

NATIONAL FEDERATION OF VOLUNTARY BODIES

Providing Services to People with Intellectual Disability

Welcome to the National Federation Newsletter

Spring 2017



The Three Voluntary Disability Services Umbrella Organisations Come Together in Joint Session on issues affecting the Voluntary Disability Sector

The National Federation of Voluntary Bodies, Disability Federation of Ireland and the Not for Profit Business Association, met on Friday, 24th March, 2017, in the Ashling Hotel, Dublin, to discuss the existential crisis which is afflicting the voluntary disability sector and the critical challenges facing people with disabilities, their families, and service providers, which are feeding into this crisis in 2017.

There were 30 participants at the meeting, including the three chairs of the respective Boards and a number of Board Members representing each. The session was facilitated by Mr. Paul Doherty. At the outset it was agreed that the reasons for the crisis are multi-faceted and complex and the reasons for coming together were articulated in each of the Chairs opening remarks who underlined the importance of greater inter-organisational partnership in order to address issues of common interest and concern.

Mr. Paul Doherty then presented key points drawn from a briefing paper that had been circulated to the workshop participants in advance: *"Capturing some of the critical challenges facing people with disabilities and the disability service providers in Ireland in 2017 and beyond"*.

There then followed an open lively discussion during which concerns were expressed in relation to a number of issues as follows:

Relationship with the HSE:

It was felt that it is now necessary to develop a new and more constructive relationship between voluntary providers and the HSE, one in which there is a greater focus on their common concerns and on the shared need to secure appropriate supports from different government departments.

Lack of a Clear National Disability Strategy:

It was noted that the UNCRPD has yet to be ratified and that the National Disability Strategy has now expired. It was suggested that the UNCRPD would form a good basis for strategic policy development at the national level.

A key consequence of there not being an up to date disability strategy is that there is a mismatch between current demands and available resources. Since 2012, there has been a significant increase in demand as a consequence of demographic changes, especially an increase in the number of people with complex needs. There is now also a higher level of awareness and consequently of expectation amongst people with disabilities and their families and friends. Against a backdrop of increasing demand, over the past decade available funding has been reduced and there has been little or no investment in new service developments. An unfair perception has taken hold that voluntary service providers are generally well resourced, when in fact the reality is that many of them have accumulated significant deficits as they have tried to sustain essential services.

For some, there is now a significant question as to whether they will be able to sustain their services. The failure to restore pay cuts is a significant concern for all.

Significant Growth in Compliance Requirements:

While accepting the need for appropriate regulatory and compliance requirements many expressed concerns about the inadequate resources which are available to meet the significant costs of compliance. It is also a matter of concern that there is a multiplicity of regulators (HIQA, Charities Regulator, CRO, Housing Agency etc.) and that their respective demands are not adequately aligned. There is no “regulator of regulators” to ensure cohesion.

The impact of growing regulatory pressure, in the absence of additional resources, is burn out and exhaustion for staff and fractious relationships between Board and CEOs as they struggle with compliance challenges. The voice of those receiving services and the impact of regulation in their lives is often absent in national debate on these matters.

Re-energising the Voluntary Disability Sector:

It was generally felt that the advocacy role and sense of cohesion in the voluntary sector needs to be recovered urgently. It is important that the added value, both economically and socially, which a vibrant voluntary disability sector brings to the state should be quantified.

Participants identified the areas around which the three umbrella organisations could take joint action as follows:

- Research and evidence gathering;
- Strategy clarification and development;
- Communication and Advocacy;
- Strengthening of Voluntary Sector.

It was agreed that a report of the day's proceedings would be produced for consideration by the Chairs and CEOs of the umbrella bodies who will meet to discuss its contents and identify issues which call for joint analysis and immediate action ahead of longer term strategic developments.

Finally, there was unanimous agreement about the importance of this joint meeting - the commonality of issues affecting the membership of all three umbrella organisations was striking, and the general view was that the coming together was the commencement of an important process rather than being an end in itself.

HSE Disability Social Care Operational Plan 2017



Dr. Cathal Morgan, Head of Operations - HSE Disability Social Care and Ms. Breda Crehan-Roche, Chair of the National Federation at the General Assembly, 5 April 2017

Dr. Cathal Morgan, Head of Operations, HSE Disability Social Care, presented the above operational plan at our General Assembly meeting on Wednesday April 5th, 2017. Dr. Morgan stressed the importance of working with voluntary service providers in a spirit of partnership in the execution of the plan. In a lively Questions & Answers session which followed his presentation, during which many key issues of concern to member organisations were raised, Dr. Morgan undertook to do all in his power to address these issues.

Policy Update

Assisted Decision-Making (Capacity) Act 2015 – Consultation on Draft HSE Guide

The Assisted Decision Making (Capacity) Act was signed into law on the 30th December 2015. This Act applies to everyone and is relevant to all health and social care services. The new legislation has the potential to significantly improve the lives of many of the people we support, as their ability to make decisions for themselves will be enhanced by the law.

The Act is about supporting decision making and maximising a person's right to make their own decisions, wherever possible and includes provisions for legally recognised supports where necessary. It sees a move away from blanket capacity tests which determine that a person has no capacity to make any decisions to a functional approach which takes account of the fluctuating nature of capacity. For example, a person may temporarily lose capacity following a serious injury. Others may have limited capacity to make complex decisions but may be able to make more routine decisions. This new approach to capacity and decision making provides a number of legally recognised supports to maximise a person's right to make their own decisions.

The HSE has developed a Draft Guide for Health and Social Care Professionals on the Assisted Decision Making (Capacity) Act. The deadline for submissions on the Draft Guide has recently been extended to **5pm on Monday 24th April 2017**.



You can download the draft Guide for Health and Social Care Professionals, and find out more information on the consultation at www.assisteddecisionmaking.ie. Please contact Jacqueline Grogan at adm@hse.ie if you have any queries or need more information about the consultation.

National Federation members are asked to forward their submissions to alison.harnett@fedvol.ie to inform the preparation of a Federation-wide response.



Comprehensive Employment Strategy - Make Work Pay Report to Government 2017

The National Federation took part in a forum in September, 2016 at the National Disability Authority, as part of a consultative process on Strand 3 of the Comprehensive Employment Strategy for People with Disabilities (**Make Work Pay**). Subsequently, feedback was gathered by the National Federation and a written submission was prepared and submitted to the Department of Social Welfare.

Following on from the consultation process chaired by the Department of Social Protection, this week the interdepartmental '*Make Work Pay for People with Disabilities*' Report to Government 2017 was published.

A number of key recommendations from the report will be implemented immediately:

- People with a long-term disability payment who move off the payment to get a job will retain their Free Travel Pass for a period of five years; this measure goes beyond the recommendation of three years contained within the report and comes into effect immediately;
- A Fast –Track return to Disability Allowance, or Invalidity Pension for people where employment does not work out;
- Development of a new “Ready Reckoner”, to calculate the net benefits and financial implications of working is already underway;
- The Department of Social Protection will review its communications with a specific focus on the needs of people with disabilities;
- There will be regular reviews of policies to ensure their effectiveness.

In his commentary, Minister for Social Protection, Dr. Leo Varadkar acknowledged the significant barrier to employment that is caused by fear of losing entitlements and benefits, and in particular loss of the medical card, and stated *“I am firmly committed to improving the responsiveness and sensitivity of the medical card system to the needs of people with disabilities, to maximise their opportunity to take up and retain employment – something which can bring such a positive benefit to their lives and to society generally.”*

He committed to pursuing a range of important recommendations from the report. This includes the earnings disregard applied to people in receipt of Disability Allowance or Partial Capacity Benefit when it comes to assessing eligibility for a medical card. The Minister stated that he is committed to substantially raising the earnings disregard for people in this category and that work has already begun between the Department and the HSE. Initially, the number of people who would stand to benefit will be determined, in addition to the most appropriate earnings threshold to use. *“This should not be an extended process,”* he said; *“Once this analysis is complete, I look forward to announcing implementation plans within the coming months.”*

Raising the earnings level disregard will ensure that those with long-term disabling conditions who have modest earnings will still be eligible for a medical card in order to address what the report finds is the single most significant barrier for people with disabilities.

Speaking at the launch, Minister for Social Protection, Dr. Leo Varadkar said: ***“We want to help more people with disabilities to achieve their employment ambitions and enter the workforce Unemployment and poverty among people with disabilities is high in Ireland and we would like to help to change that. Work is the best way forward for many people with disabilities but we need to ensure that the right support is provided.”*** Minister of State for Disability Issues, Mr. Finian McGrath said that the Government’s ‘Making Work Pay’ strategy will facilitate people to achieve the maximum independence, the maximum choice and the inclusion of people who may have physical or intellectual challenges, through working in partnership.

The ‘Making Work Pay’ report can be accessed at https://www.welfare.ie/en/downloads/2017-03-04_MakeWorkPay_Report.pdf

An easy-to-read version of the report can be accessed at the following link: https://www.welfare.ie/en/downloads/2017-03-04_MakeWorkPay_EasyRead.pdf

A plain English and executive summary are also available from the Department of Social Protection website.

Citizen's Assembly – Consultation on Responding to Challenges and Opportunities of an Ageing Population

Submissions are now being invited by The Citizens Assembly on the topic of 'How we best respond to challenges and opportunities of an ageing population.' Submissions should be made by 5.00pm on Friday 5 May.



The discussion on the topic will take place on the weekend of 10 – 11 June. Full details are available at: <https://www.citizensassembly.ie/en/How-we-best-respond-to-challenges-and-opportunities-of-an-ageing-population/>



RCPI: Towards 2016 - A Future Direction for Irish Healthcare

The final report arising from the **Leading for Quality in Changing Times** forum was launched on 29 March 2017 as part of a national conference hosted by RCPI in the Royal Hospital Kilmainham.

The report calls for a radical change that requires building health services around the person, including locally and at a community level. It outlines a future direction for hospital care and the role of the doctor in Ireland.

It is the culmination of the [Towards 2026 policy forum](#), which was established in 2016 and chaired by the former Director of the National Cancer Control Programme, Dr Tom Keane.

The report was developed through a series of consultations with more than 100 participants from across the spectrum of the Irish health system. **The National Federation participated to ensure that the needs of people with intellectual disability and their families were considered in the process.**

At the report's launch, Dr Tom Keane presented the key recommendations and noted that he hoped the recommendations would help patients, service users, the public and healthcare professionals to think differently about the health system and to recognise opportunities for improvement. Dr Tom Keane's [opinion piece](#) published in the Irish times provides further commentary on the urgent need for comprehensive reform of the health service.

Towards 2026 can be downloaded at the following link: <https://rcpi-live-cdn.s3.amazonaws.com/wp-content/uploads/2017/03/Towards-2026-Report-web.pdf>

National Implementation of the Informing Families Guidelines

The National Federation is collaborating with the HSE in the implementation of the evidence-based *Best Practice Guidelines for Informing Families of their Child's Disability*, developed earlier by the Federation, over the course of 2017. Funding was secured through the Department of Health's National Lottery Scheme, and work on the implementation has begun to take place in a range of settings.



We are working in close partnership with Dr. Ciaran Browne, General Manager Acute Services HSE, to execute the national implementation plan. This includes looking across maternity, paediatric and early service settings in hospital, community and disability services to ensure that the training and awareness raising reaches those who undertake the sensitive and emotional task of informing a family of their child's disability.

The implementation of the Guidelines aims to support professionals who undertake this difficult communication and to equip them with the tools that will support them in using good practice – to ultimately ensure that families receive the news in the best way possible.



Dr. Deirdre Sweetman, Valerie Kinsella, Clinical Midwife Manager (National Maternity Hospital) and parents Nadine Campion and Katherine O'Leary at training session in NMH

As part of the roll-out strategy, training took place for 75 staff members at the National Maternity Hospital on 28 March 2017, with a wide range of staff disciplines attending. The training was well received, with a number of consultant doctors tweeting their support for the implementation of the Guidelines in the following days. Follow up with the National Maternity Hospital will continue as plans are made to introduce the e-learning module and disseminate the Guidelines and resources hospital-wide.

Rotunda Conference

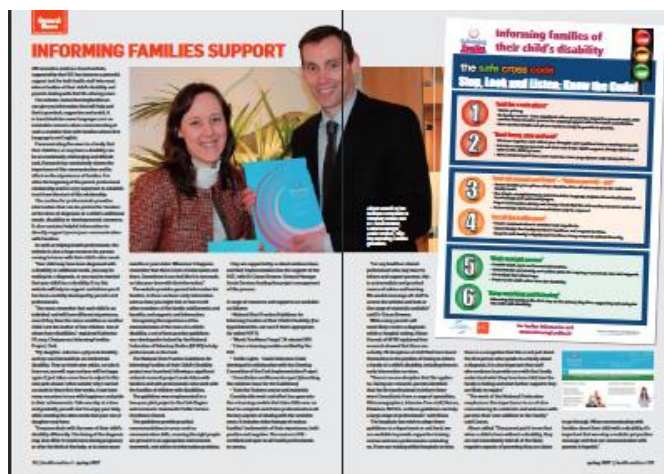
Staff at the Rotunda Hospital in Dublin invited the Informing Families project to make a presentation at their Perinatal Palliative Care conference, which took place on the 15th February. Ms. Niamh McGauley, National Federation, made the presentation at this event, which brought together a wide range of professionals involved in maternity care from across the country.

HSE Communications

The Informing Families Project featured in the HSE's Health Matters Spring 2017 edition, and a broadcast email to all 100,000 HSE staff was sent by HSE Communications, advising on the resources available to support good practice when communicating the news of a child's disability to the family.

Progressing Disability Services

Liaison is taking place with the HSE's *Progressing Disability Services for Children and Young People* programme, in order to explore the pathways for implementation of the best practice guidelines within Early Services. For further information on the roll-out programme contact alison.harnett@fedvol.ie.



Informing Families Guidelines feature in the current edition of the HSE's 'Health Matters' magazine (Pg. 52-53)

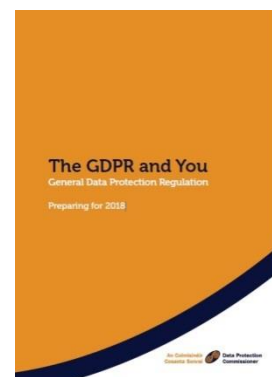
Data Protection

The **General Data Protection Regulation (GDPR)** will come into force on the 25th May, 2018, replacing the existing data protection framework under the EU Data Protection Directive. As a regulation, it will not require transposition into Irish law, so we as organisations involved in data processing need to be aware that these regulations apply directly to us in terms of the obligations they impose. The GDPR emphasises transparency, security and accountability by data controllers and processors, while at the same time standardising and strengthening the right of European citizens to data privacy.

It will affect how we do business and we all need to be aware of the consequences of any breaches as the penalties are quite substantial. As organisations who hold substantial amounts of data on individuals and groups we will be monitored and audited by the Data Commissioner's Office and we need to be prepared to meet the standards set out in the GDPR.

The National Federation held an Information Session on 5th April, 2017 which highlighted the main aspects of the GDPR and what organisations should be doing to prepare for this regulation. If you would like a copy of the presentation, please email caroline.looney@fedvol.ie. The Data Protection Commissioner has produced a useful Guide entitled: ***The GDPR and You, General Data Protection Regulation - Preparing for 2018*** – contact caroline.looney@fedvol.ie to access a copy.

Further information will be available on the following link: www.dataprotection.ie.



Charities Regulator announces a Consultative Panel on the Governance of Charitable Organisations

The Charities Regulator has established a Statutory Consultative Panel on the Governance of Charitable Organisations. The Panel will consider how the administration and management of charities can be improved and make recommendations to the Regulator on the development and implementation of governance guidelines, codes of conduct or regulations.

The panel will also consider options and make recommendations to the Charities Regulator on how best to promote compliance by charity trustees with their duty to control and manage charities.

John Farrelly CEO of the Charities Regulator said: "*Charities provide essential support and services to the most vulnerable in our society. It is precisely because of the work charities do, that it is so essential to the overall good of our society, as well as to the specific individuals they assist, that every charity is managed properly*".

The first meeting of the panel took place on the 30th March 2017. The work of the panel will include a public consultation process and will complete by the end of 2017. Following this, a final report will be prepared for consideration by the Charities Regulators' Board, before being published.

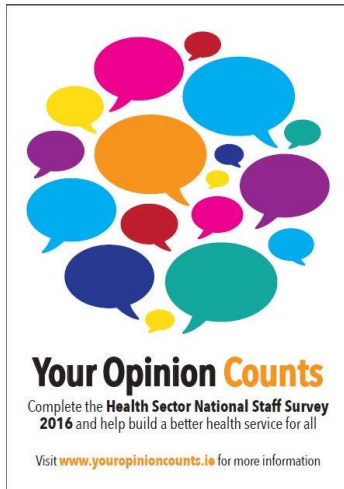
Panel Members	
Chairperson	Senan Turnbull Charities Regulator Board Member
CRA Board Member	Patricia Cronin Charities Regulator Board Member
CEO CRA	John Farrelly CEO Charities Regulator
Charity CEO	Stephanie Manahan CEO Central Remedial Clinic
The Wheel Nominee	Ivan Cooper Director of Public Policy
Charities Institute Ireland Nominee	Lucy Masterson CEO Charities Institute Ireland
Academic Nominee	Dr Oonagh Breen Senior Lecturer in Law, UCD
Governance Expert	Professor Niamh Brennan Quinn School of Business, UCD
Finance Expert	Teresa McColgan PwC, Tax Partner
Corporate Governance Association of Ireland Nominee	James Kavanagh Chairman CGAI
Department of Justice & Equality Nominee	John Laffan PO Civil Governance Unit
Charities Commission of Northern Ireland Nominee	Claire O'Hare Policy Development Manager

For more information contact: press@charitiesregulator.ie

Human Resources Matters

Operational Human Resources Group:

The Operational HR Group meets on a quarterly basis and meetings are open to human resources personnel from across National Federation member organisations. The Group is chaired by Ms. Olive Leonard, Director of Human Resources, Muiriosa Foundation. The next meeting of the group is scheduled to take place on April 27th 2017. For further information please contact Jillian Sexton at jillian.sexton@fedvol.ie



Health Sector National Staff Survey 2016: 'Your Opinion Counts', HSE:

The 2016 Health Sector Staff Engagement Survey closed with an overall response rate of 15% - a total of 19,288 respondents from across the HSE, Voluntary Hospitals and HSE Funded Agencies taking part. Staff members from a number of National Federation member organisations took part in the survey and customised reports have now been made available to these services.

The final report outlining the overall results for the Health Services is now available: <https://www.hse.ie/eng/staff/.../Main-Findings-Your-Opinion-Counts-2016.pptx>.

European Working Time Directive (EWTD): Workshop Event

In early 2017 a number of regional briefing sessions were held by the HSE in relation to the requirements of the EWTD. National Federation members are now being requested by the HSE to complete monthly templates in order to track compliance rates with the requirements of the Directive.

It has been decided to hold a **FINAL** training workshop on EWTD Compliance in Disability Residential Services, on the completion of the monthly template/return, and this workshop will take place on:

Date: Wednesday April 19th.
Time: 2.00pm
Venue: The Board Room, Dr. Steevens Hospital, Dublin 8

The workshops are targeted at HR personnel and in particular persons responsible for completing and/or 'signing off' on the template for return for their CHO Area/Organisation.

Bookings: Please email EWTD.Socialcare@hse.ie to book a place at the event.

European Commission:

The Department of Health and the HSE are due to meet with the European Commission at the end of April to provide an update on progress being made in relation to EWTD compliance. A meeting of the National Social Care EWTD Implementation Group took place on March 22nd last to discuss the issues arising for agencies in relation to the EWTD and progress in relation to this.

Recruitment Fair / Social Media Training

A number of Federation members took part in the recent Health Sector Jobs Fair which was held in the RDS on Saturday, March 25th 2017. The Jobs Fair was targeted at healthcare professionals across all disciplines and specialities and provided an excellent opportunity for job seekers to meet with Service Providers and discuss a possible career in the intellectual disability sector. A number of Federation members exhibited at the Fair and feedback on the day was very positive. The National Federation operated an information desk and provided details and advice to many job-seekers on career opportunities within the voluntary intellectual disability sector.



Clockwise Left to Right: Stands from Sunbeam House Services, National Federation, Brothers of Charity Services and Stewart's Care at the Health Sector Jobs Fair

Through the work of the Operational Human Resources Sub-Committee we are arranging a 'Using social media to Recruit Staff' Training Event – details will be circulated to member organisations once finalised.

National Federation of Voluntary Bodies Pension & Life Assurance Scheme - Retirement Planning Seminar

The National Federation of Voluntary Bodies, in conjunction with New Ireland Assurance, is inviting members of the National Federation Pension scheme to attend a one day Retirement Planning Seminar on either:



Date: Monday, 12 June, 2017
Time: 10am – 4.15pm
Venue: Portlaoise Heritage Hotel

Or

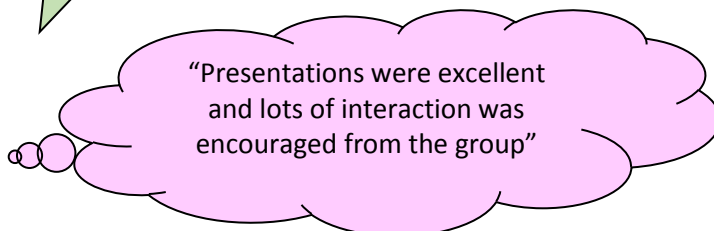
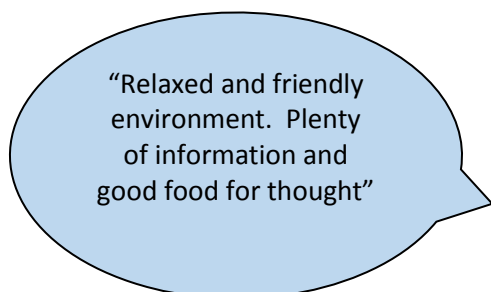
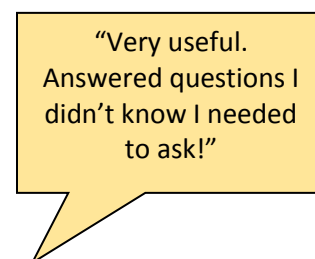
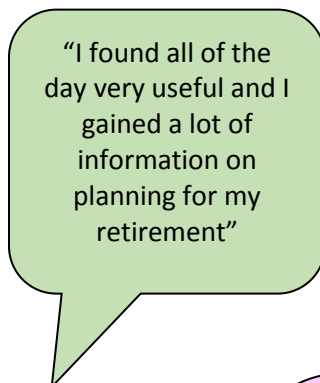
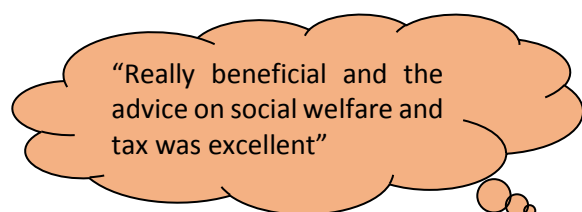
Date: Tuesday, 26th September, 2017
Time: 10am – 4.15pm
Venue: Ashling Hotel Dublin

The Retirement Seminar will be beneficial to members in respect of knowing more about:

- Up to date information on your Social Welfare / Taxation / Pension options;
- Developing a healthy lifestyle in retirement;
- Getting some guidance on changing relationships in retirement and planning a new routine and using new found time with purpose.

Outlined hereunder is some feedback from members who previously attended our Retirement Seminars.

Feedback from previous seminar attendees:



The cost to attend these Retirement Seminars is approx. €295 per person, however, in association with New Ireland Assurance, the National Federation Pension Trustees have waived the fee for members of the National Federation of Voluntary Bodies Pension Scheme. An invitation is also extended to member's spouse / partner to attend free of charge (optional, but strongly encouraged).



It should be noted that we have reduced the number of seminars taking place this year and numbers invited to attend the Retirement Seminars are limited to facilitate one to one discussions and also to ensure participant's maximum value of time and information at these events. Places will be allocated on **a first come, first served basis**. In this regard, if you are due to retire within the next five years or are availing of early retirement, and you are interested in attending one of the above seminars, please contact your organisation's Pension Administrator, who will provide you with further details and reserve a place for you.

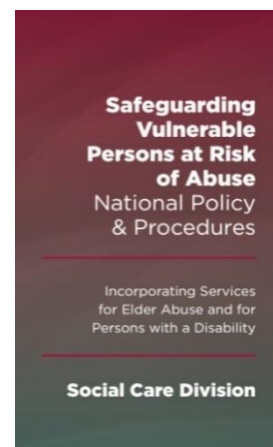
Quality & Standards Matters

Safeguarding Policy - Review:

The review of the National Safeguarding Policy is now underway and a Review Development Group (RDG) has been established to oversee the process. The RDG is chaired by Ms. Martina Quealy, Chief Officer, CHO Area 6, HSE and the National Federation has been invited to nominate 2 representatives onto the Group and the following have been nominated:

- Mr. John Ryan, Principal Social Worker, KARE
- Ms. Ciara Murphy, PIC, Daughters of Charity Disability Supports Services Ltd

The National Federation will be making a submission to the Policy Review – for further information contact jillian.sexton@fedvol.ie



Compliance Checklist

In early 2016 Federation members were requested to undertake a self-audit on their implementation of the Safeguarding Vulnerable Persons at Risk of Abuse, National Policies and Procedures – organisations have now been requested to complete a follow-up audit in Quarter 1 2017. The purpose is to measure progress from last year and assist agencies in addressing any outstanding implementation challenges. Completed templates to be returned to Mary Barrett, National Federation Secretariat:

mary.barrett@fedvol.ie

Quality & Standards Sub-Committee – Links with HSE Social Care Quality & Standards

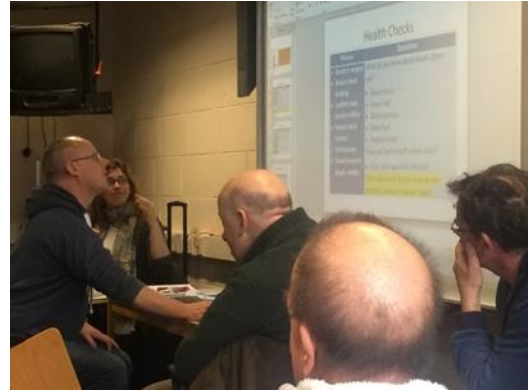
Mr. Gerry Clerkin, Head of Quality & Safety - Social Care Division, HSE, has attended recent meetings of the National Federation's Quality & Standards Sub-Committee with the aim of sharing information between the Social Care Division and HSE Funded Agencies in relation to quality, safety and compliance issues. Mr. Clerkin made a presentation at the most recent Sub-Committee meeting which provided an overview of the work of the quality and safety section of the Social Care Division and sought to identify areas for collaboration.

The Quality & Standards Sub-Committee is chaired by Ms. Anna Shakespeare, CEO, St. Michael's House.

Inclusive Research Network Update

The Inclusive Research Network (IRN) is in the early stages of a new project on Health. The Research method we have chosen for this project is focus groups and also using photos to explain the question. This was decided by a ballot of the members.

At our last meeting in Trinity Collage Dublin on March 14th we chose photos on the topic of health for the project. We also talked about general questions that we could ask in a focus group. We agreed to invite student doctors to one special focus group and discussed the questions we would ask them. We feel this will help doctors give a better service to people with disabilities.



Inclusive Research Network members at Trinity College Dublin

The IRN has also updated its consent form to include consent by members to have their photos and videos used. This consent will apply until 2019 and members are free to withdraw their consent any time.

We are inviting Artist Mick O'Dea to our next meeting in University of Limerick. He will make sketches of us as we work.

Brian Donohoe presented the findings of our previous project *Our Homes* to the Next Steps Group with Áine McDermott and also with our Chair Nancy Leddin and Carol Ann O'Toole at the National advocacy Conference in Ennis. Nancy and Carol-Ann will present at another workshop being held at Trinity College Dublin.

Written By Brian Donohoe
Secretary of IRN



Member's News

Brothers of Charity Services

The Rising 2016 National Advocacy Council Conference

The Clare Advocacy Platform hosted the Brothers of Charity Services Ireland 18th national self advocacy conference with a two day event entitled “The Rising Tide of Ambition of People with Extra Support Needs: Love, Freedom and Equality.” Chiming with the state’s centenary celebrations, regions took the opportunity to research and connect with: the history of disability services, (Limerick) the sea change in capacity laws, (Cork) relationship rights, (Galway) freedoms of people with disability then and now (Roscommon) and the proclamation of equality as people see it now (South East Services)

Links forged by Clare advocates as founding members of the Inclusive Research Network led to an exchange with Die Menschen Zuerst (Austrian People First). Our gathering coincided with their national congress and we exchanged filmed greetings. Our themes matched their own campaigns for equal status before the law in relationships, property ownership, will making and medical procedures.



**Marriage guidance from experts by experience, Brendan and Orla O'Reilly –
All you need is love!**

The ambition of advocates campaigning for law change was praised by Minister Katherine Zappone in the conference opening address. Her presentation, pre-recorded due to a clash with the Budget, acknowledged “the role played by self advocates... putting pressure on successive Governments to finally bring... rights home.”

The voice of people with disability dominated the conference, from the launch of “VoiceBox” – FedVol’s *video diary confessional* featuring advocates’ views about HIQA; to inspiring speakers in other mainstream-styled scenarios; an *Afternoon Show* discussion on the joys and pitfalls of married life with experts by experience from Dublin and Cork, Mary I College students from Brothers of Charity Clare Services, Aine Carey and Kate Crotty on ambitions fulfilled in the company of 3rd level students at Limerick’s Mary I; university accredited studies presented by chairs of the Independent Self Advocacy Platform and the Inclusive Research Network; hilarious *Republic of Telly-esque* mock disclosures of people in open public love trysts; wheelchair mountain climbers; cutting edge eye gaze directed technology... this conference had innovation and inspiration in spade-loads. As Barry Lynch from Inclusion Ireland put it “the program had several potentially life changing presentations”.



Cat Mouse Bird art work on display inspired by the "The Rising" theme

Quality innovative work was displayed on day two's Mini-Arts Fest. Speckled Egg Dance Co. from NUIG's showcased dance advocacy with a workshop and solo performances. The Irish Times award winning comic film *Silent Moves* screened alongside Clare's internationally renowned "autist aka artist" Larry O'Brien followed by country-wide responses to Clare's *three minute short film challenge*, from around BOC Ireland. Under the banner of "Advocacy Without Words" self advocates and supporters worked with their communication challenged peers giving practical examples of actions that spoke

louder than words.

The national conference maintained and developed the Brothers of Charity Services Annual Self-Advocacy Conferences' reputation for capturing up-to-the-minute developments in the field and as our eyes turn to Galway's offering in October 2017 we reflect on Minister Zappone's wish that our conference be "an uplifting and memorable event" and conclude that her ambitious desire was a hope fulfilled.

Clare Conference Organising Committee.

Walk

In September 2016, the WALK Quality Department set about devising a recruitment training program to support people who use our services to be fully involved in the recruitment process for every position in WALK. Historically we had only involved people in recruiting for individualised staffing which was bespoke to their requirements.

This resulted in a program which covers the entire recruitment life cycle. This was delivered over five weeks to a group of six people who use our services. On March 24th, the panel sat to interview people for residential relief posts.

This project is another step in our mission to support people to live self determined lives. We have committed to ensuring that people who use our services have a real voice in the organisation.

Pictured below are the panel with staff members Deirdre Hannon and Dani Brown who were program mentors.



KARE



Rights in our hands – Exploring Human Rights through art

Through funding from the Community Foundation for Ireland; a group of over 60's from the KARE services are taking part in a pilot of a creative advocacy project for older people.

The aim of the project is to explore the UN Declaration of Human Rights and to help people to identify with those rights as being inherently theirs.

Working with Mary Pat Moloney, of the Creative centre, Croi Anu in Moone; the group of 6 service users use artistic means to explore themes such as Safety, Dignity, Shelter, Having a Voice, Participation and Relationships.

The complicated language and length of the declaration can be a huge barrier to not only, but particularly people with an intellectual disability.

Working creatively on the themes of the declaration with the group has given people a voice; a way to express themselves and learn the language of rights. It has been a very powerful experience for all involved.

At the end of the work with the group, a tutor pack will be developed as a resource to share with others.



SOS Kilkenny

Dream comes true for Dreamtime

Dreamtime Studio's short film 'Tom & Alice' was entered into the Ablevision International Film Festival this year and was shortlisted, the awards ceremony was held in Drogheda in November. The film was overall winner and first prize was presented to us by Irish film-maker Darren Thorton. There were 7 films shortlisted, four from Ireland, two from England and one from South Africa, so we were very proud to keep the award in Ireland!!

David Bryan and Ciara Cahill (photo below) played the main roles in the film and attended the ceremony. We are all delighted with the film's success and would like to thank and congratulate everybody who was involved. It is the second time our studio has won the competition and we hope to build on its success and bring our work to a wider audience. Check out our youtube channel, which is close to 10,000 views, and the short film 'Tom & Alice' - www.youtube.com/dreamtimestudios



Ciara Cahill and David Bryan



Some of the Cast from the film

Back row L-R Ruth O'Connor, Alma Breen, MJ Scallon, Conor Walsh, Merrie Bergin, Deirdre O'Neill

Front row L-R Angela Holohan, Ciara Cahill, David Bryan, Billy Shaughnessy

Ability West works in partnership with Lumos on deinstitutionalisation in Bulgaria Project

In November 2016 Ability West were approached by UNESCO researcher Tanja Kovacic (NUIG & Slovenia) to request support for a charity called Lumos (<https://wearelumos.org>). Lumos was founded by Harry Potter's author, J.K. Rowling, to advance the deinstitutionalisation of children in residential institutions globally. This particular request focussed on sharing knowledge and learning generated by organisations funded under the Atlantic Philanthropies' Children and Youth Programme with countries that are in the process of transforming their systems of care and support for vulnerable children. Specifically, Lumos were seeking advice, training and support with regard to behaviours that challenge in Bulgarian services.

Following meetings and conference calls between Breda Crehan-Roche, Chief Executive, Ability West, UNESCO, Lumos and myself it was agreed and arranged that I would travel to Bulgaria in March 2017 to visit services, meet with various representatives to discuss strategy and deliver training with regards to behaviours that challenge:

- Saturday 18th March – arrived in Sofia at 9 pm after 3 hour flight
- Sunday – met with Bisser Spirov (Lumos Bulgarian Country Manager)
- Monday – met with Bisser, Emi (Interpreter); Vera (Training Manager) and was taken to visit:
 - Small Group Home (14 beds with 11 filled). 2 staff on shift. Resident's age ranging from 8-24 years of age with mixed gender.
 - Centre for Social Rehabilitation & Integration – supports children with behavioural difficulties that do not have ID or ASD
 - Day Care Centre – similar to a child development centre for children with ID and ASD
- That evening we met representatives from Moldova, Czech Republic, Georgia and Bulgaria for discussion and sharing of information
- Tuesday – Friday - delivered 2 x 2 day training events on all aspects of ID and ASD, communication strategies, models of care, behaviour management and behaviour support
- Flew back on Saturday night/Sunday morning arriving in Galway at 3 a.m.

To give a sense of the issues – below are extracts from a review of the impact of the deinstitutionalisation process in Bulgaria conducted in 2015 by Lumos focussing on 1,292 children:

- The number of children in institutions has decreased by 78% since 2009 (24 institutions were closed)
- Adult institutions are still open

- Baby institutions are still open
- There is a significant over-reliance on medication and a strong medical model. In fact prescription of medication has significantly **increased** since deinstitutionalisation inviting the phrase “re-institutionalisation”
- Mortality rate in “baby institutions” is 100 times higher than for children without disabilities
- 150 children have died in the period 2010 – 2015
- Children and Young people in the cohort of 1,292 ranged in age from 4 – 49 years old (partly based on the perception that all people with ID are essentially children/child-like)
- With the exception of 12 children no alternative communication systems were in use
- Behaviours that challenge is one of the main reasons why staff leave employment
- Institutional culture of regimented meal times is being re-introduced to Small Group Homes with as little as 1 minute 20 seconds afforded to a child’s mealtime
- Some parents that were facilitated to re-engage with their child never even knew they were still alive

I was extremely well looked after by the Bulgarian Lumos team Bisser, Adriana, Vera and Daniella as well as my interpreter Emi who worked much harder than any of us that week. In return I worked extremely hard to share as much information as I possibly could in the short time that I was there. I met so many people that are driven and highly motivated to do things right and are sponges for new information and strategies. I also learned that despite cultural and geographical issues, the “causes” of behaviours that challenge seem to be pretty much universal. I learned and discovered much more than that and will happily talk with any of you that would like more information.

Brian Mc Donald,
Positive Behaviour Support Manager.



Delivering training with Emi (interpreter)



Attendees at training from Bulgaria, Georgia, Czech Republic and Moldova

Events

STRATEGIC ALLIANCES AND COLLABORATIVE PARTNERSHIPS

Date: Thursday, 11th May, 2017

Venue: Heritage Hotel Portlaoise

Over recent years there has been little by way of investment and significant reductions in core funding. This has coincided with a substantial increase in demands of organisations in terms of essential services and changing needs. The challenge for organisations over this time is to “do more with less” and one way in which voluntary organisations are meeting this challenge is to engage in a strategic alliance or collaborate partnership with other like-minded organisations.



Collaborative working within our sector can have wide ranging benefits, from reducing costs, to sharing resources and increasing the range and scope, and accessibility, of services to the people with intellectual disability who we support.

The National Federation of Voluntary Bodies is organising a one day seminar on 11th May, 2017 in the Heritage Hotel Portlaoise to explore the benefits of strategic alliances and collaborative partnerships, whilst considering the potential challenges and providing insights into how those challenges might be overcome.

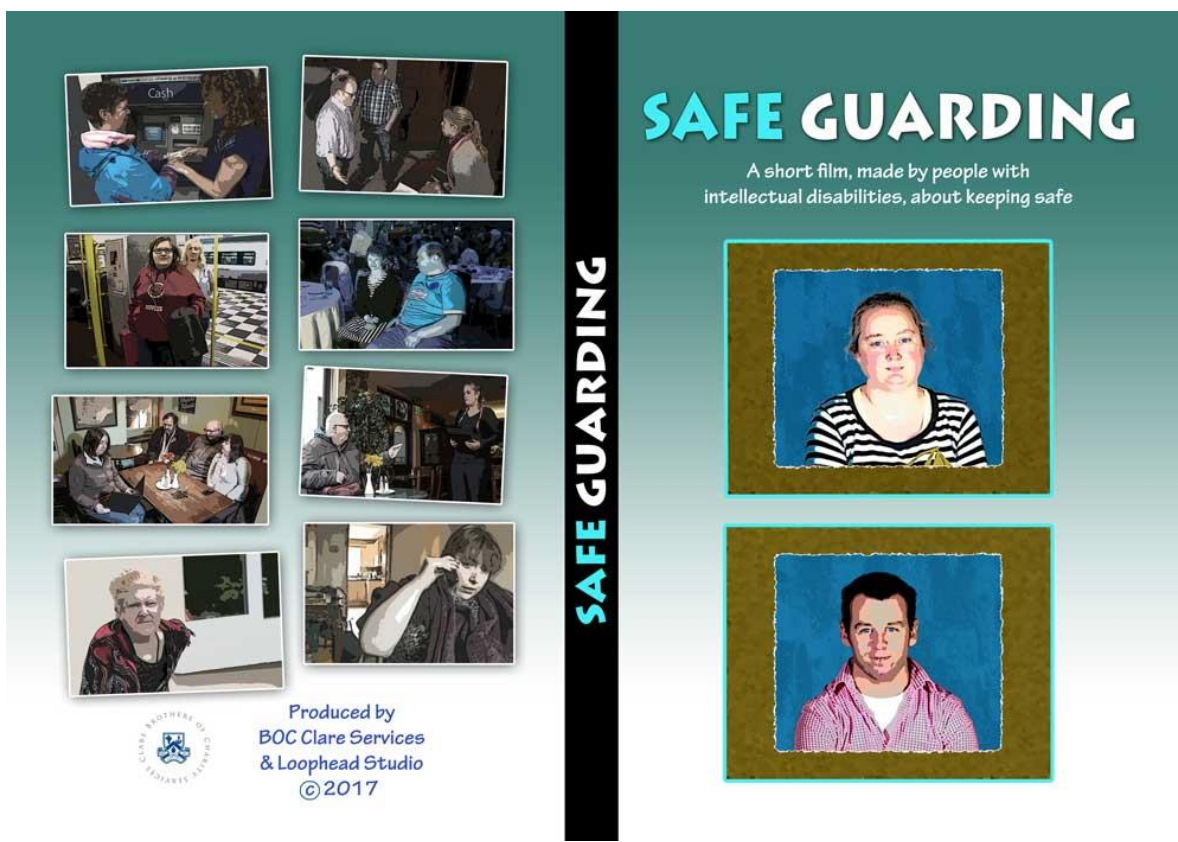


We have put together a comprehensive seminar programme with a range of excellent speakers, both from within and outside the sector (visit our website www.fedvol.ie for further programme details). The seminar will be of interest to CEOs, Senior Management Teams, Chairmen and Board Members of all member organisations. Delegate fee is €30 per person, to include tea/coffee breaks and lunch.

Bookings are now open and can be reserved using the following online link:

<http://form.fedvol.ie/seminar-on-collaborations>

Clare Advocacy Platform's Safeguarding film Launch
with the Clare Arts Office Embrace Exhibition
by National Confidential Recipient Leigh Gath
Glor Theatre Ennis - Tuesday May 9th 2-3 p.m.



With animated dramas drawn from true to life situations Clare Advocate Platform present their highly effective film...

SAFE GUARDING - Abuse and how to deal with it

Advocate actors and key role supporters at Brothers of Charity Clare worked with animation artists at Loophead Studios to create a thought provoking creative tool for training and awareness raising with support staff, advocates, family members, the broader community and professionals in the field.

Copies of the video will be available at €20

Deadline 21st April

DOCTRID V CONFERENCE

Fostering collaborations and innovations to make a real difference in the lives of those with ID and Autism

UNIVERSITY OF LIMERICK

Final call for Registration

Visit www.doctrid.ie/conference to register

Who should be there?

Researchers (social, technological, behavioural and life sciences), Health care professionals, People with Intellectual Disability or Autism, their families and carers.

What will you learn?

The DOCTRID V conference will include presentations from international experts, panel discussions and workshops aimed at fostering collaborations and innovations to make a real difference in the lives of those with ID and Autism.



University of Limerick, Ireland.

Key themes to be discussed:

- Social Inclusion
- Lifestyle and Connected Health
- Assistive Technologies

ASSISTID Fellows will provide insight into the progress and findings of their projects.

Where:

University of Limerick, Limerick, Ireland.

When:

27th & 28th April, 2017

We look forward to seeing you in Limerick!

Progressing Disability Services for Children and Young People – National Conference



The first Progressing Disability Services for Children and Young People National Conference ‘Working together to Support Children and Families’ will be held in Autumn 2017 hosted by the Department of Health. The primary theme of the Conference is PARTNERSHIP and invitations to attend will be extended to service users and their families, staff in children’s disability services and in other services and sectors, such as Education, who support children with disabilities.

This Conference will be a landmark event for the Progressing Disability Services for Children and Young People programme, celebrating achievements to date, the development of Children’s Disability Network Teams and the progress towards equity of access to services for all children with disabilities and their families, whilst acknowledging there is work still to do. It will be an opportunity for all to showcase good practice in working together and to explore innovative ideas.

Submissions are invited in particular on the following topics:

- AIM: partnership working with parent/Early Years Specialist/Health staff
- Disability, CAMHS and Primary Care Joint Working Protocols in practice
- Parent-led or young person-led initiative (supported by Health) encouraging networking, empowerment, resilience
- Health Services/County Council Inclusion Officer partnership model
- Effective practice in screening for ASD in a Children’s Disability Network Team
- Planning together to support children at transition stages in Education

Submissions can also be made on other topics under the following Conference subthemes:

- Partnership between families and services
- Collaborative working between services/sectors
- Team working
- Promoting inclusion in the community
- Innovative practice in Children’s Disability Network Teams

Please contact pdsconference@hse.ie to get a submission form and return to: pdsconference@hse.ie by close of business Thursday May 4th.

The latest bulletin from the Progressing Disability Services for Children & Young People is available at: <http://www.informingfamilies.ie/news/update-on-the-progressing-children-and-young-peoples-disability-services-process-.547.html>

Right Relationship Conference - 27 April 2017



From Brisbane, Australia, Jeremy and Margaret Ward are parents whose eldest daughter, Mena, lived with disability and required support to live in her own home, which she did successfully for over 10 years.

Jeremy's older sister also lived with a significant disability all her life. He has many years' experience in disability advocacy, in the law as it relates to people with disabilities, and in assisting families to plan for the future. He continues his interest in the areas of future planning, leadership development and advocacy. Jeremy recently published *The Shouted Goodbye*, his memoir of reflections on his life with his daughter Mena.

When Margaret became Mena's mother, she found herself being an advocate, writing policy and establishing services that respected families; all in an effort to make a better life for Mena and other people with disability. Margaret is particularly interested in inclusive design in housing and communities. Mena showed her first-hand how important it is for everyone to have a safe, affordable and welcoming home and a loving family. Margaret also learnt first-hand the importance of working in "right relationship" with paid staff to help Mena build a good life.

This workshop explores how to create a partnership between families and services that really works. It includes:

- Identifying what makes a good life;
- The importance of a vision and plan;
- Understanding what is family business, what is service business and what can be shared;
- How to make the most out of what you have, and then some; and
- What families can do now for a future when they are no longer around.

Venue-Mullingar Park Hotel, Price-€30.00

Tea/Coffee and sandwiches included in ticket price. Parking provided free of charge at hotel. Full refund given up to 25/04/17. Small number of tickets based on donation available for people with a disability and family members who are not working. Suggested donation €15 to cover lunch/tea/coffee.

To book, click on the following link: <https://www.eventbrite.ie/e/right-relationship-tickets-32915701750>

Advance Notice – Unlocking the EU Investment Plan for Social Services

A one day information event will be held by the European Association of Service Providers for Persons with Disabilities (EASPD) at the Ashling Hotel, Dublin on 19 June 2017. Further details to follow.

NUI Galway's 9th International Disability Law Summer School

Opens for Registration

Ireland, 19-23 June 2017



The 9th International Disability Law Summer School, hosted by NUI Galway's Centre for Disability Law and Policy, will take place from the 19-23 June 2017 in Galway Ireland. Registration is now open for the biggest disability law Summer School in the world, with a focus on the UN Convention on the Rights of Persons with Disabilities. This year's Summer School Convenors are Dr Charles O'Mahony and Professor Gábor Gombos.

The theme for the 2017 Summer School is on psychosocial disability. It will focus on facilitating access to justice, recognition of legal capacity, the right to liberty and community living. The aim of the 5 day Summer School is to equip participants with the insights and skills necessary to help them translate the generalities of the UN Convention into tangible reform for persons with disabilities.

Over 100 delegates from at least 30 countries are expected to attend this year's Summer School. The keynote address will be delivered by Catalina Devandas, UN Special Rapporteur on the Rights of Persons with Disabilities. Co-Director of the Summer School, Dr Charles O'Mahony, Lecturer School of Law, NUI Galway, said, *"We look forward, as usual, to a world-class Faculty and participants from around the globe including persons with disabilities, civil society groups, advocates for disability law reform, academics, lawyers, policy makers and policy analysts."*

Panels will include:

- An Introduction to the UN Convention on the Rights of Persons with Disabilities (CRPD)
- Legal Capacity & Supported Decision-Making
- The Right to Community Living
- Service Users Perspectives on the CRPD
- Mental Health Laws & Psychosocial Disability
- Mad Studies
- Regional Protection of Human Rights & Tensions with the CRPD
- Children, Psychosocial Disability & Human Rights
- Intersectionality & Psychosocial Disability
- Criminal Justice & Psychosocial Disability

The Open Society Foundations (OSF) and NUI Galway support the Summer School.

Registration is now open and will cost €360. Further information is available at www.nuigalway.ie/cdlp or by contacting Sharon at disabilitysummerscho@nuigalway.ie. No prior legal training or knowledge is necessary to participate in the Summer School. Participant accessibility (physical or communicational) requests and enquiries are welcomed. A full programme will be published shortly.

Training News

Open Training College celebrating 25 years delivering education

Celebrating 25 years of delivering education and training solutions to the health sector, the Open Training College is currently enrolling students for the [BA in Professional Social Care \(Disability\)](#). This 3-year, QQI validated, Level 7 degree is aimed at unqualified Social Care Workers; Care Assistants (Health and Social Care); SNAs and people interested in a career within disability services.

This course will help to prepare Social Care Workers for their application to register with CORU when the register opens and provide participants with the skills to work effectively within the rapidly evolving disability services sector so that students can deliver better person centred services to the people they support. This is a qualification listed in Schedule 3 of the [Health and Social Care Professionals Act 2005](#) for existing practitioners under Section 91.

There are extensive benefits in undertaking this [Professional Social Care degree](#):

- it is specific to the disability sector, and successful completion will allow graduates to apply to register as a professional Social Care Worker with [CORU](#)
- students will be supported throughout the course by a designated tutor with extensive front line experience
- students can easily balance work, family and study commitments
- our active learning community (students, tutors and learning support staff) is always there to support students as they learn
- it is an applied programme dealing with real world challenges, where the assignments tackle issues that students are likely to face in the workplace
- it reflects the current regulatory and public policy environment (incl. HIQA, New Directions), the challenges driving the sector, and best practices



What is it like to study at the Open Training College?

The College uses a blended approach where each module combines online learning, tutorials (telephone, online, virtual) and face to face workshops.

Learning materials are designed to accommodate the pressures that come with trying to balance work, life and learning. To support all online aspects of the course, the College has a dedicated elearning team to support you throughout your studies.

The Student View:

'It's an applied and practical degree programme so students get to earn a recognised QQI qualification at Level 7. The presentation and quality of information presented at workshops is excellent and motivates students to question how they currently support services users and to strive to continuously to improve the service they provide.'

Roisin O'Neill, Person in Charge, St. Michael's House

The College is now receiving applications for this course and has scheduled informal interviews for all applicants on May 26th, 2017 in Goatstown, Dublin 14. Further applications will be received in June for informal interviews in early July.

For more information please contact Conor on 01-2990580 or email cmurray@opentrainingcollege.com, or feel free to read more information at opentrainingcollege.com

Please contact Conor Murray on 01-2990580 or cmurray@opentrainingcollege.com for more information about any of the courses and the application process.



CELEBRATING 25 YEARS DELIVERING EDUCATION & TRAINING TO THE DISABILITY SECTOR

CELEBRATORY DRAW

25% OFF

ANNUAL TUITION FEES

**OPEN TO EARLY APPLICANTS (JUNE 30TH) OF THE
BA IN PROFESSIONAL SOCIAL CARE (DISABILITY)**

TALK TO CONOR FOR MORE DETAILS 01-2990580

25 YEARS LEADING EXCELLENT PRACTICE IN SOCIAL CARE



Person In Charge Training
Health Care Informed (HCI) is hosting a one day Training Course
For Persons In Charge

Tuesday 25th April 2017
Clayton Hotel Leopardstown, Dublin 18
Cost: €295 Per attendee Ex VAT

The course will provide attendees with an overview of the roles and responsibilities of the person in charge.

The training day will cover the following topics:

- *Legislation, Standards and Guidance*
- *Roles and Responsibilities*
- *Governance - structure and process*
- *Risk Management*
- *Performance Indicators*
- *Statement of Purpose*
- *Notifiable Events & External Reporting*
- *Registration Process*
- *Inspection Process*

Full Agenda [Here](#)

Pending CPD Certification

Book now to secure your place! Places are limited.

Email mairead.campbell@healthcareinformed.com or tel. 093 36126

"The content was extremely relevant and was well presented. I feel much clearer about what steps I now need to take."

- Person In Charge Training

Who are Health Care Informed?

Health Care Informed (HCI) is a professional services provider of patient safety, regulatory compliance, and quality improvement intelligence and support to health and social care organisations. HCI have been based in Ireland since 2005, working with Aged Care, Disability Services, Acute Care, Medical Imaging and Medical Transport organisations to develop and improve their quality systems.

Email info@healthcareinformed.com www.healthcareinformed.com

“How CPI Training Can Help Service Providers Comply With The Assisted Decision-Making (Capacity) Act 2015”



CPI want to work with you to help you with your service's compliance with the Assisted Decision-Making (Capacity) Act 2015. Their *CH-3SM Holding Skills for Essential Care and Treatment* programmes provides a framework that allows for clinical decisions to be reached and implemented both within the context of the Act and wider *duty of care* and *best interest* responsibilities. Section 8 of the Act outlines circumstances under which an intervention may be provided when action is taken as a result of necessity to prevent serious harm provided the course of action is 1) reasonable in the circumstances and 2) in the best interests and represents less harm than would have occurred had no action been taken. Acts of necessity "*may become a balance between continuing treatment, which is forcibly opposed by the patient and deciding not to continue with it – a clinical decision*". **The CH-3SM programme guides clinical staff through a risk assessment process that aids in the decision to continue with an intervention or not and then provides staff with the skills to implement the intervention.**

Different levels of consent

The Act stipulates that consent should be sought where possible, either directly with the service user or through an appointed assistant and/or representative. The principle of gaining informed consent is a fundamental part of clinical practice that ensures practitioners act in a manner considered lawful.

Depending upon the type of clinical care and treatment, different levels of consent will be required:

1. *Informal consent where a service user co-operates fully with instructions based on an explanation of the procedure and the need to conduct it (e.g. routine examinations and minor treatment).*
2. *Formal consent where a service user needs to provide written consent (signature) agreeing to the treatment (e.g. major or irreversible treatment, sedation or general anaesthesia).*

With regard to clinical holding the same issues around consent apply. Where service users are going to be held and the team have planned this, consent should be sought. If clinical holding is used as an emergency response to an unforeseen incident during treatment, this should be documented in the clinical notes and then consent sought for any future treatments.

Defining capacity and consent

In a legal context the term 'capacity' is used to refer to a person's ability to make a decision with legal consequences and, as such, in clinical practice the pivotal importance of decision making relates to its place as an essential ingredient for valid consent. The three ingredients to valid consent are:

1. *Consent is given voluntarily – full, free and unfettered.*
2. *Consent is given by a person with legal capacity to consent.*
3. *Consent is informed or, in other words, the doctor has discharged their duty to provide all information relevant to the decision.*

In principle, a service user should receive treatment only after consenting to it. Consent is rooted in the Irish Constitution's guarantee of bodily integrity. To be legally valid, consent should be made by a competent patient without coercion and upon relevant information about the treatment's side effects and alternatives.

CPI will be running CH-3SM training in Ireland throughout the remainder of 2017. They also have regular MAPA® (Management of Actual or Potential Aggression) programmes lined up. For details about dates and booking information, you can contact them by email enquiries@crisisprevention.com or Phone +44 (0)161 929 9777

Stop Bullying Course

Dublin City University

6 Week Training Programme starting 28th April 2017 aimed at people with intellectual disability with their supporters

The training will start 28th April and finish up mid-June. It will run for 6 weeks. All 6 sessions will start at 11am and finish at 3.30pm.



Start Date: 28th April 2017

Finish Date: Mid-June 2017

Venue: Dublin City
University, Glasnevin, Dublin

Time: 11am - 3.30pm

Booking details

Cost of completing this course is **€150 per learning couple - €75 each**

Booking steps

1. Email Geraldine - geraldine.kiernan@dcu.ie to book places
2. **Give full details** including your name, service and the number of learning couples that you want to book in for course
3. Payment can be made **either by cheque or direct bank transfer**

Please use fiona.weldon@dcu.ie in all correspondence detailing this event and future events. Thank you. **Please feel free to circulate this event.**

Funding Opportunities

HSE National Lottery Grant Open for Applications

The HSE has been allocated National Lottery Funding for distribution to community based groups and voluntary organisations under the Respite Care Grant Scheme and the National Lottery Grant Scheme.



Groups and organisations involved in the provision of Health and Personal Social Services can apply for one-off funding of between €500 and €10,000 for suitable projects.

Deadline for applications: 26 May 2017 @ 5pm

Please note the following will apply in the case of all applications received:

- Applications will be accepted from organisations both within the Community Healthcare (CHO) Area and those who geographically lie outside of CHO but provide services to clients residing in CHO.
- Successful Applicants will be required to complete a Grant Aid Agreement with the HSE and be compliant with minimum Financial and Governance requirements.
- Applications that have major on-going revenue implications which includes the employment of staff, capital funding and running will not be considered
- Applications must be for once off projects that can be completed within the year of application (excluding respite)
- Applications for projects which are already covered by HSE Funding through and SLA/Grant Aid Agreement or otherwise will not be considered
- There will be an upper limit (to be decided based on number of valid applications received) of funding awarded to an individual organisation. Where multiple applications are received by an individual organisation that same upper limit will apply. Therefore it is recommended that an organisation intending to submit multiple applications should consider this upper limit and prioritise on that basis.
- It is envisaged that generally individual grant allocations will be in the range of €500.00 - €10,000.00 approximately.
- An upper limit of €10,000 for applications relating to Transport Initiatives will apply

You can download an application form and find your local application contact at the following link:
<http://www.hse.ie/eng/services/list/1/schemes/National-Lottery-Grants-2017/>