

NATIONAL NEWS

Issue No. 5

Autumn/Winter 2003

• *Contact the Editor:*
Gina Magliocco
National Secretariat
 Kilcornan
 House, Clarinbridge, Galway.
 e-mail: gina-magliocco@galway.brothersofcharity.ie
 Phone: 091 796623

"When people not used to speaking out are heard by people not used to listening, then real changes can happen"

John O'Brien

Inside this issue:

Allocation of New Capital Funding	2
National Intellectual Disability Database Committee: Annual Report 2002	2
RNMH Special Working Group	3
Who Decides and How?	3
Conference Information & I.T.	3
Making Presentations	3
Regional Highlight South East Region	4



Brothers of Charity NATIONAL ADVOCACY DAY 23rd October 2003

National Advocacy Day is the first in what organisers hope will be an annual celebration of the rights of people with disabilities to advocate for themselves. Advocacy is the process through which people are given a voice. They are given the tools and knowledge to enable them to express their views themselves or with the help of an Advocate. The Brothers of Charity Services recognise the rights of the individual, and support the system of Advocacy through their Service User Councils.

To raise awareness **October 23rd 2003** was chosen to celebrate Advocacy. The Brothers of Charity Services hope that this date will become a national annual event with the wider Intellectual Disability Community and the State joining in as full participants.

A programme of events was organised in each of our six regions.

Events such as seminars on Advocacy organised and presented by Self Advocates, launch of Information Packs on Advocacy, Open Days where members of the public could walk into a service and talk to Self Advocates, Poster Sessions and the Launch of the National Service User Conference were just some of the events developed to celebrate Advocacy within the Brothers of Charity Services.

A successful day was enjoyed by all participants.

DEVELOPMENTS IN SOCIAL HOUSING IN THE BROTH-

The National Secretariat coordinated a workshop held in the Clarinbridge Court Hotel on Thursday 30th October to address the developments in social housing within our services.

We were delighted to have such an experienced and knowledgeable range of speakers such as Chris White, Irish Council for Social Housing, Sean Gallagher, Limerick County Council, Bro. Alfred Hassett, Brothers of Charity Services, UK and Padraic Kenna, Author and lecturer in NUIG.

5th NATIONAL SERVICE USER CONFERENCE 18 & 19th November 2003

The title of the conference was "Choice of Life". Every presentation that followed over the next couple of days reaffirmed the overarching theme of choice and Advocacy as a Right. The conference called in a clear and united voice for an Independent, State Funded Advocacy Service as a Right.

The Lord Mayor of Cork City opened the Conference. The Self Advocacy Group from Cork were up next and gave an excellent outline of what was in store for the conference over the two days.

A Video—Choices for Life was presented by Kevin Murphy, from Waterford. The video, a documentary which interviews various service users from Waterford on what they would see "Choices for Life" meaning to them.

The Keynote address, "Ireland after the Special Olympics" was delivered by Fergus Finlay, Chief of Staff with the Labour Party, disability activist, and columnist with the Irish Examiner.

The South East Region used a Drama Presentation "Choose to Trust" to get their message of the choices we make in our life and the obstacles we must overcome to achieve our goals. The Kilrush Services, West Clare presented a video "Inclusion/Exclusion" reflecting the daily experiences of life as seen by a wheelchair user.

Pauleen Keegan, Roscommon and Marie Wolf, Galway presented the "National Advocacy Website" developed by the National Advocacy Council. The Brook Centre from Cork presented a video "Equal People", the theme of this video showed how important our everyday choices are to us in our lives while the self Advocacy Group, Southern Services presented "Its our Life" a brief insight into some of our service users lives, it highlighted the unique nature of individual's home situations, work environment and leisure pursuits. This concluded the business for the first day, the conference dinner and social night followed. Con. on back page....

The workshop broke into three working groups to consider the following:

1. Personal Outcomes and the Choices surrounding where one lives and with whom one lives.
2. Whether Social Housing provision in the Brothers of Charity Services would improve if the Housing Associations were to amalgamate and form one National Housing Association.
3. What National Guidelines should be in place for Housing Associations associated with our services e.g. compliance with company law, tendering, design purchasing etc.

Allocation of New Revenue & Capital Funding in 2003

The Minister for Health & Children announced in July 2003 additional revenue and capital funding of 50m euros for Services to People with Disabilities. Twenty million will be provided in 2003, with a full year cost in 2004 of 30 million euros. Of the 20 million euros provided this year 15 million is being made available to services to persons with intellectual disability and autism. This funding is to meet costs associated with emergency residential placements during 2003, the provision of day services for young adults who have just left school and some enhancement of the health related support services for children.

Capital funding of 15 million euros is being made available to organisations that provide services to people with an intellectual disability or autism. This funding is to address such areas as backlog of maintenance, refurbishment, reequipping, replacement of vehicles and works related to fire precautions and health and safety issues. Each area health board area has been allocated funding and it remains to be seen in some Regions now the Brothers of Charity Services will benefit from this new allocation.

NATIONAL INTELLECTUAL DISABILITY DATA BASE COMMITTEE ANNUAL REPORT 2002.

This report provides profile of the population of people with intellectual disability in Ireland in 2002. It sets out details of the existing level of service provision and outlines the pattern of care required over the coming years in both residential and day care services. It also highlights some of the issues which must be addressed in planning and delivery of services for the future. This database enables those involved with the planning and delivery of services to identify not only the level of need amongst those awaiting placement in services, but also the service changes required by those already in receipt of services.

There were 25,448 people registered on the National Intellectual Disability Data base in 2002, representing a prevalence rate of 6.49 per 1,000 population. The numbers registered on the database have decreased by 1,220 since 2001 largely due to the ongoing refinement of the dataset and, in particular, the removal from the record of people with mild intellectual disability who are not accessing specialised services and do not require such services in the period 2003—2007. There are more males than females at all levels of intellectual disability, the situation within our own service reflects this where 68% of our service users are male.

There has been a steady increase in the proportion of people aged 35 years and over from 38% in 1996 to 45% in 2002. This increase is attributed to the general population increase over the period, improved standards of care, and an increase in the lifespan of people with intellectual disability. This changing age profile has major implications for service planning, including an ongoing high level of demand for full-time residential services, support services for ageing caregivers, and services designed specifically to meet the needs of older people with intellectual disability, and helps to explain the ongoing demand for additional resources for this sector.

In 2002 there were 2,262 people who were either without services or without a major element of service. The provision of 1,633 full-time residential placements and 682 day programmes is required to meet the needs of this group in the period 2003—2007. In addition, 1,446 people will require residential support services during this period.

Despite the significant investment in the intellectual disability services in recent years and a corresponding growth in the level of service provision, the demographic factors outlined above are contributing to long waiting lists for services, and in particular for full-time residential services.

Every Mans

Home

is His

Castle

Developments in Social Housing cont...

Debate developed and time ran out and we were unable to present each of the Working Groups recommendations to the Workshop at the end of the day. All the ideas and suggestions will be collated and put into report format for presentation to the National Directorate.

The National Secretariat would like to thank the speakers, facilitators and those involved in organising the day, for their help in making the day the success it was.

The report of the joint working group on the role of the RNMH has concluded and the report is now available on the HSEA website (www.hsea.ie).

The report makes a number of recommendations in relation to the following:

1. The provision of additional Clinical Nurse Manager 1 posts within the intellectual disability service.
2. The introduction of Clinical Nurse Specialists posts within the service.
3. The development of respite services.
4. The appointment of a Community RNMH on a needs basis.
5. Proposals for the development of Advanced Nurse Practitioner posts.
6. Recommendations concerning entry qualifications and reporting relationships within the service.

The issue of the pay relationship between the RNHM and Social Care Professionals was the subject of a conciliation conference under the auspices of the Labour Relations Commission (LRC). The outcome of the conciliation talks resulted in a Memorandum of Understanding which acknowledges that the appropriate mechanism to explore the full pay position of the RNMH grade vis a vis other social Care Professionals should be part of any future benchmarking process.

Is a discussion document produced by NAMHI and written by Ita Mangan BA Barrister-at-Law and researched by Christina Burke BA LLB. This document reviews the current law in relation to decision making by and for people with intellectual disabilities. It aims to explain as clearly as possible what the current law is and how it needs to be changed. It is designed for discussion by namhi's members and others concerned with the rights of people with disabilities.

Chapter 1 outlines the general issues which arise in relation to decision making and sets out namhi's approach to law reform.

Chapter 2 outlines the law on legal capacity and examines the Law Reform Commission's proposals for new legislation.

Chapter 3 examines the proposals for a new system of substitute decision making.

Chapter 4 outlines the law on consent and medical treatment.

Chapter 5 examines the law on sexual relationships involving people with intellectual disabilities.

Copies of the document are available from NAMHI, 5 Fitzwilliam Place, Dublin 2.

Tel: 01 6766035

12th World Congress of the IASSID—"Towards Mutual Understanding: Person, Environment, Community", Venue: France from 14 to 19 June 2004. For further details please consult the web site: www.iassid.org or e-mail:

gestion@corum-montpellier.com.

CONFERENCE SECTION

"Building Community Support for Inclusive Education & Social Inclusion: Lessons to be learned from developing countries" 9th December at 12.30pm in Room A106, John Henry Newman Building, UCD.

For further information and booking on UCD event contact: The Centre for Disability Studies on 01 7168333 or e-mail [cgs@ucd.ie](mailto:cds@ucd.ie).

Making Presentations

The three keys to effective speaking are:

Thorough preparation; Good delivery; and Overcoming nervousness.

Allow yourself ample time for preparation. You will probably need at least ten times as much as the actual duration of your talk. The main stages are:

Get informed—collect and assemble all the facts and arguments you can.

Decide what to say—Define the main message you want to get across.

Structure your talk—It should have the classic beginning, middle and end.

Think carefully about length—Never talk for more than 40 minutes at a time. Twenty or thirty minutes is better.

Prepare your notes—Write out your introductory and concluding remarks in full and set out in some detail the main text of your talk. Boil down your text to the key headings to which you will refer to in your presentation.

Prepare and use visual aids—Your audience will only absorb one third of what you say; reinforce your message with visual aids.

Rehearse—Rehearsal is vital, it instils confidence, helps you to get the timing right, and enables you to polish your opening and closing remarks.

Check arrangements in room—Ensure that your equipment works and you know how to operate it. Check focus and visibility. Make sure your notes are in the right order. Do you suffer from dry throat? Keep a glass of water near you!

INFORMATION TECHNOLOGY

Network Virus's

Problems that occur while using a computer may originate with the computer, the operating system a software application, external device or virus.

To avoid a virus:

- Never open an e-mail where you are unsure of its origin or its subject matter.
- Never update your system without checking with your IT technician.
- Do not use any discs or programmes that have not been authorised by your IT technician.
- Run your virus checker regularly to ensure your PC is virus free and that you are not inadvertently passing on a virus.

If you discover you have a virus, inform your IT Section immediately by phone. Do not e-mail anyone until you are given the all clear from your IT section.

REGIONAL HIGHLIGHT – SOUTH EAST

National Secretariat
Brothers of Charity Services
Kilcornan House
Clarinbridge
Galway

Phone: 091 796623
Fax: 091 796626
Email: gnamagliocco@galway.brothersofcharity.ie

We would love to hear from you—
suggestions/ articles

Next Issue will highlight the

NOTICE BOARD

The National Web Site was launched at the National Service Users Conference on 18th November 2003.

www.brothersofcharity.ie

The Methods of Planning for Service Users Report is now available from the National Secretariat.

Service User Conference Continued

The conference resumed the next morning with the delivery of the keynote address by Liza Kelly from NAMHI, "My Voice My Choice—Advocacy in Ireland". Liza raised issues around recognised and certified training for advocates, legal status of advocates and the introduction of guidelines and standards for advocacy services. This presentation was followed by a lively question and answer session.

Marie Wolfe the link person for the Service Users Council presented the "Development and Work of National Service Users Council". She spoke about her role as the link person and her hopes for the future role of the Council.

The Kilrush Services in Clare along with NAMHI screened "Our Voice is Strong" a video of the journey to Brussels of the self advocacy team and NAMHI members who attended a conference organised by the European Platform of Self Advocates.

Mairead Moroney from Clare, presented my story "Choices Mairead has in her Life" and Mary Kinsella from Galway gave a Poetry Reading of her own poems followed by a video "Choices in Work" presented by the Supported Employment Agency and the Clare Services.

Ann Hicky delivered with her usual sparkle the afternoon keynote address, Ann is the Global Ambassador for Europe/Eurasia for World Special Olympic Games.

Una Nagle, the Southern Regional Director closed the conference, congratulating the presenters on their contributions and reinforced the theme of choice of life. Once again the Service Users Conference turned out to be an excellent event with informative and lively presentations. Congratulations to all involved!

Homeshare

In 2002 the Brothers of Charity Services in Waterford launched the Homeshare Scheme. This new service is co-ordinated and operated by the Social Work Department at Lisduggan Lodge and is funded by the South Eastern Health Board.

Homeshare is an innovative family based respite scheme for children in the Waterford Community Care catchment area. Homeshare links children with an intellectual disability with families and individuals who provide them with short breaks. Individuals who provide Homeshare are known as host carers or host families.

Homeshare aims to give children with an intellectual disability a chance to have fun, meet new people, try out new activities and gain independence while staying with their host carers. Host carers spend time involving the children in everyday activities in their own home. At the same time, the child's own family get a break.

Prior to its launch, its development was publicised through interviews with the local media, newspapers and radio, shop receipt advertisements, and fliers. Since its launch in 2002, the Brothers of Charity Services have recruited, assessed and trained a small number of host carers who are now offering short breaks (typically weekends) to children.

The recruitment of additional host carers is ongoing in order to expand the current pool of host carers/families. The feedback so far from host carers, children and the child's family is hugely positive. People have recognised the valuable support that is on offer from family based services.

Anyone over the age of eighteen may apply to be a host carer. Formal qualifications or experience in intellectual disability are not essential, however, you do need energy, commitment and a desire to offer support to a child with intellectual disability in your own home. A preparation training programme, which takes place over a period of four weeks, is provided once the application and assessment process is complete. An allowance is paid to host carers who participate in Homeshare.

Prior to a child linking with a host carer, the needs of the child and his/her family are established. This involves the sharing of relevant information about the child, informal introductions and arranging initial visits. Support is provided by a social worker throughout a family's participation in Homeshare.

In the Waterford based services, we look forward to the future of Homeshare with enthusiasm and hope that by individuals giving a little time to children with intellectual disability, they will make a BIG difference to everyone involved.

Anyone who is interested in participating in finding out more about the scheme is invited to contact the Homeshare Coordinator, at the Brothers of Charity Services, Child and Family Centre, Lisduggan Lodge, Waterford.
Telephone: 051 378831.

Other Regions which have formal Homesharing Services are:
Galway, Roscommon, Limerick,

Dormant Accounts Alternative Funding for Projects



Under the new laws, Dormant Accounts monies are to be used for programmes or projects that are designed to assist the personal, educational and social development of persons who are economically, educationally or socially disadvantaged or persons with a disability. The Dormant Accounts Fund Disbursement Board has been set up to administer the funds. The Board has engaged a non-profit organisation called Area Development Management Ltd (ADM) to manage applications for assistance from the Fund for them. More information is available from the following source: ADM, Holbrook House, Holles Street, Dublin 2— phone 01 2400700— www.adm.ie or www.dormantaccounts.ie.