team of people with varied expertise and resources has strengthened my advocacy work.

As a senior advocate my work involves trying to effect change that ensures the person's rights, dignity, decisions and choices are safeguarded. The advocate's wish to help vulnerable people with a disability achieve their goal brings a focus on the

individual case. But policy work to ensure systemic change is important too so an on-going balance has to be found.

So what do I get out of doing this type of work? Well I like being involved in people's lives. I find it fulfilling to identify and understand the issues and challenges that a person faces, explore all the available options and strategise possible solutions with the person. Thus I can empower the person to make an informed choice or decision.

The senior advocate's role has brought balance into my career as along with working with individuals, I now allocate time to feed into regional and national work such as policy development, quality standards and support for the team. With the job of senior advocate, I am on a journey which has thrown up lots of opportunities and challenges and this road to achieving successes will always be under construction.

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Essential Principles: Irish Legal Capacity Law as:

Everyone should be presumed to have the capability to make decisions. The main focus of the new law must be to support people to make their own decisions and must include three different levels of support:

- a The first level is where a person has the ability to make decisions with only minimal support, e.g. easy-to-read information
- b The second level is supported decision-making, where a person is supported by someone they trust to make a decision, and

- c The third level is facilitated decision-making, used as a last resort where the person's will and preferences are not known. Here a representative has to determine what the person would want, based on what they know about the person and on their best understanding of their wishes.

See full text from Amnesty at: http://www.amnesty.ie/sites/default/files/file/MentalHealth/PRINCIPLES_WEB.pdf

Exploring HIQA standards

The Health Information and Quality Authority has developed detailed quality standards both for nursing homes and for residential services for older people and people with disabilities. The standards are based on a positive vision for the development of services and embody ideas of enablement and possibility. They are made up of statements – what is expected - and criteria – setting out how a service may be judged.

Inspection of disability services will probably begin in 2013 so everyone needs to be familiar with the standards. Quoting the standards can be a useful tool for advocates seeking a change in services for their clients.

In February the National Advocacy Service had two training days on HIQA Standards for advocates, delivered by the Open Training college.

Standards and Criteria



A Social Policy Issue presented at the NAS National Advisory Group meeting

At the March meeting of the National Advisory Group (NAG) two of the NAS managers presented cases relating to social policy issues.

The first case concerned a man of about 60 who had been placed in a nursing home following a period of acute illness. When his condition improved unexpectedly, he found it difficult to arrange an exit as he needed some support and did not have family.

NAG is a very useful forum for presenting such issues to stakeholders.

Points highlighted included:

- The difficulty in establishing which agency held the budget for this person
- The need to flag to nursing homes situations which should trigger a referral to NAS.
- The need to review care-plans for nursing home residents with the possibility of exit and an agreed professional leading the process
- The need for greater cooperation between different HSE sections and areas – e.g. Disability and Older Persons – in the case of individuals who could fall into either category
- The long delays associated with lack of maternity cover for some key HSE professionals.

Stand by me - A poem by Jo McFarlane

From Scottish Advocacy

When I was broken, on my knees,
silenced by the weight of living,
on the brink of giving up,
an advocate came by
and deftly opened up my voice
by listening, simply listening.
Soon the cage became a key,
the words ran free
and hope took root within me.

Together we unravelled all the knots,
sought clarity in breaking down the problem,
put the jigsaw back together in a workable solution.

Ready now to voice my vision
to the doctors, nurses looking after me,
I asked my advocate to stand beside me
as I still felt vulnerable and small,
faced with an impenetrable wall
of professional power.

We walked into the meeting, took our place.
I saw respect light up the faces of my gaolers
as I spoke the words, tentative at first,
then full of confidence, conviction
as they soon began to listen.
My advocate sat quietly by my side,
didn't have to interject
but for the blanks in memory
caused by the haze of medication.

We came to a solution
which I felt I could accept with grace.
I didn't get discharged as I had hoped
but in the course of being listened to
my gaolers had become my carers
and the treatment plan became a contract
which empowered me.

By standing with me on the journey
my advocate had helped to set me free.
I left the ward soon after with my head held high
because the roots of confidence and hope
she planted in me now had grown into a tree.

Watch Jo read her poem on YouTube

NUIG: Disability Legal Information Clinic

The Centre for Disability Law and Policy (NUIG) in partnership with NUI Galway Free Legal Advice Society provides a free, accessible and confidential legal information service on the first Wednesday of every month from 6pm until 7.30pm. It is primarily designed for students with disabilities but is open to other people with disabilities (and occasionally family members) as well. The service is provided by trained volunteers (law students) who are supervised by a legal practitioner. The CDLP is fully accessible (sign language interpretation can be arranged on request). Both drop-in and appointment clients can be catered for. Issues dealt with include social welfare, medical negligence and reasonable accommodation.

The Centre also provides a research resource which will provide trained volunteers to undertake practical legal research on issues highlighted and will seek to link with other similar clinics. At present research is being undertaken on *Blind people voting independently* and *People with disabilities serving on state boards*. Links with universities in the US and Europe are being set up.



CASE STUDY: How can we tell what someone wants when they don't use language?

A recent National Advocacy Service (NAS) case dealt with this dilemma. When a change in residential service was proposed for Mary, she began to work with an advocate. Her residential service had been unable to find a way of communicating with her and could not cope with her sometimes challenging behaviour. Mary has few opportunities to choose and restrictive practices are used to deal with her behaviour. Unfortunately, the new service proposed appeared to have even fewer supports.

Mary is able to use a computer and the advocate has helped her to upload pictures of things she does and doesn't like. The advocate has also

worked with the service, questioning the use of the restrictions and suggesting alternative ways of working with Mary including communication supports. The service has begun to engage with the advocate, recognising the need to build up Mary's skills and allow her to participate more in life in the community. While the advocate's presence at all meetings about Mary was not at first accepted, a greater shared understanding has now come about. The advocate is now able to represent Mary's views and ensure to some extent that these are taken into account.

Adapted from advocacycase.ie. All names changed.

CASE STUDY: Katya, Child Benefit and EU Rules

Katya who is Estonian has lived in Ireland for several years and has been in employment except for two ten month periods. She is currently a supervisor in a supermarket. For the last six years she has claimed Child Benefit for her three children who live with her. On occasion she has had to get a Child Benefit form stamped by her children's school to confirm that they were attending.

In February 2011 she received a letter stating that she owed Child Benefit Section a large amount of money. Her Child Benefit is paid under EU legislation and as a result she should only have received it during her periods of employment. Katya had no knowledge of this. With the help of the CIS she put in an Appeal. However, in May the Child

Benefit Section informed her that they would start clawing back the overpayment at the rate of €100 per month from her present Child Benefit payment. Katya asked them to postpone the deductions until after the Oral Appeal hearing but they refused.

Katya's appeal was allowed in September and the overpayment was cancelled. Child Benefit Section also refunded her the money they had deducted. Katya and the CIS were delighted. The CIS has suggested that Child Benefit Section add a sentence to the form, stating clearly that Child Benefit paid under EU legislation depend on the parent remaining employed in Ireland.

Adapted from advocacycase.ie. All names changed.

New *Managing Advocacy* course begins at the Institute of Technology, Blanchardstown

The new Certificate in Management Skills for Managers of Advocacy Services (which when completed gives 20 credits at NFQ level 7) began this May in the Institute of Technology Blanchardstown (ITB) after an induction day at the end of April. Developed by a partnership of the CIB Training Department, a number of CIS Development managers and the School of Business Studies and Humanities ITB, this is an intensive course with four modules, two of which will take place on Wednesdays in May and June. The other two

modules will be delivered in the Autumn of 2012. Fourteen Development Managers have enrolled for the first run of the course. It will be repeated in 2013 subject to demand and available resources. Modules are:

Principles and Practice of Advocacy

Advocacy: Case Review and Supervision

Human Resource Management

Managing Advocacy in Practice

Facts and Figures from Annual Report on the National Advocacy Service for people with disabilities (NAS) 2011

The first six months were largely taken up with establishing the service nationally. NAS has worked hard in the first year to up-skill advocates and to mentor and shadow them in areas where they needed support. As the priority group is now vulnerable people with disabilities including those who live in large institutions, cases have become more complex and require substantial time investment. They include child protection and *Wards of Court* cases and support for people who have complex disabilities, dual diagnosis and sometimes behaviour that challenges. Access and eligibility criteria are now in place with the object of concentrating NAS resources on people with the greatest need while those with the ability to advocate for themselves are directed towards mainstream services in the CIS.

The table shows cases *opened* since January 2011 – along with the cases transferred from the C&V projects at the start of 2011. Total client numbers (at 856) are smaller than for the comparable period in 2010, as was expected because of the changeover. The average number of clients per advocate for the year stands at 25. Most cases were new and 34% of the total were closed during the period.

Counties with the highest numbers of clients were Dublin (184/22%), Cork (65/8%), Roscommon (46/5%) and Galway (43/5%). The most common issues involved Health (25%) followed by Social Welfare (22%) and Housing (21%). This may reflect greater difficulty in accessing health and social support services, due to cutbacks in these services. *Social Welfare* led the list under *Outcomes*. Almost two thirds of cases had 2-7 issues, illustrating their complexity.

Client and Case Numbers Jan-Dec 2011

Cases transferred from pilot projects **206**

New Clients **650**

Total client numbers **856**

Initial Interviews with Clients **748**

Number on Waiting List **34**

Closed Cases **291**