

Speaking up for Advocacy

First six months of NAS and 414 new clients have been served.

The National Advocacy Service generated a lot of interest at its launch event in Dublin Castle on 30th March. Speakers included the Minister for Social Protection, Joan Burton, Tony McQuinn, CEO of the Citizens Information Board, Caroline Casey of the Kanchi Network, Angelina Veiga of St John of God's Carmona Services and Marie Wolfe a self-advocate.

Caroline Casey gave the keynote speech which had plenty of the Obama *Yes we can* spirit. Marie Wolfe's account of how advocacy had helped her move into independent living was enthusiastically received and Angelina Veiga spoke of the cultural shift in services from one stop service provision and the role of advocacy in responding to this challenge. Sylva Langford and Tony McQuinn

detailed the seven year odyssey which led from the commissioning of research through the pilot projects to the launch of a fully-fledged service.

Minister Burton congratulated everyone involved and said that "essentially the service will level the playing field and provide a voice for the more vulnerable of people with disabilities".

Citizens
Information



National
Advocacy
Service

for People
with Disabilities



Tony McQuinn,
CEO CIB

Sarah Campbell,
NAS advocate

Minister Joan Burton,
Department of Social Protection

Marie Wolfe,
self advocate

Caroline Casey,
Kanchi

Advocacy Support Workers (ASWs) come to Town

Five Advocacy Support Workers (ASWs) have recently been employed by Citizens Information Services in Offaly, West Cork, Clare, Longford and Dublin (Clondalkin). ASWs will work with all CISs in their region to improve advocacy services to all citizens, working with the National Advocacy Service to ensure seamless access to advocacy for people with disabilities. Each ASW has a large geographical area to cover but with a gradual approach and modern technology this is not impossible.

The new ASWs are: Gráinne Griffin (Clondalkin CIS), Eibhlin Harrington (Longford CIS), Philip Judge (Offaly CIS), and Caroline Roche (West

Cork CIS) and Sheila Kilkerr (Clare CIS). Grainne, Eibhlin and Sheila have previously worked in CISs while Philip and Caroline come from the legal sector.

ASWs will coach and mentor CIS information providers in the processes and skills of advocacy case-work including interviewing, case recording, negotiation, representation and preparation for third party/hearings/appeals. Over time ASWs will work with CIS managers to build consistent advocacy capacity across Citizens Information Services. In this way the mainstream and specialist advocacy services can complement each other.

National Advocacy Service gets an Advisory Group



John Hynes,
Chair of the National Advisory Group

In any new development it's important to involve the sector and as a result, the Advisory group for the National Advocacy Service has been formed. It is chaired by John Hynes, former Secretary General of the Department of Social and Family Affairs.

The external members include Bairbre Nic Aongusa and Cate Hartigan from the statutory sector, Brendan Broderick, Deirdre Carroll, Madeleine Clarke, John Dolan, Michael Quinn John Saunders, Diarmuid Ring and Donal Toolan who represent different areas of the disability sector. Eileen Fitzgerald and Helen Lahert from

CIB will also be members along with one of the five NAS managers who will have a rotating membership. It is hoped that the Advisory Group will lead to greater involvement of and feedback from the disability sector as happened with the Steering Groups in the Community & Voluntary Programme.

At the first meeting one of the managers presented a case relating to the rights of parents who have impaired capacity to be fully supported throughout child care legal proceedings so that they understand the process and so that their Human Rights are protected. This case was presented to inform the discussion on case prioritisation and boundaries and the need to ensure that managers and advocates have time to be pro-active in seeking out those who cannot self-refer or who do not have parental or other supports. The second meeting offered advice on the Access and Eligibility policy.

Five regions, five managers, five administrators, thirty five advocates, seven senior advocates, 414 clients...lots of team spirit

NAS is now fully operational - advocates administrators, computers and filing cabinets all now in their new offices!

Advocacycase.ie shows that 414 clients have been served in the first six months – a considerable feat, taking into account the difficulties of moving, assigning people to locations, finding suitable premises and keeping local services informed of the changes.

Team spirit is growing and many advocates comment on the benefits of working closely with colleagues. Promotional work is starting and managers plan for close contact with residential services where some very vulnerable people with disabilities live. Managers are also working together on common policies. The most common issue arising involves quality of life; in one case example a lady who had spent her life in a residential centre went on her first holiday and renewed contact with family.

Region 1 Clondalkin CIS <i>Dublin mainly within the M50</i>		Position	Location
Ben North	086 0218778	Manager	Clondalkin, Dublin 22
Suzy Byrne	086 8378757	Senior Advocate	Dublin City Centre
Margaret Tumbleton	087 7505374	Senior Advocate	Clondalkin
Sarah Ann Campbell	086 0204142	Advocate	Tallaght
Sarah L. Campbell	086 0203795	Advocate	Blackrock
Jim Comiskey	086 3658885	Advocate	Dublin City Centre
Jenny Cullen	087 1360611	Advocate	Clondalkin, D22
John McCrudden	086 0203834	Advocate	Dublin City Centre
Ruth McCullagh	087 9800161	Advocate	Blackrock
Tessa Van Keeken	086 0203698	Advocate	City Centre
Catherine Curran	086 0452398	Administrator	Clondalkin, Dublin 22

Region 2 Westmeath CIS North East		Position	Location
Louise Loughlin	086 4102083	Manager	Athlone, Westmeath
Louise Dawson	086 4102094	Senior Advocate	Louth
Andrea Reynolds	086 6077244	Advocate	Cavan/Longford
Pauline McKenna	086 0211396	Advocate	Monaghan
Mary Chapman	086 8358829	Advocate	Westmeath/Longford
Catherine Marsh	087 127 6438	Advocate	Meath
Ann Saurin	086 0211346	Advocate	Fingal
Mandy Price	086 7702020	Administrator	Athlone

Region 3 Offaly CIS South East		Position	Location
Selina Doyle	086 0409978	Manager	Tullamore, Co. Offaly
Christina Devine	086 6093508	Senior Advocate	Offaly Laois
Rachel Bergin	087 2666720	Advocate	Kildare
Jolene Kelly	087 2350161	Advocate	Wexford
Mary Linehan	086 0218745	Advocate	Kilkenny
Gerald McCann	086 8060768	Advocate	Carlow
Patty O'Malley	086 8065641	Advocate	Wicklow
Sharon Cornally	086 0466526	Administrator	Offaly

Region 4 Waterford CIS <i>South West:</i>		Position	Location
Patricia O'Dwyer	086 0223984	Manager	Waterford.
Deirdre Lillis	086 0400974	Senior Advocate	Waterford
Gerry Rattigan	086 0223998	Senior Advocate	Cork City
Mary Carroll	086 0224022	Advocate	Kerry
Israel Finnerty	086 0224051	Advocate	West Cork
Grace Moore	086 0224054	Advocate	Limerick
Anna Newman	086 0224023	Advocate	Tipperary
Anne-Marie O'Sullivan	086 0224073	Advocate	Cork city
Anne-Marie Collins		Administrator	Waterford

Region 5 Leitrim CIS <i>West & North West</i>		Position	Location
Josephine Keaveney	086 0201095	Manager	Carrick-on-Shannon, Co. Leitrim
Clare O'Neill	086 0200713	Senior Advocate	Mayo
Helen Collins	086 6010830	Advocate	Clare
Carmel Donovan	086 0232477	Advocate	Roscommon
Greg Duff	087 9697404	Advocate	Galway
Andrea Farrell	086 0291948	Advocate	South Mayo
Marion Gallagher	086-1736421	Advocate	Donegal
Martina Kilgallon	087 9980152	Advocate	Sligo
Rebecca Leavy	087 0641163	Advocate	Galway
Elaine Morris	087 0529111	Advocate	Leitrim
Lisa Mulvey	086 7707096	Administrator	Leitrim

New website to provide assistance with HSE complaints

Healthcomplaints.ie has been developed for people who use health and social care services in Ireland, as well as for their families, care-givers and advocates.

It is not always easy to complain and the process can lead to a need for information, advice and advocacy. Information has improved enormously; most health and social services websites now advert to customer rights in services and what grievances can be the subject of formal complaint. But formal mechanisms – though necessary for natural justice – do by their nature disadvantage those unused to them, particularly those who may be ill, disoriented or need to absorb a lot of

medical information. Some complaint systems are so demanding (in terms of the forms and documentation they require) that they effectively deter people from complaining. The process should be as straightforward as possible with information readily available – as on the new website, healthcomplaints.ie. "Advocacy can empower people to make their own complaints, it can help them prepare a case, give an independent view on their chances of success, and in some cases it can take the complaint on their behalf" said Sylva Langford, chairperson of CIB, speaking at the launch of healthcomplaints.ie. Your local CIS or the Irish Patients Association may be able to help you, if you wish to make a complaint.

Challenging Times: Ensuring values support ordinary lives.

The National Federation of Voluntary Bodies held a seminar in Maynooth in June: It looked at new ways of configuring services for people with disabilities in a time of change and sketched out a flexible provision landscape very different from the past. There was a wide range of speakers and John O'Brien provided the inspirational focus of the day reminding us that funding constraints did not limit ideals of justice and focusing on good leadership. He quoted Mary Oliver:

"There are things you can't reach
But you can reach out to them,
and all day long."

Realising the vision of individualised supports means dealing with risk, uncertainty and loss. Leadership demands the ability to observe, interpret, and intervene in emotionally charged situations & mobilize people with different interests. Changes are called for, not just in the organisation but in ourselves.

John O'Brien reminded organisations of the advantages of being small with a wonderful drawing of ships and boats in an estuary.

It was good to see an event that quoted partnership as an ideal having so many partnered presentations.



From John O'Brien's presentation at Challenging Times.

Time to Move on from Congregated Settings

A Strategy for Community Inclusion (2011)

This report was commissioned by the HSE in 2007 from a working group chaired by Christy Lynch. As expected it recommends an end to congregated settings - the closure of 72 institutions, which accommodate more than 4,000 people with disabilities at a cost of about €500 million each year. These people are still isolated; their living conditions are usually institutional with a lack of basic privacy and dignity. Most have multiple disabilities and complex needs.

The report acknowledges the efforts of service-providers to change things but hones in on a core group of people "who have no access to the options, choices, dignity and independence that most people take for granted in their lives". In the words of one participant who moved just before joining the working group:

"My dream was to have my own place and I got ... my own apartment in July 07. It was the best thing that has happened to me."

The Working Group proposes a model of support in the community where people will move to dispersed housing (mainly provided by local authorities) in ordinary communities. They will access mainstream community health and social services, such as GPs, home help, public health nursing services and primary care teams in the same way as other citizens.

The report acknowledges the challenges involved in making the recommendations a reality. It makes explicit the need for advocacy to support people to understand the process and to have as much choice in the move as possible. NAS advocates will be ready.

The full report is available at: www.hse.ie

UK Mental Capacity Act 2005

As Mental Capacity legislation is again under consideration by the Irish Government, it may be timely to look at the British Mental Capacity Act

The UK Act covers a wide range of decisions made, or actions taken, on behalf of people who may lack capacity to make specific decisions for themselves. These can be decisions about day-to-day matters – like what to wear, or what to buy – or decisions about major life-changing events, such as whether the person should move into a care home or undergo a major surgical operation. It states that some decisions – mainly concerning marriage, divorce and family relationships cannot be taken by someone else, though action may be taken to protect a vulnerable person from abuse or exploitation.

The five statutory principles underlying the Act are:

1. A person must be assumed to have capacity unless it is established that they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

The Act makes provision for an Independent Mental Capacity Advocate (IMCA) service. Its aim is to provide independent safeguards for people who lack capacity to make certain important decisions and, at the time such decisions need to be made, have

no-one else (other than paid staff) to support or represent them or be consulted. IMCAs must be independent.

In certain cases services are obliged to use an IMCA. Local authorities (which in the UK have the role of the HSE in Ireland) are obliged to make IMCAs available.

The Code of Practice provides guidance for specific people in specific circumstances and includes a number of scenarios, one including an advocate

Jane has a learning disability. She expresses herself using some words, facial expressions and body language. She has lived in her current community home all her life, but now needs to move to a new group home. Staff conclude that she lacks the capacity to decide for herself which new group home she should move to.

The staff involve an advocate to help Jane express her views. Jane's advocate spends time with her in different environments. The advocate uses pictures, symbols and Makaton to find out what is important to Jane, and speaks to Jane's circle to find out what they think she likes. She supports Jane at a meeting with care manager, and checks that the new homes suggested can meet Jane's needs and preferences.

When the care manager has found some suitable places, Jane and her advocate visit them. They take photos to help Jane distinguish each one and work out which she prefers. Jane's own feelings can now play an important part in deciding what is in her best interests – and so in the final decision about where she will live.

You can find out more about the UK Mental Capacity Act at <http://www.justice.gov.uk/guidance/protecting-the-vulnerable/mental-capacity-act/index.htm>