NATIONAL FEDERATION OF VOLUNTARY BODIES

Providing Services to People with Intellectual Disability

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Welcome to National Federation Newsletter Issue 40 – Winter 2013



Budget 2014

The National Federation of Voluntary Bodies welcomes the following announcement in the HSE's Service Plan in respect of Disability Services:

- No cut in baseline funding for Disability Services in 2014;
- New Directions Personal Support Services for Adults with Disabilities reconfiguring day services. Provide for the emerging needs of the estimated 1,200 additional young people leaving school and Rehabilitation Training Programmes using a newly developed, streamlined approach, and for emergency cases (€10m and 50 WTEs);
- Progressing Disability Services for Children and Young People (0-18s) Programme. (€4m and 80 WTEs) Engaging in the development of a service framework to support the provision of pre-school services for children with a disability informed by cross-sectoral discussion.

The Service Plan also requires us to introduce specific measures to achieve efficiencies through a focused approach to procurement and shared service models as well as the introduction of new and sustainable models of person centred service. Target savings of €5m for section 38 and section 39 agencies.

In relation to compliance with HIQA standards in residential care it was acknowledged that significant capital investment is required. In response to a question the Federation raised at the launch of the HSE's Service Plan on 18th December, 2013, Mr. Tony O'Brien, Director General, HSE, replied that while there is no specific capital provision in the Service Plan the matter is being considered by Government in the context of its Construction Industry Stimulus Plan.

The above announcement is very much in line with the Federation's best expectation and reflects well on our whole-of-Federation approach to our Pre-Budget Campaign Strategy.

The HSE' Service Plan is available on our website www.fedvol.ie

The Inclusive Research Network attend the Consultation Symposium on the Assisted Decision-Making (Capacity) Bill in Dublin Castle



Back row (I-r): Brian Donohoe, Brian Hogan, Minister Alan Shatter, Ger Minogue & front Martin Dooher.

Since the publication of the new Assisted Decision-Making (Capacity) Bill 2013 on the 17th of July 2013, the IRN have been very active informing their members on how this Bill will impact on their lives. As this law will have a big impact on people with intellectual disability, Chairperson Patrick Santry sent an **expression of interest** to the Department of Justice to attend the Consultation Symposium on the Assisted Decision-Making (Capacity) Bill in Dublin **Castle** on the 25th of September last, to highlight the concerns of IRN members. As a result of this letter invitations to the symposium were sent to all members.

In preparation for this, a meeting was held on the 5th of September in Portlaoise where Maria



Walls gave an insightful presentation to over 50 delegates from all over the country, explaining how this new legislation will work and highlighted the good and bad points within it. For example decisions affecting the person will now be based on the 'will and preference' of the person compared to the paternal 'best interests' method previously used. Personal

relationships are not currently addressed in the new Bill, this was of major concern for all attending as they had been informed it would be by the Law Reform Commission back in 2011.

A lively discussion followed the presentation with many voicing their concerns, and the need for their voice to be heard on this matter. Many were frustrated that the Bill didn't come in an easy to read format. Many felt forgotten about, how were they to give constructive feedback with the Bill in its current format? Chairperson Patrick Santry asked the group if they were in favour



of making a submission on the Bill to highlight their concerns. The group agreed unanimously. The regional groups agreed to



put together 3 positive and 3 negative points of the bill at local level in preparation for the next officers meeting.

The next meeting of the IRN Steering group took place on the 18th of September in Limerick



University where all the regional submissions were put together. Along

with the letter of submission to the Department of Justice, a document was put together for discussion at the Dublin symposium.

Consultation symposium on the Assisted Decision-Making (Capacity) Bill in Dublin Castle

IRN's participation in the symposium was without doubt an enormous success. Members highlighted their concerns at the round table discussions as well as personally with the Minister for Justice Alan Shatter who was very responsive to the concerns raised. The issue of the necessity for an easy read document was taken on board and plans are now being put in place to accommodate this need. Carol Baxter, from the Department of Justice has agreed to attend the next IRN meeting to hear first hand the concerns of the group. The preparation



and forward thinking of the group has ensured that their concerns about the Bill will be taken into consideration and could possibly result in amendments being made to the final draft. Congratulations and well done to all involved.

Billy Arnold – Winner of Art Competition to Design the Cover of the National Intellectual Disability Database Committee Annual Report 2012

The National Federation of Voluntary Bodies, in association with the Health Research Board (HRB) invited people supported by our services to design the cover of the National Intellectual Disability Database Committee Annual Report 2012. The picture below shows the winning entry by Billy Arnold, who was presented with his prize on 7th November, 2013, in Brothers of Charity Services, Deer Park, Ballinasloe, Co. Galway.



Enda Connolly, Health Research Board; Anne Geraghty, Brothers of Charity Services; Councillor Michael Kelly, Mayo of Ballinasloe; Billy Arnold, Prizewinner; Councillor Liam Carroll, Mayor of County Galway; Sarah Craig, Health Research Board; Brian O'Donnell, National Federation of Voluntary Bodies.

DELAROSE (Delivering E Learning Accreditation to Reduce Occupational Stress in Employment)

Following the success of the ROSE (Reducing Occupational Stress in Employment) Project through which an on-line stress management module for staff working in the health and social care sectors was developed – the National Federation has been invited to participate in a follow-on Project entitled DELAROSE (Delivering E Learning Accreditation to Reduce Occupational Stress in Employment). The Project is led by Waterford Institute of Technology and the main objective will be to deliver an e-learning accredited programme to reduce occupational stress in employment. The Project is funded through the European Commission Lifelong Learning Programme and will run until the end of 2015. Further information can be obtained by contacting Jillian.sexton@fedvol.ie

Employee Assistance Programme - VHI Corporate Solutions

At a recent meeting of the National Federation's Operational Human Resources Group Mr. Joe Doddy, Senior EAP Consultant, Vhi Corporate Solutions, gave a comprehensive presentation on the National Federation Employee Assistance Programme (EAP) and the updated features of the Scheme. To date there are 32 Federation member organisations involved in the EAP, covering approximately 10,000 employees, and Mr. Doddy confirmed that the rate of €10 per employee negotiated by the National Federation will be continued for the next 3-year period. In terms of usage of the EAP the main issues which are arising for employees include:

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 - Workplace demands,
 - Stress related issues,
 - Bullying / Line Manager concerns,
 - Changes in the workplace.

The main features of the EAP include: Counselling Service / new website launched / parenting & career coaching / Specialist information service / Critical Incident Support service (there is an additional cost involved for this service). A notable new feature of the EAP is the provision of a Senior Care / Home Instead Programme through which members can avail of up to 5 hours home care for an elderly parent or relative.

For additional information / to join the EAP please contact Joe directly - joe.doddy@vhi.ie Mobile: 085 1100427 / Website: www.vhi.ie

Health & Safety Working Group:

At the most recent meeting of the Health & Safety Working Group a very useful presentation was made by Mr. Thomas Doyle, Inspector, Health & Safety Authority, who discussed a broad range of issues arising in relation to health and safety inspections within the healthcare sector. The presentation dealt with key areas relating to lone working, occupational first aid, driving for work, elements of the Safety, Health & Welfare at Work Act, 2005 & what to expect when an inspector calls? Copies of the presentation are available from Anne Clinton Members of the

group have also developed a 'Health & Safety Audit Tool' which will be available in early 2014 and will be a very useful tool for organisations. The group is presently working on its work plan for 2014 and anyone interested in finding out more about the work of the group should contact: Anne Clinton, St. Michael's House, Chair, or Therese King, Ability West, Secretary

Brian Donohoe presents to the Dail on behalf of Inclusive Research Network.

On the 3rd of December, 2014 a delegation from the Inclusive Research Network (IRN) met with Carol Baxter & Brídín Ní Dhonnghail from the Department of Justice to discuss the Assisted

Decision Making (Capacity Bill). Carol & Bridin gave details of the Bill and then the members from the IRN delegation had an opportunity to ask questions and raise issues which included issues about Assessment of Capacity, the Sexual Offences Act, families and services having too much power over decision making, and the non existence of an Easy to Read version of the bill. Carol and Bridin both said that the decision making options in the Bill i.e. co-decision Making and Assisted Decision Making will only be put in place for people with Disabilities if they are seen as necessary by the Courts. The IRN members agreed to meet with Department in six months when the Bill is ready to be made into law.



Brian Donohoe presenting to the Dail on behalf of Inclusive Research Network on the Assisted Decision Making Bill. Also in the photo Senator Catherine Zappone and Eilionoir Flynn NUIG

After the meeting the Secretary of the IRN Steering Group Brian Donohoe went to Leinster House to make a presentation to a briefing of TD's & Senators which was being chaired by Senator Catherine Zappone and co-Facilitated by Eilionoir Flynn from the Centre of Law & Policy at NUI Galway. Unfortunately only Brian Donohoe and Maria Walls were allowed to attend. The other members of the IRN were not happy with this as they also wanted to attend. There were three speakers at the event, an advocate for people who use Mental Health services, Brian Donohoe speaking on behalf of the IRN and another advocate for Age Ireland.



Brian Donohoe and Senator Catherine Sappone

All three speakers spoke for 10 minutes and took some questions from the audience. Senator Zappone thanked everyone for coming and said the briefing would be very useful to Law-Makers. The briefing was then concluded.

Article written by Brian Donohoe.

The European "Journey to Belonging Project" co-ordinated by the National Federation concludes its work

The two-year "Journey to Belonging" European Project, funded under the Grundtvig stream of the Lifelong Learning Project has concluded. The project, which was co-ordinated by the National Federation of Voluntary Bodies provided eleven people supported by our member organisations and thirteen staff members with opportunities to contribute to the shared learning around good transition practice and to experience the culture and customs of the partner countries.



The importance of good transition support and planning

Transitions are very important times in life for everyone; e.g. leaving school, moving house; changing work or dealing with a family bereavement. Development, growth, and the change process are times of opportunity. They can also bring stresses, upheaval and realignment of thinking and acting. Without appropriate and adequate information, communication and cooperation; transition times can become a crisis.

Alison Harnett, National Federation and Siobhan Wallace, Leargas at a Leargas event on 10 December to celebrate the conclusion of the current stream of Lifelong Learning Projects.

To address the specific goals of the UN Convention on the Rights of Persons with Disabilities a collaboration from Ireland, Finland, Austria, France, Germany and Slovenia developed the 'Journey to Belonging' Project focused on building capacity and enhancing social inclusion for people with ID at times of transition, change and challenge. The project aim was to facilitate adult learners and staff supporters to meet with the purpose of identifying, sharing, and learning effective methods of working through transition points at different times across the life-cycle.

Existing materials that had been developed across Europe providing evidence based best practice guidelines, training, programmes and tools to support people with intellectual disabilities at various specific times of transition. The Journey to Belonging Project brought together the partners from across Europe in order to share and explore the existing research on transitions at different times of the lifecycle.

How the project worked

The partnership shared information about good practice at times of transition with each country taking responsibility for gathering the information related to one particular point on the lifecycle. The specific areas that we explored were:

1. How families are first informed of their child's disability (co-ordinated by Ireland and sharing the Best Practice Guidelines for Informing Families of their Child's Disability <u>www.informingfamilies.ie</u>)

- 2. Moving into older age (co-ordinated by Slovenia)
- 3. 'Moving Out' (moving out of home for the first time, or moving to a new home Finland)
- 4. Moving from a congregated setting (institution) into community life (France)
- 5. Personal Futures Planning use in planning and supporting transitions (Austria)

The project focused on:

- Sharing information and learning in innovative and accessible ways that encouraged participation from all

- Gathering information from different countries that looks at transition times across the life-span and collating these to form a repository of information

- Sharing that information using our network of partners across Europe.

- Learning about each others' countries and cultures, and about being active European citizens as we work through this project.



Carmel Boylan shares her experiences during the Slovenian mobility looking at the experiences of older people with intellectual disabilities. Carmel is supported by staff member Margaret O'Neill from the Daughters of Charity.

Through the mobilities in the Journey to Belonging Project we used a variety of innovative techniques to transfer skills and knowledge including participatory strategies for including people with intellectual disability.



The final night of the European Project being celebrated at Salzburg Castle in Austria

You can find further information on the Journey to Belonging Project on our website, <u>http://www.fedvol.ie/Journey_To_Belonging/Default.2002.html</u> including advice on how to include and support people with intellectual disabilities in a multi-lingual environment: <u>http://www.fedvol.ie/Inclusion_of_people_with_ID_in_a_multilingual_environment/Default.2004.html</u>

Leargas will be providing a number of information days in January and February 2014 around the new Erasmus + funding stream which is coming on stream next year. Check the Leargas website for dates: <u>http://www.leargas.ie/programme_main.php?prog_code=7128</u>

How are we doing since Immersion?



As part of supporting our members who participated in the Immersion Project the National Federation organised an event entitled *"How are we doing since Immersion"* which took place on 24th September 2013. This event gave the Immersion Change Teams the opportunity to reflect on the learning gained from Immersion and to share their experiences of the process so far.

The day began with an address from Ms. Marion Meany, Interim Assistant National Director, HSE and was followed by a presentation

entitled "The challenges of the ever changing need to change" from Ms. Pat Fratangelo. Muiriosa Foundation gave several inspiring presentations on their change process which gave delegates the opportunity to hear what worked and what did not work. It was an honest review of the process and included hearing from individuals, families, frontline staff and senior staff.

Roundtable discussions took place in the afternoon and were facilitated by Prof Roy McConkey. They explored the six key themes for organisations implementing change as follows:

- Person centred
- Family involvement;
- Roles for support staff.
- Dealing with management:
- Funding:
- Partnerships



Christian O' Leary presenting at the event and supported by Tom Madden, Muiriosa Foundation

Back Care & Manual Handling (Refresher) Module:

The online 'Back Care & Manual Handling (Refresher) Module' which has been developed through the work of the National Federation's Learning-on-Line Working Group is now available to all organisations to access. The module, which is available through the Open Training College, covers the theory element of the refresher training which employees are required to undertake. An accompanying practical session will need to be arranged for staff following completion of the theory element. The Learning-on-Line Working Group is now focusing on its programme of work for 2014 with a view to supporting organisations to expand their on-line learning opportunities. Further details in relation to the Back Care & Manual Handling (Refresher) Module can be obtained from jillian.sexton@fedvol.ie

Workshops on Cancer Screening and Early Detection



National Cancer Screening Service



The National Cancer Screening Service (NCSS) has identified that people from minority groups have greater difficulty in accessing screening services – specifically those with Intellectual Disability (ID) where difficulty in giving consent is a known barrier to screening.

NCSS developed and delivered a one-day training programme in three locations in 2012. Following on from this training programme, the NCSS in conjunction with the National Federation of Voluntary Bodies (NFVB) ran three one-day training sessions on cancer screening during October/November 2013 in Galway, Cork and Dublin. The sessions focused on the national population-based cancer screening programmes in Ireland – BreastCheck, CervicalCheck, BowelScreen and Diabetic Retinopathy. This training was offered to staff working with clients with an intellectual disability.

The aim of this training was to provide participants with the knowledge and skills needed to provide accurate information about screening services to clients with intellectual disability using appropriate language and promotional materials adapted to their needs (e.g. pictorial leaflet). It also explored specific issues which may arise for clients with an intellectual disability including requirement to screen and obtaining informed consent.

All training days were well-attended, with representation from a range of support agencies and the feedback was very positive:

'Really enjoyed the day, really makes me think about what to do and endeavoring to improve information sharing for our service users. Learned so much from listening to other participants'

'Ladies were very good at course delivery and answered all queries we had'

'Excellent Course'

'A huge amount of important information prepared by you, greatly appreciated'

'Very interesting, thank you'

The training has been approved for Continuous Professional Development Category 1 by An Bord Altranais. It will also assist agencies in meeting Theme 4: Health and Development of The Health Information and Quality Authority (HIQA) standards for Residential Services for Adults with Disabilities. The standards outlined under this theme specify that the health needs of people with disabilities are reviewed and they have access to universal health and social care services on the same basis as others in order to maintain and improve their health status. The NCSS is planning to continue this training in 2014 – with training days planned in May 2014 in the midlands and a Dublin venue. The NCSS is exploring the delivery of in-house training to larger organisations and agencies supporting people with an intellectual disability – proposing to deliver the training at an organisation's training centre or headquarters. These services will be contacted directly. Please contact Fiona Treacy (Fiona.treacyl@cancerscreening.ie) or Jillian Sexton (Jillian.sexton@fedvol.ie) for more information.

Enabling Excellence Training - Provided by Genio in collaboration with the National Federation of Voluntary Bodies



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Providing Services to People with Intellectual Disability

In April 2013 the National Federation of Voluntary Bodies organised a very successful week long Immersion event which proved highly transformational for those involved. Hope Leet Dittmeier was one of the international speakers at the event, and following Immersion there was a significant increase in the demand for further training from our members, in particular from Hope. The National Federation and Genio have worked together in order to respond to this demand and the result of this collaboration is the **'Enabling Excellence'** programme which is Provided by Genio in collaboration with the National Federation of Voluntary Bodies.

On Monday 7th October, 2013 an information day took place for National Federation member organisations who expressed an interest in having their personnel involved in the Enabling Excellence programme. In addition to providing an introduction to all aspects of the 'Enabling Excellence' training, the primary purpose of the day was to ensure that members had a clear understanding of the commitment required by participating organisations in order to facilitate and embed the kind of changes 'Enabling Excellence' is designed to bring about.

Enabling Excellence training will be provided at two venues, one in Dublin and one in Limerick, in four separate week long sessions over a nine-month period from February to September 2014. There has been a huge response to the training and to date 30 member organisations have registered and the Dublin venue is fully subscribed.

For more information please email Maria Walls at <u>maria.walls@fedvol.ie</u>

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Member Organisation News:

Awards for Blue Teapot Theatre Company

It has been an autumn of awards for Blue Teapot Theatre Company. The "Teapots" won the Dublin Airport Authority Overall Award at the Allianz Business to Arts Awards in the Bord Gais Energy Theatre in September, and they also won the Galway County Mayor's Award for Arts and Culture in November.



Founded by the Charity Brothers of Services Galway in 1996, Blue Teapot's mission is to effect positive change in public consciousness concerning people with disabilities, promoting their creativity and contribution to cultural life by delivering three unique arts programme strands specifically for adults with intellectual

disabilities. The three strands are the Blue Teapot Theatre Company, the Performing Arts School which delivers quality assured, FETAC accredited performing arts skills training, and Bright Soul - an Outreach project that encourages arts participation by people with intellectual disabilities.

Blue Teapot's highly acclaimed play *Sanctuary* was a sell out at the Galway Arts Festival and the Dublin Fringe. The play deals with the very complex issue of intimate relationships between people who have intellectual disability. In commissioning Christian O'Reilly to write the play, Blue Teapot's Artistic Director, Petal Piley said that she wanted to give artistic expression to the restrictions experienced by people with intellectual disability in Ireland in the area of relationships and sexuality. This bitter sweet production is particularly powerful because the roles are all played by actors who have intellectual disability. In reviewing the play in the Irish Times, Peter Crowley wrote "O'Reilly's play is a romantic comedy written for the Galway-based ensemble of actors with intellectual disability. As it shears this couple away from a group of their peers – some bitter and jealous, some with romantic designs of their own – it cracks open a political quandary about the sexuality of people with special needs and asks intriguing questions of the theatre."

Clinical Education and Research Department LauraLynn Authors Louise Neary and Claire Quinn

LauraLynn (formally Children's Sunshine Home) opened as Irelands Children's Hospice in September 2011. This was the beginning of an exciting journey for the greater development of children's palliative care in Ireland and just one year later LauraLynn established the first center specifically dedicated to the education needs of professionals working within this area as indicated in the policy document *Palliative Care for Children with Life-Limiting Conditions in Ireland' – A National Policy* (Department of Health & Children 2010).

Programmes delivered to internal and external delegates are focused towards areas such as end of life care for a life limiting condition, community care, communication and research. Lauralynn initiated the first Irish children's palliative care conference held recently. The department is led by Ms Claire Quinn, a Registered Nurse, who has significant clinical and academic training within children's palliative care. Claire also lectures at the National University of Ireland in Galway. The departmental team members include Ms Louise Neary RNT RCN RNID, Ms Amanda Vaughan Training & Administration and Dr Rowan Hillis Research and Data Officer. The Department is affiliated with both NUIG and UCD and works closely with Dr Joanne Balfe, Consultant Paediatrician with a special interest in Community Child Health who works at LauraLynn and the NCH, Dublin.

St Christopher's Services Ltd, Longford

St Christopher's Services Art Programme has been awarded first prize in the IPB Pride of Place Award for 2013. Pride of Place is an All Island competition that acknowledges the work that communities are doing all over the Ireland. The competition focus is about people coming together to shape, change and improve daily lives in their communities. The St Christopher's Art Programme, run under the guidance of Programme Director Jean Healy offers an exposure to art in all its forms, encouraging creativity, self expression and the development of artistic skills.

A major focus of the Art Programme is Integration through Art to the wider community in County Longford. This is done through projects involving Service Users working with Primary and Secondary Students in County Longford, and also working with Active Age groups and other art groups in the community.

Many venues are accessed around Longford to showcase the talent of the service users. Regular solo and group exhibitions are held throughout Longford and surrounding counties. The art and craft works produced are displayed and sold throughout the year at craft fairs and through a unique Christmas pop up shop.

The St Christopher's Arts Programme took first place in the Community Arts category and the award ceremony took place in Derry on the 16 November 2013. The judge's commendation stated that:

"The joy and pride by those taking part is amazing. The commitment and dedication of the project leaders, and their innovation deserves the highest praise. This is a self sustaining project that touches many lives in a wholly positive way. A truly remarkable project."

The work of St Christopher's Art Programme will continue to build on the links forged with the community of County Longford and looks forward to supporting and championing the Service Users in all their future artistic endeavours.



Ms. Jean Healy, St. Christopher's Art & Crafts Instructor and Longford's Mayor, Councillor Larry Bannon.

Brothers Participate in 20km Rock n Roll Dublin Half Marathon

Ciaran Clifford from Greystones is supported by Sunbeam House Services. His brother Joe ran the 20 km Rock n Roll Dublin Half Marathon in August 2013 in aid of Sunbeam House, pushing Ciaran the whole way in his wheelchair. Here is what Joe had to say about the experience:-



"We did it - one of the happiest days of Ciaran's and my life. We felt really good and strong right through the race, in fact so good Ciaran decided to read his book on the way round. But he had a ball throughout the race, reaching out and grabbing struggling runners and pulling them alongside.

We wanted to dedicate the run to all the carers in Sunbeam House Services and throughout the country - those who are parents,

brothers, sisters, friends or relatives who day in day out tend to mentally and physically challenged children or adults.

All that is left for Ciaran and myself is one race, as we have ran in many 10k's and a 20k run. Watch this space in spring of next year. Our official time was 2 hours 4 minutes and 53 seconds. We finished 2655 from a field of 6,500.

It was such an amazing day with all the well wishes from people and runners throughout the race, and having an opportunity to share and do something that brings both Ciaran and I a lot of joy. In fact it never felt like it was an effort - not when you see the smile on Ciaran's face !"



A DECADE IN HER BOOTS



Laura Ryan from Knocklyon is celebrating a decade working in Boots Nutgrove this year. Laura has completed a training and employment programme with Cheeverstown House Employment Support Service. Cheeverstown is a voluntary organisation that provides a wide variety of services and training to children and adults with intellectual disabilities throughout various locations in Dublin.

"Laura has worked for Boots since October 2003. I have had the pleasure of working with her for the last 18months here in Nutgrove. We always know its Tuesday when Laura arrives with a big smile on her face and a chirpy hello. She brightens up the day and helps make our store a great place for our customers to shop. Over the last ten years Laura has made some great forever friendships within the team and has also built up fantastic relationships with our regular customers. They know her by name and don't

hesitate to seek Laura for help when they call to our store. She has a passion for makeup and loves trying out the latest product and always gets behind any new launch in our store with great enthusiasm. She shows genuine care for her colleagues, is always willing to help them out and never forgets a birthday or special occasion in someone's life. She is a real asset to our team and here's to the next ten years of her Boots journey" Lauren Gorman, Store Manager, Boots Nutgrove.

"I love working in boots I'm very happy there. I've made loads of new friends over the years. I have been working in boots ten years now". Laura Ryan, Store Assistant, Boots Nutgrove.

If you would like to know more about Cheeverstown's Supported Employment Program contact Susan Mansfield, Job Coach, smansfield@cheeverstown.ie

COPE Foundation's Advocacy Working Group

COPE Foundation's Advocacy Working Group was established in January 2013 to explore ways of developing advocacy mechanisms across the organisation. The Working Group, which includes people supported by the organisation, presented their findings and recommendations to the Board of Directors on 14th of November. Among the recommendations was the formation of a formal Advocacy Council to represent people supported by the organisation. This council would be recognised and consulted in the same way as trade unions are for staff. In addition, as part of the group's work, discussions were held with Cork Institute of Technology around developing a formal advocacy course that people supported by COPE could access. CIT have kindly agreed to develop this with a view to the course commencing in 2014. We are delighted to say that all of the recommendations made by the Working Group were passed unanimously by the Board of Directors and work will begin on their implementation in January 2014. This is the first time in COPE's history that the voices of the people we support have been given formal recognition. It was a very significant occasion for COPE Foundation and we were extremely proud to be a part of it.

(COPE Foundation's Advocacy Working Group findings and recommendations are attached for your information).

Caroline Riordan Chair COPE Foundation Advocacy Working Group

Early Intervention Community Nurses, Brothers of Charity Services, Roscommon

When a child is born with Down Syndrome:

Following diagnosis the family will be assisted in making a referral to the Early Intervention referral forum by their health professional e.g. midwife, Paediatrician, GP, PHN...

Early Intervention Community Nurses offer the following:

- Child development screening to provide an early intervention home programme
- Parent and baby groups
- Nurturing hands Infant Massage groups
- Parent and Toddler groups
- Support around transition to pre school
- Parent support groups, including Fathers Forum
- Facilitate parent training and information sessions
- Support in relation to medical issues and needs



Informal contacts:

While families are waiting to access formal EIS the Community Nurse can be contacted directly by families to provide help, support and advice- over the phone, in maternity unit or family home.



Going to College - Including Students with Intellectual Disabilities at NUI Galway

Students with intellectual disabilities at NUI Galway are now in their third year in college, supported by the Going to College initiative. Going to College is a university/community partnership supporting the inclusion of students in the typical student experience, i.e. involvement in academic, social, volunteering and work placement activities. Students are registered full-time students and are included in undergraduate lectures and all other class activities, with opportunities emerging to work with their undergraduate peers. All students supported by the Going to College initiative are encouraged to volunteer and achieve their President's award for volunteering. NUI Galway's student volunteering programme, ALIVE, supports a reciprocal relationship between the student and the wider community and provides opportunities for the development of knowledge and transferable skills. Each student also has the opportunity to undertake a meaningful work placement during their college experience and join college clubs and societies. Students are encouraged to use public transport to travel to college, further promoting their independence.

Aiming to support each student to develop the vision, knowledge and transferrable skills to live a more independent, inclusive life after university, Going to College is underpinned by a rights base and recognises the strengths and potential of each student to achieve, given the opportunity and appropriate needs-led support. To date students have been included in undergraduate courses in Archaeology, Celtic Civilisation, Earth & Ocean Sciences, Engineering, Human Rights, Irish, Italian, Marketing, Sociology & Political Science, and Theatre & Performance. Going to College works in partnership with each student, their family, university staff, intellectual disability service providers, volunteering organisations and employer organisations. Consistent with UNESCO's principles for inclusion in education and the UN Convention on the Rights of Persons with Disabilities, Going to College promotes citizenship, inclusion and participation, with a focus on the will and preferences of each individual student.



Front row (I-r): Dr Edward Herring, Dean of College of Arts, Social Sciences and Celtic Studies, NUI Galway; Maria Walls, Director of Research & Policy Development, National Federation of Voluntary Bodies; Margaret Glacken, Director of Services, Brothers of Charity, Roscommon; and Professor Pat Dolan, UNESCO Chair, NUI Galway. Middle row (I-r):Brian O'Donnell, Chief Executive, National Federation of Voluntary Bodies; Breda Crehan-Roche, Chief Executive, Ability West; Anne Geraghty, Director of Services, Brothers of Charity Galway: and Professor Gerard Quinn, Centre for Disability Law & Policy, NUI Galway. Back row (I-r): Breda Casey, Going to College Project Co-Ordinator; Danielle Kennan, UNESCO Child and Family Research Centre, NUI Galway; Bernard O'Regan, Executive Director, Western Care; and Professor Nollaig McCongail, Deputy President and Registrar, NUI Galway.

Going to College Project University/Community Partners

Community: National Federation of Voluntary Bodies; Ability West; Brothers of Charity Galway Services; Brothers of Charity Roscommon Services; Western Care Association

NUI Galway: UNESCO Child and Family Research Centre; Centre for Disability Law and Policy, NUI Galway.

More Information:

If you would like more information, please contact: Breda Casey, Going to College Project Co-Ordinator, AM124 Arts Millenium Building, NUI Galway, Phone: 091 493621, Email: <u>breda.casey@nuigalway.ie</u>

Mark "Steps Out to College

Mark told us he wanted to do a course in agriculture when the CoAction educational grant scheme was announced. Now Mark is a student on the "Certificate in Agriculture, Level 5" course in Clonakilty Agricultural College. A number of carefully planned supports had to be set in place: The college installed a fully accessible wheelchair toilet and purchased a hoist. They also installed a ramp to enable him to get into the canteen.

Mark stays in Teach Cairde, a COPE run residential group home in Clonakilty four nights per week. Volunteers and CoAction staff help him during his stay. A driver from the Irish Wheelchair Association brings him to and from the college morning and evening. His family even bought a new car to take him back and forth between Castletownbere and Clonakilty at the weekends. Mark says, "It's a



great new experience for me. I never thought that I could do something like this and we kept fighting until we got there and here I am. My day is crazy busy. The college staff are very easy to talk to and I couldn't do it without my helpers. I intend to go further when I finish."

The Kerry Parents & Friends Association--Killarney Community College Film Project 2013: Road Safety for Pedestrians

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Early this year, Kerry Parents and Friends Association (KPFA) Killarney Community Programme members participated in a community-based film project. The programme was a joint project with the Applied Social Studies students from Killarney Community College.

Supported by Kerry Education and Training Board (Community Education) the programme involved making a DVD on road safety for pedestrians and was run over a 10 week period. The programme was facilitated by Kerry Education and Training Board tutor, Kevin Langan. The Applied Social Studies students developed friendships with Community Programme members. Everybody participated in brain storming sessions to tease out the important aspects of road safety for pedestrians. Both groups worked well as a team when out filming road safety clips. The DVD is presently being used by Kerry Parents and Friends Association to promote road safety.

Grace Murray said she would like to work with the students from the community college again.....Elaine Horgan said "It was a very good experience"

The Road safety DVD is available by contacting Kevin Langan. E mail <u>info@kevinlangan.ie</u>



Participants in the project included: Jerry Lyons, Elaine Horgan, Brendan Sullivan, Grace Murray, Denise Kearns, Martina Healy, Katie Gleeson, Amanda O Leary, Stephanie Shine, Zorah Velchel Malon, Jackie Sheehan, Anne Marie Murphy.

The 2013 KPFA-Killarney Community College Film Project group.

RehabCare Achieves Top European Quality Award – EQUASS Assurance

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RehabCare has been awarded a top European quality honour in recognition of the standard of the services that it provides. The European Quality in Social Services award – EQUASS Assurance – recognises RehabCare for its quality assurance and quality control in 48 of its resource centre services countrywide.

The award, which is overseen by an international awarding committee, is only given after an extensive process of external verification. As part of the process, people using RehabCare's services, staff and other stakeholders were interviewed. Over 100 criteria were reviewed, including participation by the individuals and families in the development of a range of supports, staff training and development, external partnerships, linkages developed with stakeholders, and corporate governance. In their comments, the auditors paid tribute to staff members' passion and enthusiasm for their work, a strong "can do" attitude, and a clear focus on improving the quality of life for each individual.

Laura Keane, Rehab Group's Director of Health and Social Care Services, commented, "We are delighted to have received EQUASS Assurance, an independent European stamp of approval, verifying RehabCare's commitment to best practice. The award is a tribute to our committed and flexible staff who each day work to enable the people who attend our services to achieve their goals."



Brothers of Charity Services South East National Advocacy Conference - *Advocacy beyond Services* (October 2013)

For the past 15 years the Brothers of Charity Services self advocates have organised a national advocacy conference. The service has 6 regions and each year regions rotate responsibility for organising the conference. This year it was the turn of the South East services which provides services for people in Waterford city, county and South Tipperary. The organising of the conference began at the end of 2012. An organising committee was established with advocates and staff members with support from the training, development, advocacy, and quality department. The theme for this year's 1-day conference, which took place on October 17th last, was "Advocacy beyond Services" *claiming your rightful place as a valued citizen*. The concept of the conference was to give advocates and their supporters an opportunity to think about and discuss the concept of advocacy being more than just within services, that it affects all aspects of their lives. The UN convention on the rights of people with disabilities is something that the lrish government have signed but have not ratified. This conference was an opportunity for advocates to become more familiar with the UN convention. MC for the day was Mr Billy Gear who is a member of the South East regional advocacy council.

Article 9 of the UN convention states addresses accessibility and the South East focused on accessible information .Their presentation was based on the work they have been doing as members of a working group working with the referendum commission on making information on referenda more accessible for people with an intellectual disability. Other regions presented on a variety of different themes linked to the overall theme and also the convention such as Limerick regional council's consultation with HIQA on draft HIQA standards. Limerick's council submitted feedback to HIQA in regards to the HIQA standards for residential services for adults with disabilities. Roscommon regional council focused on Article 30 of the convention which focuses on taking part in sports and leisure. They presented on how they have linked with their local councillors and politicians on what they are doing in regards to the convention, they even managed to get an interview with TD Luke 'Ming' Flanagan. They also spoke about how they have worked with a local kayaking club to make it possible for one of their advocates who has a physical disability to go kayaking. Clare and Galway regional councils presented on accessibility to their local communities. Both Clare and Galway linked with their local councillors/senators on issues such as traffic in their local town, the lift at the local train station not working and also the importance of ensuring that issues are brought forward and worked on with in collaboration with other community members and also local county councillors and politicians. Cork's presentation focused on a very topical and current issue of 'Capacity' and the ability to make your own decisions.

Key Note speaker, Christina Burke BL, Senior Lecturer in Law, Athlone Institute of Technology, addressed the UN Convention on the Rights of People with disabilities. Brian Harvey, Independent Social Research Consultant, author of 'Working for change. A guide to influencing policy in Ireland' also presented. Brian presented on the importance of lobbying and on how to be a successful advocate. Our final guest speakers were members from the National Advocacy Platform. This is a platform set up by and for people with intellectual disabilities. It if funded from Genio and it aims to develop an Advocacy platform for people that is national and separate from any service organization. At the conference they spoke about their vision and asked the audience for feedback on the future of the platform.

The conference gave all people supported by the Brothers of Charity Services throughout Ireland the chance to look at their lives and see that in fact they have as much a right to services in Ireland as every other citizen of the country. The regional advocacy council in each region worked really hard on their presentations and passing on the information about the convention to their local groups. This was a great opportunity for people supported by the Brothers of Charity Services Ireland to get together and showcase what is happening in their region. It was also an opportunity for a number of other services not linked to the Brothers of Charity to attend and see what we are doing in promoting advocacy not only within our service but also in the wider community. The day concluded with an evening dinner and entertainment where advocates could celebrate their successful day and dance the night away.

Siobhán Flynn on behalf of the Regional Advocacy Council Brothers of Charity Services South East



Research Project



Invitation to families to participate in a research study exploring cancer awareness and screening in women with intellectual disabilities.



What is the research about?

Waterford Institute of Technology in collaboration with the HSE-SE are carrying out research about breast and cervical cancer awareness and screening in women with intellectual disabilities in the South East region.



The members of the research team are Dr. Suzanne Denieffe, Ms. Sinéad Foran and Ms Mary Reidy from the Department of Nursing at Waterford Institute of Technology.

As part of this research study we are inviting the families of women with intellectual disabilities

to participate in a survey about cancer awareness and screening. The survey will begin in early October and finish in mid December 2013. The results of this survey will be used to develop education programmes to improve screening uptake for women with intellectual disabilities. This may lead to the earlier diagnosis and treatment of cancer with better outcomes for the women.

What would you need to do?

There are no medical tests involved. If you decide to take part you would complete a questionnaire on cancer awareness and screening. The questionnaire takes about 15 minutes to complete.

You can complete the questionnaire over the telephone at a time that suits you. The research team will make arrangements to phone you at that time.

or

If you would rather complete a paper copy of the questionnaire, we will send you a copy, as well as a stamp addressed return envelope.

or

You also have the option of completing an online version of the questionnaire which is available from <u>mreidy@wit.ie</u>

Confidentiality

All the information that is collected will be anonymous and kept strictly confidential and your name will never be used with this information.

If you are interested in taking part in this research, please contact Ms. Mary Reidy, at the Department of Nursing at Waterford Institute of Technology. E-mail: <u>mreidy@wit.ie</u> Phone: (051) 845593

Conferences / Events

Please diary this date

Sharing Innovative Learning Event

"Assisted Decision Making"

Presentations will be made on the recently published

Assisted Decision-Making (Capacity) Bill (ADM) by:

Eilionoir Flynn, NUIG Maria Walls, National Federation Grainne Tinney, Prosper Fingal Christine Delany, Prosper Fingal Laura Powell, St John of God

on Wednesday, 29th January 2014

10.30 am – 4.00 pm

in the

Heritage Hotel, Portlaoise, Co. Laois

The presentations on the Assisted Decision Making Bill by Eilionoir Flynn and Maria Walls will outline the current debate on revisions to the Bill and the issues relevant to individuals, family members and service providers. Laura Powell will present on 'The South Australian Supported Decision Making Project' and it's relevance to assisting decision making. Grainne Tinney will present on total communication approaches and their role in the decision making process. There will also be opportunities to discuss the key issues raised. The National Federation of Voluntary Bodies is an active member of the Legal Capacity Coalition seeking progressive legislation in this area.

Who should attend this event?

People who avail of services, their families, CEOs, front line staff & managers.

Cost = €60 with a reduced rate of €30 for people with disabilities or their family member.

ONLINE BOOKING is now available at http://form.fedvol.ie





Inclusion worldwide - supporting people with disabilities and their families

International Short Breaks Association Conference 2014 - Call for Papers.

The 9th International Short Breaks Conference will take place in Germany from September $9^{th} - 11^{th}$, 2014. A call for papers has been issued with a submission deadline of January 31st 2014. For further information see: www.isba.me / Facebook (www.facebook.com/isba.me).

Wishing you all a Very Happy Christmas & Best Wishes for 2014

