FEATURE: ADVOCACY

07 INTELLECTUAL DISABILITY IN IRELAND: Changing Perspectives Fintan K. Sheerin
09 A STRONG VOICE Claire Rodgers
10 ADVOCACY TRAINING IN THE MIDLANDS Mairead Sheedy
11 TWENTY YEARS ON: The Commission on the Status of People with Disabilities and the development of advocacy for people with disabilities Jim Winters

REGULARS

03 Editorial
04 News Update
—New Toolkit on workplace bullying
—Disability Allowances
—Man with Autism to take High Court action
—Magdalenes Report & Intellectual Disability
—Lynch welcomes new disability and mental health initiatives
—Major audit in HSE South
—Inclusion Ireland on National Disability Strategy
—Employment

06 People’s pages
—VISION FOR THE FUTURE Marcia McDonagh

MAIN ARTICLES

13 DECISIONS Senator Mary Moran
14 PARENT ADVOCACY PROGRAMMES Jean Spain
15 TALKING OUT IN THE KINGDOM Liz Lernihan
16 QUESTIONS AND QUANDARIES TO PONDER IN OUR EFFORTS TO ADVOCATE Kathy O’Grady
17 National Advocacy Service Máiríde Woods

25 Snippets:
—RESEARCH ACTIVE PROGRAMME: IDS@UL
—Rhythm Room

26 Men’s Health: MEN GET A RAW DEAL Michael McKeon

27 Memory Lane: BACK TO BALLYMUN Máiríde Woods

28 Forensic Disabilities: DISABILITY PSYCHOTHERAPY IRELAND CONFERENCE Angelina Veiga

18 Sexual Violence: SEXUAL VIOLENCE AGAINST PEOPLE WITH DISABILITIES: DATA COLLECTION AND BARRIERS TO DISCLOSURE Elaine Mears

20 eLearning: eLEARNING FOR INCLUSIVE CUSTOMER SERVICES Siobhán Barron

21 Drama: HEAR OUR VOICE Derek McNamara, Damien McLoughlin and Jane Fitzpatrick

22 Disability awareness: STICKS AND STONES: Disability awareness in schools services Michael Teehan

23 Disabled Organisations: THINKING IN DISABLED ORGANISATIONS Angelina Veiga

24 Wellbeing: WELLBEING Jonathan Egan

29 HIQA: DRAFT NATIONAL STANDARDS FOR RESIDENTIAL CENTRES FOR PEOPLE WITH DISABILITIES Kieran Murphy

31 Book reviews:
—HOW TO BREAK BAD NEWS TO PEOPLE WITH INTELLECTUAL DISABILITIES
—THE ART AND SCIENCE OF MOTIVATION: A THERAPIST’S GUIDE TO WORKING WITH CHILDREN
**FROM THE EDITOR**

_Senator Mary Moran highlights the age-old struggle for parents of trying to get people responsible for services to engage with them in a flexible and approachable way. In 1849, Jean Baptiste Alphonse Karr expressed this struggle well in his much quoted expression ‘the more it changes, the more it stays the same.’_

**Stephen Kealy**

---

**Oral health and intellectual Disability**

_Frontline will, in the next three issues address in a series of articles: Oral hygiene and caring for the teeth of others; The importance of preventive treatment; Overcoming challenges in receiving dental care; Maintaining oral health_

---

**Contributors to this issue:**

Máiríde Woods
Marcia McDonagh
Fintan K. Sheerin
Jim Winters
Jean Spain
Liz Lernihan
Kathy O’Grady
Máiríde Woods

Senator Mary Moran
Derek McNamara
Damien McLoughlin
Jane Fitzpatrick
Elaine Mears
Siobhán Barron
Michael Teehan
Angelina Veiga

Jonathan Egan
Michael McKeon
Kieran Murphy
Seamus Ryan
Stephen Kealy
Claire Rodgers
Mairead Sheedy

---

_The Board of Frontline ask all subscribers to renew their subscriptions for 2013—we totally rely on subscription income to cover the production and distribution costs of the magazine. This is a precarious undertaking for the voluntary Editorial Board, and we are grateful to all our subscribers for their support._
New Toolkit on workplace bullying

A NEW TRAINING toolkit has been launched that aims to tackle workplace bullying of adults with an intellectual disability. It is aimed at employers, trainers and support staff. The project is called ‘Let me be Me’ and is funded by the European Commission under the Leonardo da Vinci Fund. The training toolkit, which is available online, is divided into five modules, and provides background information on the problem, its nature and the extent in Europe, current projects, initiatives and approaches to tackling workplace bullying and best practice Europe-wide. It also gives practical guidance and resources for trainers working with groups of people with an intellectual disability, and employers working in the field of supported employment. The toolkit is available in English, German, Spanish and Portuguese, and aims to do the following:

- better equip people with an intellectual disability on what is defined as bullying;
- help maintain and sustain the employment of people with an intellectual disability;
- increase the confidence and skills of people with an intellectual disability;
- gain an in-depth understanding of the issue of bullying and how it affects the lives of people with an intellectual disability;
- transfer (including adaptation) existing training materials to create a new resource for learning and training;
- promote the widespread uptake and use of the training course focusing on member countries of the European Union of Supported Employment;

More details on the project are available at www.letmebeme.eu/en/, where you can also download the toolkit.

Minister says State cannot afford to widen eligibility for Disability Allowances

DESPITE SERIOUS CONCERNS raised by the Ombudsman over the legality of restricting two allowances so as older people cannot apply, Health Minister James Reilly has said the State cannot afford to widen eligibility. Funding for the mobility allowance and the motorised transport grant is currently €10.6 million a year, and widening eligibility would cost the exchequer €500 million over three years, Dr Reilly told an Oireachtas committee.

Ombudsman Emily O’Reilly was heavily critical of the exclusion of older people from eligibility for the allowances, saying it contravened equality legislation. The Department of Health said the number of recipients of the mobility allowance could increase from the current 4,700 to 63,500 if eligibility was widened, and the numbers availing of the motorised transport grant could rise from 300 to 19,250.

Man with Autism to take High Court action on circumstances of his arrest

A MAN WITH autism has been cleared to take High Court action over circumstances when he was arrested. The High Court action is for false imprisonment, intentional trespass to the person, negligence and breach of duty. It is claimed that no effort was made by Gardaí to contact his parents before he was arrested under the Mental Health Act. The man is 27 and was arrested by Gardaí after allegedly chasing two women with a stick. It is claimed he was subjected to inhuman and degrading treatment through the use of handcuffs to restrain him when he was conveyed to a garda station and held for nearly an hour before his parents arrived. The man is suing the gardai and the State through his testamentary guardian and next friend. His guardian said the man has very high support needs.

When Gardaí attempted to speak with the man about the alleged incident, the officer arrested him under the Mental Health Act, handcuffed him, and brought by patrol car to the local station. When another officer at the station recognised him, his parents were contacted. The man asserts that no effort was made by the arresting Gardaí to speak with his parents, and that as a result of his detention in unusual surroundings, he was caused acute and unusual distress.

Magdalenes Report shows 107 women and girls with an intellectual disability in Laundries

THE ‘REPORT OF the Inter-Departmental Committee to establish the facts of State involvement with the Magdalene Laundries’ was published on the 5th February. The Committee was chaired by former Senator Martin McAleese. Approximately 10,000 women and girls entered Magdalene laundries since 1922 and the Report found “significant” State involvement in the laundries. Mr. McAleese said the women admitted to the laundries “have for too long felt the social stigma” of the “wholly inaccurate characterisation” of them as “fallen women”. He said this characterisation was “not borne out of facts.”

The committee found a wide range of reasons women and girls entered the religious run laundries operating in the State between 1922 and 1996. Reasons included referrals from industrial and reformatory schools, rejection by foster parents, abuse in the home, being orphaned, and having intellectual or physical disabilities. Referrals were made or facilitated by the State in 26.5% of cases for which reasons are known. Almost 7% of these referrals came from health and social services. The Report said some women were referred to laundries by the health and social services because it was cheaper than State-run facilities. The report found direct State involvement in: routes of entry, workplace regulations and inspections, funding and financial assistance to laundries, routes of exit, death registrations.

The route of entry into the laundries was known in 8,025 cases, but unknown in an additional 3,173 cases. Of those cases that route of entry is known, 107 women entered Magdalenes from “psychiatric hospitals and institutions for intellectually disabled”. The youngest person to enter Magdalenes from such institutions was 14, and the oldest was 50.

Among the extracts relating to women with a disability was that in 1953 the Dublin Health Authority proposed financial support to Magdalenes in the form of a contribution: “towards the maintenance of the 32 totally disabled persons, none of whom have any income and who are by residence in an Institution precluded from receiving a Disabled Persons (Maintenance) Allowance”. The level of payment proposed was a grant “at an approximate weekly rate of 30/-d. for each disabled person, that is £2,500 in a full financial year”. The approval of the Department of Health was sought for this proposal.

At the time of writing Taoiseach Enda Kenny was due to make a statement on the findings of the Report, and was being pushed to apologise on behalf of the State.
**Lynch welcomes new disability and mental health initiatives in HSE South**

MINISTER OF STATE, Kathleen Lynch with responsibility for Disability, welcomed the publication today of the HSE South Regional Service Plan. The Plan highlights a number of new initiatives in the areas of disability and mental health despite the Region operating from a reduced financial position. This has been achieved through careful consideration and input from HSE senior managers and clinicians, and through the ongoing development of close working relationships and partnerships with groups and associations in the voluntary sector.

The new initiatives include:

**Disability**
- The transitioning of 10 adults with an intellectual disability from Grove House into community based, inclusive and person centred services with the support of the COPE Foundation team
- The opening of an 8 bedded regional specialised therapeutic service for Cork and Kerry to support adults with intellectual disability who present behaviour that challenges
- In line with the congregated setting policy, A Time to Move On, the implementation of 11 demonstration projects in partnership with Genio, to lead on the move towards a person-centred model of service and support

**Mental Health**
- A new replacement acute inpatient unit to be developed at Cork University Hospital commencing in March
- A reconfiguration of acute in-patient services away from old institutional settings towards modern community based services
- Development of plans for more appropriate modern residential services and a move away from long term hostel accommodation
- The move to a 7 day service Acute Day Service in Day Hospitals
- Appropriate allocation from the additional 2013 €35m national funding for mental health to be utilised in 2013 to enhance Community Mental Health Team capacity in General Adult and Child and Adolescent Mental Health Services, to support the development of services for older people with a mental illness, those with an intellectual disability and mental illness and forensic services.
- Further investment will also be made in implementing the recommendations of the suicide prevention strategy Reach Out.
- The establishment of a comprehensive community-based, person centred response to dementia in Kinsale in partnership with K-CORD

Welcoming the publication of the Plan, Minister Lynch said “as Minister of State with responsibility for Disability and Mental Health I am especially pleased to see the improvement in disability and mental health services that are envisaged in the Plan. These improvements will, I believe, enhance care and treatment for service users across the HSE South Region. Progress thus far has been achieved by working together in partnership at local and regional level and I look forward to supporting this work into the future.”

**Major audit in HSE South**

THE HSE INTERNAL audit section has asked the HSE finance unit to ensure all voluntary and charity groups hand over a “minimum set of information to the public” to guarantee transparency, following an audit in the HSE South area. The Irish Examiner newspaper published findings from a HSE audit of a number of groups, including disability organisations. The audits were conducted in 2010 and 2011, and involved 17 groups in the HSE South region. The organisations in question weren’t named. Among the findings was that of “serious fraud” at one organisation.

Among the other issues revealed as a result of the audit, are that a third of the organisations audited are allowing some of their members’ pay to exceed strictly set levels.

Issues were also raised over staff vetting, as one organisation said staff working since before 2001 were not vetted, and that it was awaiting guidance from the HSE over the matter. The audit also found that “the majority of agencies surveyed showed significant cash/bank balances”, and the report said following on from this, there is potentially room to reduce grant payments to those groups. The report highlighted that income some of the organisations receive from other funds, is “often not sufficiently analysed”. Among the report’s recommendations, are that each organisation publishes its full policies and audited financial statements.

**Inclusion Ireland publishes Position Paper on National Disability Strategy**

INCLUSION IRELAND HAS published a position paper that sets out what Government must address in a new implementation plan for the 2004 National Disability Strategy (NDS). The current government is committed to publishing an implementation plan for the NDS. Inclusion Ireland has contributed to the drafting of an implementation plan through its participation on the Disability Stakeholders Group.

As a national organisation advocating for the rights of people with intellectual disabilities, Inclusion Ireland sets out in the position paper, what the Government’s implementation plan for the NDS must address. Among other issues, the document examines the failure to fully implement the legislative commitments in the NDS, and the number of important policy developments since the launch of the NDS in 2004, including the Congregated Settings Report, the New Directions Report on day services, and the Value for Money and Policy Review of Disability Services. Another very important development is Ireland signing up the United Nations Convention on the Rights of Persons with a Disability. The document is available at www.inclusionireland.ie or in hard copy format by calling the Inclusion Ireland office on 01-8559891.

**3% disability employment target reached for the first time in public service**

2011 IS THE first year the target of 3% employment of people with disabilities in the public sector was reached, since it was introduced in 1977. The 3% target was implemented to ensure that the public service plays its part in providing jobs for people with disabilities. It was made a statutory requirement from 2006. The target was achieved in a number of ways, including initiatives to improve policies to recruit and to retain staff with disabilities, to accommodate staff with disabilities to do their work, and to make public sector workplaces more disability-friendly.
VISION FOR THE FUTURE

by Marcia McDonagh

AS PARENTS WE want the best future for our sons. When we think of this future for our children we hope that they may attend college, working on a course that interests them, fires their imagination and fulfills their dreams. We then hope that they find an occupation that they enjoy, and that both challenges and rewards them. Finally we envision that their life is filled with rewarding relationships that add colour and variety to their lives. We envision the tapestry of their lives as being textured, rich and vibrant, filled with many details.

However, this has not always been the case; there was a time when we did not have the same vision for all our boys. There was a time when we allowed our dreams to be buried. Too often in life we are all guilty of allowing our hopes and dreams to be shelved. We allow them to be lost in the realities of daily living. We spend so much time listening to others telling us why our dreams don’t make sense, how our dreams may just be too difficult to fulfill; and so we bury our dreams. We have spent many a year not daring to dream—accepting and conforming to others expectations, doing as we are told. Now we no longer do so.

As parents of three boys with different support needs, we allowed the feedback from experts to shape our expectations. We allowed others to shape our dreams. This did not happen consciously or overnight. Slowly over years we allowed the biased world to influence how we thought and how we acted as a family. We spent a great deal of time and energy living with the things that were not possible and with the things that could not happen.

These limiting boundaries meant that our family lived in a small restricted world. Often we chose to stay at home rather than go out, fearing that we might encounter too many obstacles or difficulties. In the first five years we lived in the small rural village that we called home—there were members of our community who had not seen our entire family together. As a family we were unaware of the long-term consequences of our actions; we did not recognise the natural supports that were available to us and that we were not tapping into.

It was at a family activity weekend with LEAP in April 2012 that we recognised the full extent of the limitations we had been living with. It was a weekend that changed our view of our world and reshaped our dreams. We spent the weekend with nine other families sharing meals, activities and time. Every member of the family was included and supported in all of the activities that were on offer throughout the weekend. On our first morning the schedule of activities was studied by the younger members of the group. The various possibilities were analysed and the pros and cons debated. With much negotiation the schedule was agreed.

Our first activity was to be the high ropes. Not being an outdoors type of individual, I have to admit that I genuinely did not know what high ropes were. As the family groups were divided up according to the activities that they were attending, we begin to gather and chat among ourselves. I had assumed that I and one of our sons, Liam, would have some mild mobility support needs would watch the event, but not actually participate. Often steps and climbing, even getting in and out of a vehicle, can trigger a seizure in Liam. I did not begin to become anxious until I realised that not only were we expected to participate, but that there was specialised equipment we were required to wear. My immediate thoughts were of the obstacles and difficulties that could arise in the activity. I was more comfortable in not challenging the status-quo. When the team suggested that Liam needed to go out as far as he was capable and happy to, I realised there was no major difficulties or obstacles—only those in my own head.

My husband and I stood on either side of Liam and supported his initial steps onto a log lying at an incline leading to the first set of ropes. As the other families cheered and clapped Liam made his way up the log. The smile that was plastered all over his face said everything. He met the challenge and taught us a very valuable lesson: It was not Liam who could not meet the challenges of this world but his parents. The limits that were in place had been established by our own fears and bias.

The families, facilitators and staff did not see difficulties, limitations, or disabilities; they just saw people and potential. Regardless of the support needs of any individual there is always a way to facilitate the fulfilment of their potential. Our family left that weekend with a renewed vigour and optimism for our life and for the future. We decided that we were going to create a dream for our family’s future that was not dictated by fear, prejudice, or others’ limited vision. And so our new journey has begun.

We haven’t completed that journey, in fact we have only just begun. We are still building the new vision and we are aware that this may not be easy—there will be obstacles and difficulties along the way, but we are no longer fearful of them. I am willing to forgive our past prejudice as I recognise it came from a place of fear. We spent so many of the early years fighting to care for and protect our children that caution became our default position. However, if we continue to wrap our children in cotton wool we will not allow them to challenge their own abilities and grow. They will not be able to show the world what they are truly capable of.

Marcia and Michael McDonagh, from Crusheen, Co. Clare, have three boys, Liam, 17; Coleman, 13, and Oisin, 11. Liam has a diagnosis of intellectual delay with epilepsy. He has attended St Clare’s special school in Ennis for the past 11 years.
INTELLECTUAL DISABILITY IN IRELAND: Changing Perspectives

Fintan K. Sheerin starts off our series of articles on Advocacy with a call for changes in how those with ‘intellectual disability’ are treated by the disability services.

Setting the scene
Having worked for more than 27 years in Irish intellectual disability services, nursing and disability education, it is my assertion that, despite the onset of new philosophies of service, not too much has actually changed for many people with intellectual disabilities in Ireland at a fundamental level, and that apparently improved outcomes may actually be changes in hue, rather than changes in substance. In the light of this assertion, I propose that there is a need to revisit people with ‘intellectual disability’ through a different lens than the disability one through which they have been viewed for so many years. Furthermore, I propose that such a realignment of the social lens may result in a need to reconsider the roles of frontline carers, and others, who are involved in current service provision.

Many of us involved in professional frontline care (nurses and social care professionals) have been formed to work within accepted societal and service models. Both training and experiential components of our preparation have played a role in this formation. The concept of formation is an important one, as the training component of caring programmes is akin to other vocational training involving the imbvement of societal values and beliefs, in this case pertaining to intellectual disability service provision (Lum 2003). Anecdotal evidence from many student carers (nurses and social care professionals) suggests that these values and beliefs are reinforced during service-based placements where they quickly learn that asking too many questions and having a critiquing approach to practice can often lead to negative outcomes for them. So, they stay quiet, in the same way that people with intellectual disabilities often do (Gates 2005). Indeed, not only do they ‘keep their heads down’, but they learn how to navigate the service system in a blinkered fashion, being able to push rights violations and deprivations to the periphery of their vision. Such social formation encourages the development of a potentially dissonant workforce, deprived of initiative, motivation and power; able to accept a different set of realities for people with intellectual disabilities than apply in their own lives. The result of such formation is the creation of a culture of fear and silence in which the status quo is maintained and challenges from within the caring disciplines are unlikely (Mooney and Nolan 2006; Hooks 1994; Freire 1996, 1998). It is such a culture which allows unacceptable practices to develop and persist.

Changing the perspective
Sometimes it is good to step back, take a few steps to the side, and look at things from an alternative angle to what has shaped one’s view of the world. When I did this some years ago, I realised that validity of my role was challenged when alternative perspectives on intellectual disability were considered. Indeed, what I realised was that the role I was playing may have actually been the antithesis of what I had believed it to be. At the time, I was reading the pedagogical work of Paolo Freire, as well as Jon Sobrino’s writings (2008) on liberation theology. They offered a viewpoint which, when applied to people with intellectual disability, portrayed them as oppressed people who share many of the experiences and stereotypes that had hitherto been applied to the oppressed poor. For Freire, these people had been dehumanised through oppression and were caught in the duality of being at once oppressed and, at the same time, the internalised image of their oppressor. To the oppressor they were ‘good for nothing, know nothing and are incapable of learning anything...sick, lazy, and unproductive...’ (Freire 1996: 45). They were deviants, ‘rejects of life’ (ibid. 27); ‘beings for others’ (ibid. 55) whose lives were exploited for the betterment of those who oppress, and who were ‘cheated in the sale of their labor’ (ibid. 32). Deprived of their voice and of their humanity, they ‘extend their trembling hands’ to receive the ‘false charity’ of their oppressors (ibid. 27). Sobrino (2008) posits that their life experience is characterised by injustice, cruelty and death. How did this offer any useful perspective on people with intellectual disabilities?

The oppression model
It struck me that, from a Freire-Sobrino perspective, the societal response to people with intellectual disabilities in Ireland was strikingly oppressive, such as to constitute a systematised model of oppression. Consideration of this oppression model offers a view that brings into focus the role of intellectual disability service, and the workforce therein, in subjugating the development of people with intellectual disabilities.

Within this model, people with intellectual disabilities have, for centuries, been cast into historical deviancy roles, and marginalised through processes of segregation and congregation (Sheerin 1998, 1999). This, allied to fundamentalist attitudes, led to them becoming objects of dread and of fear, ‘immoral, diseased, irrational, mindless’ (Rafter 1992:25). Such views and responses to persons with intellectual disabilities served to foster dehumanisation, leading to the point where the central focus of service provision became one of control (Rafter 1992) and the means of control—means not always acceptable in mainstream society—became sanitised within the context of the professionalised practice (see, for example, Wolfensberger (1973) on aversive punisher/ment). These things happened because, as Judith Klein (Director of the Open Society Mental Health Initiative) said of atrocities committed against children with intellectual disabilities in Bulgarian state homes, ‘these people don’t count as people’ (Klein quoted by Brunwasser 2010: 1). The origins of such service provision in Ireland have been described elsewhere (Robins 1992, 1986; Finnane 1981) and what is described is the emergence of formalised ‘care/control’ structures around groups of people who had become
increasingly marginalised from mainstream society. It was within this context that people with intellectual disabilities repeatedly came to accept that their reality is different from that of other human beings. They became objects of charity (UN 2010) ‘extending their hands’ (Freire 1996: 27) to receive the generosity of others. It is arguable that this marginalisation not only physically separated people with intellectual disability from mainstream society; it also facilitated the movement of this group out of societal consciousness so that they essentially became ‘forgotten’ by society. Thus, away from the ideals of the Republic, the civic virtues embodied in civic republicanism, ‘virtues of participation, democracy, liberty, equality and social solidarity’ (Taskforce on Active Citizenship 2007: 3), did not apply, and charity, rather than solidarity was afforded those in institutions. Freire (1996) proposes that this form of charity is, in fact, false generosity in its essence and antonymous to solidarity. He argues that such false generosity, deriving from the oppressors, actually benefits the conscience of the donor rather than effecting any real form of solidarity, and is discordant with such solidarity.

Poverty grounded in oppression
Wolfensberger (1995, 2000) has written extensively regarding the wounds of people with intellectual disabilities. His writings concur with the position proposed above, as he suggests that service providers collude, albeit unwittingly, in the wounding of service recipients. It is undeniable that offering such a perspective fundamentally challenges the base of service providers and caring professionals who may have dedicated many years to the service of people with intellectual disability. Their despair will not be allayed by Freire’s suggestion that by dehumanising others, even unwittingly, the oppressors themselves became dehumanised.

It may be further suggested that the current social response is oppressive in its nature and, through its inherent control, segregation and tendency to marginalise people both physically and socially, constitutes a form of violence. The result of such violence is disempowerment and dehumanisation. The responses of the oppressed may be twofold. The first, withdrawal, is discussed by former residents on the Scottish NHS video Just ordinary people (Gates 2005), in which they noted that in order to avoid trouble in the institution, they stayed quiet – ‘you keep your mouth shut to have a peaceful life’. The second response may be to fight back against the perceived injustice. Such a response may, however, be considered by oppressors to constitute unprovoked and meaningless violence (Freire 1996).

In the context of intellectual disability, the still-present pathological perspective may interpret such violence towards self or others as challenging behaviour warranting interpretation and intervention, whether behavioural or pharmacological. The successful outcome of such intervention may be interpreted as a return to quiescence with re-conformity to the requirements of the oppressive society.

The expectations of society regarding people with intellectual disability are therefore mediated through the health system and its body of frontline carers and other professionals, who are prepared for their task through a process of education, training and socialisation.

Implications for service and practice
If we consider the validity of the oppression model as a possible explanation for the continued marginalisation of people with intellectual disability, the potential implications for service and practice are significant. Despite the well-meaning intent of service and practitioners, it becomes apparent that both may be engaged in an historically-grounded model of societal rejection and oppression that is both disabling and dehumanising. Such a revelation should not be met with despair, but rather with a resolve to realise the well-intentioned action that led people into such service provision. The answer to these problems cannot be addressed overnight and calls for immediate cessation of specialist service provision would be inappropriate.

**Figure 1:** Frontline carers’ locus of action in relation to intellectual disability service provision (Sheerin 2011).

Within the oppression model the involvement of formal carers similarly has its basis in a form of generosity that is not centred on the virtues of civic society. If it were, marginalisation of people with intellectual disabilities and arbitrary denial of their human rights would no longer be an issue; the carers were the people who did what most people would not consider doing and, in doing so, they appealed the unconscious guilt of society. Instead, they may be unwittingly working to maintain the margin (Fig. 1). The emergence of service-based rights commissions and of national groups is evidence of their continuation, albeit in more attractive guises. No-one doubts the intentionality of goodwill that underpins the work of carers (including this writer) but, as long as that goodwill is directed solely towards the provision of care/service for disabled individuals, it will maintain those individuals in their states of disability. Thus, the status quo is protected, with generations of carers and service personnel metaphorically reaping the good things of life on the backs of those on whose disablement their comforts depend (Freire 1996; Sobrino 2008). Moreover, the operation of service-based rights commissions and advocacy groups may be viewed as further examples of goodwill intentionality which may be fundamentally compromised if considered from the context of an oppression model of service.

Professions within intellectual disability services have justified their existence on the basis that they provide a specialist service to a specific group of people (Northway et al. 2006). The image that emerges of service, and of its place in society, is one in which the failure of mainstream society to address the individualised needs of people with intellectual disabilities leads to the potentially determined failure of these people to achieve mainstream societal norms in various outcomes. As people with intellectual disabilities form a marginalised and dehumanised group, the solution to this problem is not located in mainstream society but, rather, is in the development of specialists who can address their needs where they are, thus, perpetuating the reality of their separation from human society.
answer is, alternatively, the engagement of people with intellectual disabilities and practitioners in human rights action that challenges the situation by maintaining specialist action for as long as it is needed, whilst concurrently campaigning for a re-evaluation of the social and political model that has supported the continuance of this situation (Fig. 2).

Furthermore, service providers and care providers need to conceive of a time and a set of conditions where they may no longer be required; a time when the mainstream has been widened to include those people who have been made deviant by society. This will necessitate much work on the part of specialist intellectual disability services and practitioners, as it will require them, together with the people they support, to call the mainstream to account for its failure to include these people. They will also be required to ensure that proper structures are put in place in mainstream service, as well as in the preparation of mainstream professionals, to support the real inclusion of people with intellectual disability in society.

Conclusion
Many people with intellectual disabilities have seen changes in the character of service provision over the past few decades. This has included a move from congregated to more individualised settings; increased ventures into mainstream society; for some, a more positive image; and apparently greater recognition of rights. All of this has taken place whilst the overall approach to intellectual disability has remained the same. It is this writer's perspective that much of this is window-dressing. The evidence to support such a perspective is growing, as the recessionary forces have hit hard and funding cuts have disproportionately targeted those who do not fit in the mainstream. With anecdotes emerging of frontline services being reduced, it appears that human rights for people with intellectual disabilities and practitioners in human rights action that challenges the situation by maintaining specialist action for as long as it is needed, whilst concurrently campaigning for a re-evaluation of the social and political model that has supported the continuance of this situation (Fig. 2).

Figure 2: Levels of action for frontline carers and service providers (Sheerin 2011).

I FIRST APPROACHED the National Advocacy Service seeking support in August 2011, after I had heard about the work and ethos of the National Advocacy Service. I knew that their key objective was to empower people with disabilities to voice their needs issues and concerns with the support of a trained advocate. At the time I was experiencing a number of difficulties due to a lack of HSE-funded personal assistance hours. Although I had continually tried to negotiate the issue directly with the HSE in the past, it was becoming clear to me that I would really benefit from the support of the NAS.

The reality is that many people with disabilities experience issues and problems related to their lack of freedom of movement and choice because of a lack of adequate support to meet their individual needs. Of course, the financial constraints, especially in the current economic climate, are the main reason for the reduced supports and services for people with disabilities. However, this does not change the everyday lives and needs of people with disabilities. For many, the question for support of any kind can be a very individual, intimidating and lonely one if a person is attempting to negotiate it alone.

This is why the National Advocacy Service is a vitally important service for those living with a disability. This is why I had no hesitation in approaching the service with my issue.

Within a short time I was allocated an advocate, who works in the region where I live. Since that time and on an ongoing basis my advocate has been working closely with me and supporting me to address my particular issue.

My advocate works in an incredibly supportive and empowering way. It is clear to me that she, and indeed all staff of the service, work according to a person-centred approach. The main focus of the service is the needs and the desires of the person.

As a client of the NAS, I would say that one of the most important things about the service is that it is completely independent. The significance of this is that it means that it is much easier to express your true feelings, needs and desires without fear that it might impact negatively on any existing services you may already have or indeed on relationships with family or friends.

To have a free and independent voice and, more importantly, for your voice to be listened to and heard is the one of the most important experiences which a person, any person, can have. For a person with a disability, it is very empowering to realise that, with sufficient support, equality can be achieved. Disability is not a barrier to participation, it is simply another way of being. In my experience, this is the objective and message which the National Advocacy Service achieves through its work. It for this reason that I recommend the service to anyone who may need its support.

References available upon request from the editor

Claire Rodgers talks about her experience of the National Advocacy Service

Fintan K. Sheerin is a lecturer in intellectual disability nursing at Trinity College Dublin. He is also Acting Director of the National Institute for Intellectual Disability, Trinity College. He is passionate about the need for participatory social action alongside people with intellectual disabilities towards the achievement of their human rights.
ADVOCACY TRAINING IN THE MIDLANDS

Mairead Sheedy of the Muiríosa Foundation writes about putting in place Advocacy training and explains how the committee ‘Advocate 4 One’ come together to support each other.

THE MUIRÍOSA FOUNDATION recognised the need for advocacy training for service users in the Laois/Offaly region and contact was made with a local Vocational Education Centre (VEC) to discuss the training required. Following a number of discussions, a training package was designed and a tutor from the local VEC agreed to act as facilitator. Over the six-month training period, representative service users attended the course from Dove House (Abbeyleix), Rowanberry (Portlaoise), Oak House (Portarlington), and The Tanyard Resource Centre (Tullamore).

The eight training modules included personal development and communicating one’s concerns appropriately, choices etc. Training involved preparing and presenting a short video on a personal experience (for example, asking for a key to your own home). This demonstrated the skills learned—speaking out about what you want and need, how to approach a situation and who to approach to address the issue. Each participant was assessed on their presentations, recordings of interview techniques and assignments completed on individual modules. The self-advocacy training programme was accredited by FETAC at Level 3.

Participants say:

*Most of us found the self-empowerment training module invaluable. We were enabled to recognise the need for change and to gain knowledge on how to make changes happen. The opportunity to discuss and share our problems also highlighted that we had issues, concerns and experiences in common, empowering us to voice them and make changes. Self-advocacy enables us to speak up for yourself and make decisions about your life. That is why this group is very important to us all.*

*After we completed and graduated from the course we were presented with our FETAC Certificates along with other successful FETAC graduates. We told our friends about the course, and by now about 25 more people have successfully completed the training.*

*When we’d finished the self-advocacy course, we did not want our journey to end. We had made good friends and we wanted to use the skills we had learned. In the beginning we met as a large group three or four times a year to discuss issues we felt were important to us as individuals and as a group. We told staff, the line manager and our families about our issues, and we felt that they listened to us and included us in decision making.*

The self-advocacy group eventually became too large, as everybody who had completed the training wanted to be involved and it was difficult for everybody’s voice to be heard. So we decided to elect two to three people from four areas (Portarlington, Tullamore, Abbeyleix and Portlaoise) to form a committee to represent us and our issues and we voted to name the group ‘Advocate 4 One’.

Representatives were elected in each of the four general areas and a committee chairperson and vice chairperson were also elected. Each committee member on the regional self-advocacy group represents the views and opinions of their electors. Local self-advocacy groups are also operational. ‘Advocate 4 One’ has an email address and we contact each other to share information.

We meet every 2 to 3 months, and we are in contact with members of the committee on a regular basis. The agenda for our meetings is set by the members and we discuss topics of interest to us all. The group has achieved many important feats over the past two years, but most importantly we have a voice and are confident to speak up and represent ourselves and our peers. Some of the issues which we have raised are:

- Concerns on budget cuts to the organisation and how this will affect our service.
- Need for consultation with us about changes to our service and on local policy development.
- Why do staff or family members need to accompany me to visit the GP? –Some of us are happy with this arrangement, but others do not need this support. Sometimes the GP will direct the conversation to our family member or staff and ignore us and we are not happy with this.
- Need for us to have access to our own money as we need it.
- Need to have a key to our own home. When the organisation introduced a new Person Centered Support Plan, members of the group felt it was too broad, too personal and intrusive on our private lives. We didn’t like that so many people could read it.

Mr Brendan Broderick, CEO of the Muiríosa Foundation, has met with the committee on a number of occasions to listen to our concerns and to discuss reasons why certain decisions are made within the organisation. We feel confident that we have a forum to speak and are being listened to by the Muiríosa Foundation.

At our AGM on 31 January, 2013, new committee members were elected and we are confident that they will continue to advocate on behalf of service users within the Muiríosa Foundation.
TWENTY YEARS ON:
The Commission on the Status of People with Disabilities and the development of advocacy for people with disabilities

This year marks the 20th anniversary of the first meeting of the Commission on the Status of People with Disabilities (the Commission). Advocacy featured prominently in the work of the Commission. In this article, Jim Winters, Inclusion Ireland, looks at the some of the significant milestones in the development of advocacy for people with disabilities since that inaugural meeting of the Commission in November 1993.

Introduction
The 1990s was an important decade for the advancement of human rights of people with disabilities. Internationally, the UN ‘Decade of Disabled Persons’ came to an end in 1992. This culminated in the UN adoption of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities in 1993. The Standard Rules provided governments with a human rights framework for disability policy and legislative reform.

It was against this background that people with disabilities in Ireland began to mobilise and claim their rights as equal citizens. The Forum of People with Disabilities, a grassroots advocacy organisation led and managed by people with disabilities, was established in Dublin in 1990. The Forum advocated for the recognition of people with disabilities as citizens with equal rights. Mary Robinson, a barrister and human rights advocate who endorsed the aims of the Forum, was elected as the first female President of Ireland in 1990. The concept of equality was a recurring theme throughout Robinson’s electoral campaign. In 1992 the first Irish Centre for Independent Living (CIL) was established by people with disabilities in Dublin. The right to independent living and participation in society as equal citizens were key aims of the CIL. The prevailing narrative of disability as charity was challenged by people with disabilities. Disability, they argued, was a human rights issue and the concept of advocacy was central to that. They wanted government action.

The Irish government responded by establishing a Commission to ‘advise on measures necessary to ensure that people with a disability can exercise their rights to participate, to the fullest extent of their potential, in economic, social and cultural life’. The Commission on the Status of People with Disabilities held its first meeting in November 1993. Over the following three years it engaged in a comprehensive process of research, engagement and consultation on a wide range of issues affecting people with disabilities. Advocacy featured prominently in the deliberations of the Commission. Its final report, A Strategy for Equality, was presented to government in November 1996.

Understanding advocacy
There is no widely accepted definition of advocacy. It is a broad, contested concept, subject to a variety of interpretations.

‘Advocacy is both local and global, individual and collective, and a personal and political process’ (Birmingham, 2001: 9).

Advocacy can assist people with disabilities to make decisions that might otherwise be made for them by others. It recognises that every person has the fundamental right to self-determination and personal autonomy. Advocacy comes in many forms and operates at different levels. It operates both formally and informally. Some of the most widely used forms of advocacy associated with people with intellectual disabilities include self-advocacy, citizen advocacy, representative advocacy, and parent/family advocacy.

- Self-Advocacy involves the act of speaking up for oneself. It can take place individually and collectively.
- Citizen Advocacy involves the provision of advocacy support by a volunteer advocate. Citizen advocates develop long-term relationships with their advocacy partners.
- Representative advocacy involves the provision of independent advocacy by a professional advocate. It is usually short-term and deals with complex issues.
- Parent/family advocacy involves a parent or family member advocating for a child/family member.

There are strengths and weaknesses to each form of advocacy. Each has the potential to be used to protect and promote the human rights of people with disabilities, and they are not mutually exclusive. A person may require different types of advocacy support for different issues. For example, a person with an intellectual disability who has a parent or family member supporting them may also require the services of a representative advocate in respect of a critical or complex issue (e.g. in order to participate in a tribunal or in legal proceedings).

Advocacy and the Commission
The Commission acknowledged the importance of the various forms of advocacy in the lives of people with disabilities. However, it also placed a strong emphasis on the importance of self-determination and personal autonomy.

‘The Commission believes that advocacy is essential because it allows people to participate more fully in society by expressing their own viewpoints, by participating in management and decision-making and by availing of the rights to which they are entitled.’ (A Strategy for Equality, 1996: 95).

The Commission recommended that independent advocacy services should be mandatory in all institutional-care settings. It recommended that the post of advocate be established by statute. The Commission also made a number of recommendations in respect of the need for self-advocacy and citizen advocacy. The Commission acknowledged the fundamental right of people with disabilities to access justice on an equal basis with others. It recommended that ‘funding be provided by the Legal Aid Board to ensure that people with disabilities can employ an advocate to access expert legal representation, where necessary’ (A Strategy for Equality, 1996).

The Commission warned that proper implementation of many of its recommendations was dependent on the availability of effective advocacy services.
Advocacy since the Commission

The establishment of the Irish Council of People with Disabilities (the Council) in 1997 was one of the recommendations made by the Commission, believing that the Council would fulfill a central role in advocating for the implementation of the Commission's recommendations. The Council was a publicly funded body comprised of people with disabilities. It established a national office and regional and local networks of people with disabilities. The Council was renamed as People with Disabilities in Ireland (PWDI) in 2000.

In 2002 Comhairle was established as the public body with responsibility for information, advice and advocacy in respect of access to social services. In the early 2000's Comhairle provided funding to a number of organisations to develop advocacy for people with disabilities. It also commissioned Goodbody Economic Consultants to report on how advocacy could be developed for people with disabilities. The Goodbody Report (2004) set out a strategic approach to developing advocacy services for people with disabilities, recommending a three-stranded system. This was to involve a programme of support for community and voluntary organisations to provide advocacy services; a Personal Advocacy Service with statutory powers; and a Community Visitors Programme. The Community Visitors Programme was to be a form of citizen advocacy, which would focus on children and adults with intellectual disabilities in institutional care. The Goodbody Report mirrored many of the advocacy recommendations previously made by the Commission.

Following the recommendations of the Goodbody report, Comhairle introduced a programme of support for community and voluntary organisations to provide advocacy services. Although the majority of the funded projects provided representative advocacy to people with disabilities, a range of other forms were supported, including a number of citizen advocacy initiatives. In 2011 the Citizens Information Board (formerly Comhairle) introduced a National Advocacy Service for people with disabilities, providing a representative advocacy service with a particular focus on more vulnerable people with disabilities. The National Advocacy Service replaced the CIB programme of advocacy in the community and voluntary sector which ended in 2010.

The introduction of the Citizens Information Act 2007 marked a significant milestone in the context of advocacy for people with disabilities. This groundbreaking piece of legislation provides for a legal right to advocacy for people with disabilities. It provides for the introduction of a statutory ‘Personal Advocacy Service’, with the post of Personal Advocate established in law (as recommended by the Commission the Status of People with Disabilities). Personal advocates would have legal powers to enter premises, make enquiries on behalf of people with disabilities in residential and day services, and pursue a right of review or appeal on behalf of a person with a disability. It would be a criminal offence to obstruct or hinder a personal advocate in the course of his or her official duties.

However, in 2009 the government announced that it would not yet proceed with the section of the Citizens Information Act dealing with the Personal Advocacy Service because of ‘budgetary constraints’ (Mary Hanafin, Dáil Eireann Debates, 30 April 2009). It remains to be seen when the Personal Advocacy Service will be introduced.

UN Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the UN General Assembly in December 2006 and entered into force in May 2008. The CRPD reaffirms the right of every person with a disability to self-determination, autonomy, equality and dignity. The CRPD sets out the steps that governments and public bodies must take to ensure that people with disabilities have their human rights protected, promoted and fulfilled. A key provision of the Convention is the right of people with disabilities to receive assistance in exercising their decision-making capacity (Article 12). This has particular relevance to people with intellectual disabilities.

Ireland was one of the countries to sign the CRPD when it was opened for signature on 30 March 2007. 155 countries have now signed the CRPD and it has been ratified by 127 member states. Although it has not yet ratified the CRPD, as a signatory, Ireland has demonstrated agreement with the principles enunciated in the Convention, and its intention to comply with its provisions.

Conclusions

There have been significant developments in the area of advocacy for people with disabilities since the first meeting of the Commission on the Status of People with Disabilities in 1993. However, the intervening period is marked by examples of the withdrawal of funding and support for a number of advocacy initiatives and organisations. The Forum of People with Disabilities, which had been such a driving force behind the development of advocacy for people with disabilities, closed in 2006. PWDI closed in December 2011. State support for advocacy has almost exclusively focussed on representative advocacy. There has been little support for the development of self-advocacy and citizen advocacy.

The introduction of the National Advocacy Service has been a positive development. This is of particular significance to thousands of people with disabilities living in unregulated residential services. However, the continuing failure to introduce the Personal Advocacy Service is a considerable setback for people with disabilities and disability rights.

As the Commission on the Status of People with Disabilities and the UN Convention on the Rights of Persons with Disabilities have enunciated, the availability of a range of advocacy services is vital in ensuring that people with disabilities enjoy full and effective participation in society as equal citizens. In Ireland, adequate support and funding for a broad spectrum of advocacy are essential.

References

Goodbody Economic Consultants 2004 Developing an advocacy service for people with disabilities, Dublin: Comhairle.
IN FEBRUARY 2011 I made a decision to contest the General Election – a decision that has changed the course of my life.

For ten years I had been trying to advocate on behalf of people with a disability when my son was diagnosed at the age of three with a moderate intellectual disability. He had attended early intervention services with the HSE until the age of four. However as soon as he entered a St John of Gods school I was dismayed to be informed that he was no longer eligible for HSE services and could instead only receive them from St John of Gods despite there being no services available there. And there started the long journey that is familiar to every parent and carer of a child with a disability – the road to find services, to access services and to keep informed.

I joined the Parents’ association in the school, later joined the board of management and continued over the next ten years to advocate locally for better services in respite, physiotherapy, speech therapy, occupational services all of which continue to be so difficult to access.

In 2010 my son had an operation which required him to remain in a wheelchair for several months and I saw for the first time the additional obstacles that wheelchair users have to overcome. I was horrified to discover that we could not access wheelchair transport despite a wheelchair bus travelling in our locality to the school on a daily basis.

I wrote to the Department of Education, wrote to Ministers and tried to point out that their proposed means of transport was in fact costing them and us more money and that there really was a much simpler answer. However my letters, phone calls and pleas fell on deaf ears. I became more vocal and frustrated as I received one line standard replies from Ministers and officials. In January 2011 I relayed my deep concerns in a conversation one night and was surprised when I received a phone call from the Labour Party Head office the next day to meet and discuss the forthcoming General Election.

Over the following week I had a series of meetings with Labour head Office where we discussed my running for Election. At first I dismissed the suggestion, citing family commitments, work commitments and numerous other reasons not to run. However I realised that there was no point in me complaining about the system if I was not prepared to do something about it. So I decided to make a stand. That was probably the most monumental decision in my life to date.

Within hours of reaching my decision to contest the election, poster photos were taken and I was drafting Election Literature. My life had taken a completely different and daunting direction.

I had nineteen days to canvass. After half an hour on the road I was hooked. I was heartened by the support I received from people who fully supported my efforts and the many people who had similar views and experiences to me and who encouraged me every step of the way.

My main goal for standing in the General Election was to highlight the huge gaps in services and supports for people with a disability. I was delighted to receive 4,500 first preference votes and an overall final vote of just under 7,000 votes. Despite not being elected I felt I had achieved a great deal. This was supported when I was honoured to receive the nomination to contest the Seanad Elections from Inclusion Ireland. This was a different kind of election and involved travelling around the country to seek support. Once again I narrowly missed being elected. However I had gained so much from my experience. On May 20 I was honoured to receive a Taoiseach’s nomination to the Seanad.

Since then I have acted as Seanad Labour Spokesperson on Disability. I am delighted to receive constant support from Minister Kathleen Lynch in this area. I welcome the opportunity to meet with and support the work of disability groups throughout the country and the many representations that I have received from parents, individuals and organisations alike. It is a difficult time to be in government. Huge challenges remain in all areas of disability. The economic downturn has seriously impacted on all sectors of the community and the Government cuts in the area of disability have been hard to say the least. The recent decisions on the cuts to Respite Care Grant and on the Motorised Transport Grant and mobility allowance in particular have caused widespread concern throughout the country. However some of the proposed alternative cuts would have been much more difficult and I continue to work to ensure that cuts in the disability sector can be kept to a minimum.

There are many strong advocates for disability in the Seanad- people from all parties who have firsthand experience in the area or who have worked with people with a disability for many years. It is important that the voice of the disabled is heard at all times and I welcome the cross party support in the Seanad for many disability debates that have come before the house in the past two years.

Life has many unexpected twists and turns. Sometimes we wonder at the direction it takes. I am so grateful for the opportunity that I have been given in the Seanad and know that I would not have had the courage and determination to undertake this journey were it not for my son, and the many people I have met who strive daily in many different ways to achieve a better, more equal world for people with a disability.
PARENT ADVOCACY PROGRAMMES

Jean Spain outlines the services and positive feedback for the Communication and Supporting Skills and the Pathways to Possibilities programmes

FOR MANY YEARS the Communication and Supporting Skills Programme and The Pathways to Possibilities training courses for parents have been taking place all over Ireland. The courses have been funded by GENIO and administrated by Inclusion Ireland.

The Communication and Supporting Skills programme was originally developed by Gerry Hornby, Ray Murray and Linda Davis. The Pathways to Possibilities course was developed by Julie Simpson, a parent of a person with an intellectual disability. The courses are unique as they are run by parents for parents. Parents who facilitate this course have gained accreditation through attending a course for trainers given in Ireland by psychologist Ray Murray and Julie Simpson.

Communication and Supporting Skills

This programme aims to empower parents and to encourage them to be as effective as possible in their demanding role as parents of a person with a disability. There is no writing necessary for this course which can be off-putting for some parents. The course is based on Robert Bolton’s book entitled People skills. One element in the practical work of the course covers the importance of ‘self-care’—it is often difficult for parents to realise the importance of taking care of themselves, in order to prevent burnout. The other main elements of the course are:

- Stress management as means of reducing stress
- Mutual support for accessing support for self and others
- Networking and learning from other parents
- Listening skills as a means of enhancing relationships (within the family and the service their child attends)
- Assertive skills as a way of claiming rights and having needs met
- Information to ensure awareness and confidence.

Comments from parents who have taken part in the course:

- This course has changed my life.
- I wish I had done this course years ago.
- I have learned so much, this course has opened up totally new concepts of communications to me and has pinpointed a lot of places were I go wrong in communicating with services.
- I feel better about myself as I feel I have taken on board problems and blame in the past that I didn’t need to. I will be more prepared for situations in the future.
- I really enjoyed the course, I feel stimulated!

Pathways to Possibilities

Pathways to Possibilities is a guided journey towards a desirable future for people with a disability, their families and allies. The idea is for small groups to work together to encourage each other to learn about possible and positive alternatives to change the lives of their person with disabilities. This can be achieved by building a network of connections and sharing experiences with each other. Parents explore ways to plan and begin to take actions towards a better future and the steps along the way to bring dreams to a reality.

The aims of the programme are:

- mapping personal strengths, gifts, capacities and strengths and those of their persons with a disability
- Deciding what works and what doesn’t work for their child
- Developing a range of tools to sustain self-care
- Writing a plan for their child’s future and building networks of support
- Making the journey towards a desirable future for their child

Where possible, the parents attend with an ally/professional to work with them on the Pathways programme. An ally is a professional or community member who supports the parent to move from feelings of resignation or frustration, to actions that move towards more realistic hope.

Some comments from parents who have attended the Pathways to Possibilities programme:

- The Pathways to Possibilities have been really helpful.
- I made a plan for my daughter, brought it to the staff at my daughter’s service. They were very supportive and went out of their way to make that plan work. This meant that my daughter no longer bored and loves going to her centre now as she is taking part in drama, art, swimming and a lot more besides.
- Planning gives me goals—direction and steps to follow.
- It helped me to find who to ask and where to look.
- I have gained more confidence to ask for what is needed, or to say when thing’s aren’t right. Services providers are responding to me better. I also know I am a better advocate and feel more empowered.
- Thank you all so much for running such a fantastic course, my mind has been working overtime since it ended—how to ensure my daughter has a better life—how to get the help we need. I am so grateful there are people like you in the world to show us parents the way.

For further information on dates/venues or to book a place on the Communication Skills or The Pathways to Possibilities courses, contact Inclusion Ireland, tel: 01-8559891; email: info@inclusionireland.ie or website: www.inclusionireland.com
IN 2009 WE set up an advocacy group in The Old Monastery Day Service, Killarney. We spent some time working on personal and interpersonal development which helped our self-awareness and also improved our abilities to be part of a group. Using role play, we developed good communication skills. Our aims were:

- Develop our ability and confidence to speak up
- Drive change through our individual and group voice
- Be involved in policy development and service planning.

We teased out our expectations of each other as members of the advocacy group and all agreed to honour these. Breeda Daly has supported our group from the very start, helping us to research information and access any resources.

In Dec 2009 we were appalled along with everyone else when the Christmas disability bonus was cut in the budget. We decided that we would like to have our voice heard and we wrote to the then Minister for Social Protection Mary Hanafin to express our dissatisfaction with this decision. We received a standard reply to this.

In 2010 we wrote to the Department of Social Protection to express how disappointed we were when the disability allowance was cut. We stressed that we had always been encouraged to face the consequences of our decisions in our life. We expressed our disbelief at having our allowance cut to pay for bad decisions we neither made nor benefitted from. We got no reply to that letter.

Our member Josephine had started going weekly to the swimming pool in the Killarney public leisure centre. There was a hoist there that makes entry into the pool a comfortable and dignified process for people with mobility problems. Josephine loved the freedom she had in the water, which was very different to how she felt in her wheelchair. She found doing her physiotherapy exercises in the pool helped build her strength. She got to know many of the staff working there and enjoyed her weekly chats with them. When Josephine heard that there were plans to close the pool it was a huge worry to her. Swimming had become a very important activity in her life. Working with her keyworker, Josephine failed to find another swimming pool in Killarney with facilities that suited her. She wanted the people who would decide the future of the pool to hear her voice. She met with Patrick O’Donoghue, a town councillor, and explained her situation to him. Josephine asked him to let the other people involved in the decision know how important the swimming pool was to her and other people in a similar situation. The pool remains open today, now named the Coral Leisure Centre, and Josephine has started working in reception one morning a week.

In 2011 we were involved in a project to update the shower area and design new wheelchair accessible toilets in the Old Monastery. Michelle, Kathleen and Josephine met with the people using this space the most in the Old Monastery, to hear their opinions and suggestions. We made a list of the changes and things we would like to have included in the plans. We identified specific difficulties experienced by people using wheelchairs in the Old Monastery building. We presented our findings to the then Chief Executive Tony Darmody, and reported to our group after we met Tony. We explained that while most of our ideas would be included, some of them could not be, due to resources. We now have a bathing/shower and toilet area that is easily accessible to everyone supported by the service. We took great pleasure in emailing Tony Darmody to express our satisfaction with the changes.

Our dental service had changed. We used to have a review every 1-2 years that spotted issues before they became a problem, but the service had deteriorated to management of acute pain. People were advised to visit local dentists, which created difficulties with access and records. We wrote to the head of dental services in Kerry and within two weeks a date was organised for a review. We now enjoy an improved service.

We have been involved in programme development in the Old Monastery. We discussed new programs and activities we wanted to try, and involved ourselves in organising them. After three months we were involved in discussing how the new plans had worked out. This was a great opportunity to try new things and look back at things we did.
QUESTIONS AND QUANDARIES TO PONDER IN OUR EFFORTS TO ADVOCATE

Kathy O'Grady, Muirisósa Foundation, Mullingar, considers the potential quandaries of Advocacy through some real life examples

ADVOCACY IS AN ALLURING concept. Everything thinks it is great—like apple pie and motherhood. But advocacy, while intellectually seductive, is nothing if it is not complex. An advocate is defined by Webster's dictionary as ‘one who pleads the cause of another; one who defends, vindicates, or espouses to the cause by argument; a pleader in favour of someone; an upholder; a defender who supports and vindicates.’ Essentially to advocate for someone is not simple or easy, but then things worth fighting for seldom are simple or easy. To illustrate from clinical practice the many questions that present when attempting to advocate, consider the life of Mary.

Mary is now 30 years of age. Unlike her five brothers and sisters, who are married and have moved out of the family home, Mary continues to reside with her mother and father in their terraced house in a small village in the midlands. After Mary finished in special school, she began attending a local Activation Unit run by the Parents and Friends-sponsored service. This worked out well for Mary’s mother and father for several years. She was collected every morning in the white minibus and brought to the nearby town, 12 miles away, by the clean and tidy bungalow out of the downtown. His mother married Danny’s father after he had become a widower. His new wife, Catherine, moved into his home and helped to rear Danny’s older five half siblings. Sadly Danny’s father passed away when he was 10 years of age. When Danny’s mother was unwell, her stepchildren, Danny’s half siblings, vowed that Danny could continue living in his home and that they would take turns staying there with him. They assured her that there was no need to make a will, and that they all had Danny’s best interests at heart. After all, she was their stepmother and had been good to them and that they all had Danny’s best interests at heart. After all, she was their stepmother and had been good to them when their father’s first wife had died.

Danny is 42 years of age. Since his mother died thirteen months ago, he has been living on his own in a bungalow outside a busy town. His mother married Danny’s father after he had become a widower. His new wife, Catherine, moved into his home and helped to rear Danny’s older five half siblings. Sadly Danny’s father passed away when he was 10 years of age. When Danny’s mother was unwell, her stepchildren, Danny’s half siblings, vowed that Danny could continue living in his home and that they would take turns staying there with him. They assured her that there was no need to make a will, and that they all had Danny’s best interests at heart. After all, she was their stepmother and had been good to them when their father’s first wife had died.

Danny was asked what he thought about his life. He stated that he was lonely and that he missed his mother. He said that he went to the pub in the evenings because it was warm, and he wanted someone to talk to. He did not want to leave the only home he had ever known, but he was afraid at night when he heard noises.

In this case, efforts to advocate for Danny are thwarted by his half siblings who have done a u-turn on the promises they made to their stepmother before her death. In fairness, their circumstances have changed, they are busy people, they do not have time for Danny, and due to the downturn in the economy they would benefit from the bungalow being sold so they can liquidate the assets associated with their inheritance. The biggest barrier is that their solution focus is restricted by the one-dimensional problem solving which is simple as far as they are concerned—i.e. move Danny to a staffed facility. They are resistant to a range of other suggestions such as supporting Danny to continue to reside with supports where he is, moving funding from his day service to support Danny in activities of daily living within his own residence, and engaging a circle of support around Danny.

Now let’s consider Fiachra, who is the eldest son of three now-adult children. He has two highly skilled professional parents. Fiachra is now 24 years of age and his siblings are all at university. His mother and father are thinking about retiring from their professions. Fiachra is a relatively bright young man whose autism imposes restrictions on his coping skills. For example, Fiachra can do many things for himself, but he will sit in a self-absorbed state unless verbally prompted by his mother, when he is at home. Both
Fiachra’s parents are concerned that when they retire their lives will be dictated by Fiachra’s support needs. While they live in a large palatial home, they are seeking an out-of-home placement for Fiachra. They feel this would be in a village complex for people with autism.

An obstacle advocating for an individualised service for Fiachra is that his parents are adamant that they want him ‘away’ as soon as possible. They feel that because Fiachra has autism, he should be prioritised on the waiting list for a residential place that they think they are entitled to.

Fiachra tries hard to please his mother and father and becomes distressed when they are not happy with him. He has not expressed a desire to leave home.

In advocating for Mary, Danny and Fiachra (and many other people with similar stories), the need for a set of guiding principles becomes evident. The quandaries outlined suggest such questions as:

1. What is the best interest of the individual?
2. How can we safeguard the individual’s basic civil rights as a citizen of Ireland? (Shouldn’t they have the same rights as you and I?).
3. Is what we are doing ultimately going to leave the person in a more vulnerable position? (This often happens when people leave their home and find themselves in staffed facilities where they do not have as much autonomy as previously.)
4. Is the solution we propose from ‘off the shelf’ in ‘service land’? Examples of this are common enough, i.e. someone dies in a community residence and suddenly a vacancy becomes an opportunity for someone on a waiting list. While this may provide a ‘bush in the gap’ solution, does it really reflect the vision we might have for each individual?
5. Are the needs of the agencies and service providers overshadowing the needs of the individual? For example, is the threat of losing funding if they do not provide a traditional service?
6. Is what is being offered driven by other agendas (perhaps better ‘value for money’)?
7. What Guiding Principle in Advocating for Vulnerable Adults do we have reference to?
8. How can families be guided towards a sustainable ‘good life’ for their family member with a disability?

---

**THE NATIONAL ADVOCACY Service**

The National Advocacy Service (NAS) is funded and supported by the Citizens Information Board and results from the National Disability Strategy, which also produced the Disability Act. The purpose is to give the person with a disability a spokesperson/interpreter/assistant, particularly at formal decision-making forums where they might be at a disadvantage. It does not yet have statutory powers. The NAS operates on a regional basis with five managers and 35 advocates.

NAS has now been up and running for two years and has served around 1500 clients. About a third of these would have an intellectual or learning disability. Some cases are straightforward—for example, assisting with an appeal where a social welfare allowance has been refused or with a particular case conference; but in the majority of cases the advocate will work with the person for several months or a number of interconnected issues. For example, where a person wishes to live more independently, there are a number of areas to be explored: Is the person’s choice an informed one—are they aware of the responsibility/duty that will fall on them? Can they get suitable accommodation from the local authority or social housing or disability provider? Can they get support services (home help, PA, day service)? Are there informal supports (family/friends/local groups) available to them? Can they manage any family issues that arise? Can they access transition supports—where they can receive training and perhaps live in a simulated ‘independent living’ environment?

This gives some idea of the range of elements an advocate may need to bring together to conclude a case. Much of the work involves accompanying the person in the process of making a decision and putting it into effect; but it also involves negotiation with official bodies and providers, making the person’s case at formal meetings or supporting them to do so. In some situations the advocate also has the role of putting forward options they (or their families) had not considered or signalling to providers that the person’s human rights are not being safeguarded. In the context of the Congregated Settings and Value for Money reports, this work is particularly important in ensuring that people are moved in a way that takes their individual preferences into account, rather than providing brownie points for the service.

Essential to all advocacy is the establishment of a good and trusting relationship with the person. Respect for the person and their decisions and, usually, their wishes is a key principle for advocates; although they must work within the law and within the resources currently available to the person.

The most common issues for clients relate to the old reliables, health and housing, followed by social welfare. A number of cases also involve the justice system; there are a few cases where the person with disability has been accused of a crime or where a parent with a disability is the subject of childcare proceedings because the HSE believes their children to be at risk. In such situations the advocate’s main role is to ensure the person understands the proceedings, has their voice heard and has access to any supports that exist.

The advocate’s work often exposes the gaps in support within our system, particularly at a time of recession: inadequate personal assistance hours, insufficient staffing for individualised programmes; delays in accessing appropriate housing and supports. The NAS annual reports bear witness to these and will shortly be available on the Citizens Information Board website.
IN JUNE 2011 the National Disability Authority commissioned Rape Crisis Network Ireland (RCNI) to undertake research on sexual violence and disability. This research aims to inform policy on providing appropriate disclosure support and abuse monitoring data systems to people with disabilities who are subjected to sexual violence. It identifies international models of good practice on data collection and makes practical recommendations for the collection of reliable data on people with disabilities who are subjected to sexual violence.

The research is structured into three strands:
- Analysis of three years of Rape Crisis Centre (RCC) data from the RCNI Database,
- Analysis of an online survey for people with disabilities What stops us talking about sexual violence?, and
- A review of 5 currently available data collection models.

**Strand 1: RCNI Database 2008-2010**

Data entered into the RCNI Database by 14 Rape Crisis Centres over a period of three years was analysed to produce the first detailed set of statistics on sexual violence against people with disabilities in Ireland. The RCNI Database is a highly secure online data collection system which equips RCNI to analyse detailed national data and deliver reliable, evidence-based findings and insights.

Between 2008 and 2010, 197 people with disabilities attended Rape Crisis Centres (RCCs) for counselling and support. (It is important to note that survivors do not always self-identify as having a disability and the counsellor may not probe into detail of a disability where not relevant to the healing process.) More than nine in ten of those 197 were survivors of sexual violence (93%).

Key findings include:
- There were few notable differences in the details of the sexual violence experienced by clients with disabilities and clients without disabilities, however,
- Survivors with a disability disclosed a lower incidence of sexual violence solely as children (48% compared with 61%) and a higher incidence of sexual violence solely as adults (42% compared with 30%) than people with no disabilities,
- Female survivors with a disability disclosed an increase in vulnerability to sexual violence as they age compared with female survivors with no disability who are disclosing a decrease as they age (48% compared with 33%),
- Survivors with disabilities who attended RCC services were more likely to have been subjected to a greater number of multiple incidents of sexual violence, than those with no disabilities (39% compared with 25%). (An incident is not necessarily a once-off act of sexual violence. It instead identifies if the sexual violence was connected by the same perpetrator acting alone or a specific group of perpetrators acting together. An incident of sexual violence may last hours, days, weeks, months or years. The RCNI Database collects data on a survivor’s abuse details by incident because it is the internationally recognised best practice method of doing so (Department of Health and Human Services, USA, 2009).

**Strand 2: Online survey – What stops us talking about sexual violence?**

The barriers for people with disabilities to disclosing sexual violence were explored through an anonymous online survey. In total, 137 people with disabilities participated in a nine-question survey with 111 respondents completing the survey.

About the participants:
- Seven in ten respondents were female, three in ten were male (72% and 28% respectively)
- 45% disclosed that they were survivors of sexual violence
- The highest percentage of sexual violence was disclosed by people with sensory and mental health disabilities (67% and 65% respectively).

Key findings include:
- Of the 50 respondents who identified as survivors of sexual violence, 30% were disclosing the sexual violence for the first time.
- Seven in ten men and four in ten women had never received any information on where to go for support surrounding sexual violence (71% and 44% respectively).
- Seven in ten of all respondents said that nobody had ever asked whether they had suffered sexual violence (71%).
When asked what would stop them from disclosing sexual violence, those who were survivors were far less confident to disclose than those who had not experienced sexual violence.

Approximately half of all survivors would not disclose sexual violence for fear of being blamed, fear of not being believed, fear of the abuser, or fear of the legal process (54%, 52%, 48% and 44% respectively). These were the top barriers to disclosure.

Approximately one quarter of all survivors would not disclose sexual violence for fear of getting into trouble, fear of losing support, fear that telling would decrease safety, or not trusting anyone enough (26%, 24%, 24%, 24% respectively).

(These findings represent only people participating in the online survey and cannot be used to make assumptions about the overall prevalence, incidence or attitudes surrounding sexual violence in Ireland.)

**Strand 3: Data collection models**

Comparable national data collection is important and states have responsibilities under international human rights law to collect disaggregated data on sexual violence, to support research and to monitor and report on sexual violence. Datasets from different data collection models are generally difficult to compare owing to differences in definitions, the absence of standardised national and international reporting requirements, and issues of data protection. A collaborative approach to data collection will strengthen understanding of issues and shape policy and practice. As survivors may disclose experiences of sexual violence to a very diverse range of people or places, effective data collection requires buy-in by many organisations.

Five relevant active data collection models were identified. Each model was developed specifically for use by sexual violence-related service providers. The five models were compared and contrasted across 10 different criteria, including disability indicators.

- **GBVIIMS:** UN Gender-based Violence Information Management System
- **SATU:** Sexual Assault Treatment Unit statistical database (Ireland)
- **RCNi:** Rape Crisis Network Ireland Database
- **Modus SARC:** Case management system developed in UK for inter-agency use
- **ViCLAS:** Royal Canadian Mounted Police (RCMP) Violent Crime Linkage Analysis System.

**Key findings include:**

- The lack of coordination and standardisation between agencies and countries means that none of the currently available datasets are comparable nor provide a complete national picture. Creating a set of shared indicators and definitions is key standardisation of data collection. These indicators and definitions should be based on international best practice.
- **RCNi Database** is a model of best practice and the lead data collection system in the Republic of Ireland. The best way forward in Ireland is to work with this existing structure. **RCNi disability indicators** are as in line with census questions as possible. These indicators should be implemented as standard throughout all data collection relating to sexual violence.

**Recommendations**

**Supporting disclosure by people with disabilities who have been subjected to sexual violence**

1. Train individuals, youth groups, peer groups, teachers, parents, carers, disability advocates and the disability sector on sexual violence, including how to respond to disclosures,
2. Ensure that education programmes and training aim to improve disability awareness and capacity in non-disability specific agencies including: An Garda Síochána, SATUs, carers, RCCs, and medical professionals,
3. Develop and update policies of disability service providers and support organisations on disclosure of abuse, to establish referral linkages and sign-posting to sexual violence services, in conjunction with Citizens’ Information Board and Personal Advocacy Service.

**Accessibility of sexual violence services**

1. Ensure that sexual violence services are accessible and skilled in delivering appropriate services and supports to people with disabilities who contact them, and that they are perceived as accessible by people with disabilities. **Cosc Awareness Raising Fund** should support strategies to improve perceptions of accessibility, confidentiality, referral and relevance of existing sexual violence services among people with disabilities.
2. Develop and display a code of practice for accessibility and consider dedicated personnel roles to respond to disclosure of abuse against people with disabilities. Consult National Disability Authority (NDA) free online materials for service providers in order to inform services, staff and volunteers and to disability-proof strategies for service provision.
3. Promote awareness of existing disability-accessible sexual violence services.
4. Work with disability service providers (building on HIQA residential standards) and support organisations to ensure vulnerable adults and children have access to supports external to their service provider.

**Research and data collection**

1. **RCNi Database** is a cost-effective, proven and established model for the collection of data on sexual violence against people with disabilities. Ongoing national development and buy-in from all services providing services to survivors of sexual violence with disabilities should be encouraged and supported by the Cosc Data Committee and the Health Service Executive (HSE).
2. As lead agency in the collection of national data in the sexual and domestic violence sectors, **RCNi disability indicators** are as in line with census questions as possible. **Cosc Data Committee** and **HSE** should ensure that these agreed disability indicators are standardised and recorded in all existing and new data collection systems relating to sexual violence, including RCCs, Refuges, Domestic Violence services and the SATU database amongst others.
3. Further data-mining and research on the **RCNi Database** as well as a national representative quantitative survey alongside relevant qualitative research as suggested by these findings. These should be publicly funded.

For more information email info@rcni.ie or go to www.rcni.ie/disability-1.aspx
HAVE YOU EVER wondered about how people with intellectual disabilities can access public services? Have you ever been curious about the best way to engage with a person with sight loss, or a person with autism?

The National Disability Authority has produced a short eLearning course to train public service staff to work with customers with disabilities. The course is available at http://elearning.nda.ie and takes about 70-90 minutes to complete. The course is open to everyone, though the best results will come when all staff within an entire organisation take the course. This will help all staff to think about the needs of customers with disabilities.

What is eLearning?

eLearning is the computer and network-enabled transfer of skill and knowledge. This course uses a computer and the Internet to train staff on dealing with customers with disabilities. The course follows Niall, a young man with an intellectual disability as he goes to renew his passport. Niall enjoys his independence, but sometime when he needs help, Audrey will support him. Using a mix of video clips, text and visual images, staff learn about working with people with intellectual disabilities, and indeed all disabilities. They overcome any nerves to find that it’s not that difficult to provide great customer service to people with disabilities.

eLearning can offer many advantages over traditional classroom training. The major advantage is flexibility. The course is available online, and can be taken anytime (24x7) that suits the student. It can be broken up over a few short sessions, if the student prefers. So there is no need to schedule staff, trainers, classrooms and all the other bits and pieces that are required for a classroom session.

Research suggests that eLearning allows for ‘learning compression’, where learning occurs at a faster pace than generally occurs in a classroom. Students can take the course at their own pace. They aren’t held up by the slowest person in the room, and they don’t have to wait for the teacher to answer other people’s questions.

What’s in the course?
The course provides a general introduction to disability, and some details about relevant legislation in Ireland. It introduces the concept of ‘reasonable accommodation’—those changes that service providers must make to allow people with disabilities to use their services. The course explains about how different types of barriers can cause problems for people with disabilities. This includes physical barriers (such as steps or heavy doors), attitude barriers (such as the way we think or speak about people with disabilities), and unintended barriers (such as complex language or small print on a website). An Irish language version of the course will be available shortly.

The course sets our four key principles to be considered when dealing with people with disabilities:

• Take your time
• Be flexible
• Don’t assume
• Just ask.

These four commonsense principles apply to any customer service situation, but are particularly important for people with disabilities. Some people might need more time to speak, or more time to handle their paperwork, so it’s important to give people the time they need.

Service providers will need to be flexible when dealing with people with disabilities. Some people will be unable to stand in a queue for long periods, or may find it difficult to read smaller print or a form or leaflet. So the provider might need to arrange an appointment at an agreed time, or provide a large-print version of a form or leaflet. This kind of flexibility goes a long way in allowing people with disabilities to access services.

Providers should avoid making assumptions about people’s abilities or disabilities. Some people will assume that persons with obvious disabilities are unable to make decisions for themselves. It would be rude and patronising for staff to deal with a carer or a parent first, or to assume that somebody needs assistance without checking beforehand.

The final principle, ‘Just ask’, encourages staff to check what assistance is needed, if any. If help is needed, then provide whatever reasonable assistance is required.

Exam time

The course includes ten multiple-choice assessment questions, to test that learners are picking up on the key
points. If the learner doesn’t get the question right first time, they can go back through the relevant parts of the course and then retry the question. Learners must get at least eight out of the ten questions right in order to pass the course and get their completion certificate at the end.

Accessible to all
The course has been carefully designed to be usable by everybody. For anyone who does not use a computer, there is a booklet version of the course available for download. All videos have been scripted to make sure that people with sight loss can follow them. Subtitles and transcripts are available for all the video clips, for those who are deaf or hard-of-hearing. Considerable care has been taken to keep the course content as short and simple as possible. Feedback from previous learners is generally very positive, including:

- ‘I like how they use plain and simple language to get things through.’
- ‘It is easy to understand.’
- ‘Easy to complete and yet very informative.’

Many public bodies are currently using the course to provide cost-effective Disability Equality training to staff. The course has been used by staff in local authorities and libraries around the country, and in agencies such as the HSE, An Post, along with a number of government departments. Over a thousand transition-year students have used the eLearning module to help prepare for their work experience over the year.

Try it out.
If you think this course might be relevant for your organisation, try it out—see http://elearning.nda.ie. If you would like to arrange for a custom-branded learning environment for larger organisations of at least 50 learners, please contact the National Disability Authority at admin@training.nda.ie or 01-6080405 for more information.

ON 4 NOVEMBER 2012, staff of STEP and City Gate in County Dublin and some of the men and women they support attended the Inside Out performance of their original show entitled Branching Out in the Smock Alley theatre. Derek McNamara, Jane Fitzpatrick and Damien McLoughlin left the emotive and informative performance with the message that now is the time to branch out and let people know what it is like to be a person with extra support needs.

The show was a stirring account of the challenges such people face as they attempt to integrate themselves into modern day society. The cast of Branching Out conveyed to their audience that despite their extra support needs they are entitled to the same freedom of choice as a typically able person would have when it comes to having friends, finding a job or seeking a sexual partner, should they choose to do so.

In a conversation after the show, Jane spoke to Derek about how the performance really showed ‘how angry people with extra support needs are. They were holding up signs with their feelings written on them like, ‘sadness’, ‘happiness’, ‘anger’, ‘fear’ and ‘loneliness’, to show people that no one is any different than anyone else just because they have extra support needs.’ Jane went on to say: ‘We just need to use our words and use our voice to show people what we want to have in our lives.’ Damien McLoughlin added: ‘The show was highlighting that we can talk for ourselves and it is our voice that people should be listening to when they want to ask about us, not our keyworker’s or our family’s voices.’

After the performance the cast members held an open forum with the audience, discussing what had happened in the show, and discussing their own experiences of what it is like to be a person with extra support needs. Jane noted that ‘the talk after the show showed me the strength that is needed to speak up for myself when I need to, and I got to see people speak strongly and confidently to an audience about what it is like to have extra support needs.’ Damien also spoke about the post-show discussion: ‘The challenge is for me to bring myself on in my own life. I have spent years not knowing how to read and write, but the chance is there now that I have found my voice and asked for help.’

Derek, Damien and Jane all agree that this show was a shining light amongst a population of people who at times are kept in the dark. The cast of Branching Out delivered a powerful story that meant something to them, and their passion inspired their audience to pick up on their strength and bring their message forward. Damien and Jane’s message in return to the Inside Out Project and the Connect People Network is that we have heard you and now we too want to be heard. However, they have also issued a warning to the cast to watch out—because next year they want to take the leading roles!

Derek McNamara, Damien McLoughlin and Jane Fitzpatrick from STEP and City Gate in Dublin went to see Branching Out, an original show by the Inside Out Project in association with the Connect People Network.
DISABILITY AWARENESS

STICKS AND STONES:
DISABILITY AWARENESS IN SCHOOLS

Michael Teehan, Sunbeam House Services, Co. Wicklow

Do you remember the first time you met a person with an intellectual disability (ID)?
Do you remember the preconceived ideas you had about people with ID?
Do you remember the names people with ID were called? (spa, simple, mentaller, etc.)

If you are not acquainted with anyone with ID and you don’t work in the disability area, the answers to those questions still give a lot of food for thought and reflection.

Why we decided to create a disability awareness programme
In recent years people with disabilities have been receiving a much more positive profile in the media. To a large extent this can be attributed to events such as Special Olympics, the trend towards mainstreaming children with ID in schools, and—not least—the strides made by the disability movement towards community integration. The media have also been highlighting the serious psychological effects of bullying on individuals. In view of all these factors, we assumed that the level of harassment and negative attitudes towards people with ID was on the decrease. However, when the grand-daughter of one of our staff members confided that some kids in her class enjoyed taunting and jeering people with ID, we decided it should be part of our role to try to do something to change this.

How we devised the Disability Awareness Pack
In keeping with the ethos of inclusive research and the People First motto of ‘Nothing about us without us’, we enlisted the help of our service users from the beginning of the project. We were guided by the issues that were important to them. One of the first areas we looked at was the extent to which jeering and taunting was still a problem. We set up focus groups and broached the topic of negative experiences in the community. We were surprised to find that many service users, particularly the more independent people and those who travelled on public transport, still experience a significant level of taunting and jeering. They also told us about some of their experiences of everyday life where they felt they were treated unfairly in pubs, shops and on public transport etc. Some of the older service users said that ‘It used to be a lot worse in the past. Sometimes the staff had to call the guards.’ But another independent traveller told us that she is afraid of ‘teenagers on the buses’, because she had been taunted and jeered by them. Her way of dealing with the problem was to change bus routes, even though this added an extra 30 minutes to her commuting time. An older service user told us about his experience of serious harassment in his locality, which has been going on for years in the small town where he lives.

Following these discussions, we asked the groups why they thought people jeered and taunted. The answers were very varied and insightful. Some service users dismissed the experience and said the people who jeered were ‘just ignorant and stupid’. They seemed to be able to take it in their stride. However, more worryingly, some people seemed to indicate that it was a normal part of their everyday lives. Unsurprisingly, most people in the groups said they found it very hurtful and upsetting when it happened.

We then consulted the service users about what other topics we should include in the training. The main topics the groups wanted to include were:
- Equality and human rights
- Treating everyone with respect and dignity
- Making allowances for people with specific disabilities in certain situations
- ‘Look at the ability and not the disability’
- We all have the same feelings and should be treated in the same way.

The format of the training. No fancy graphs or statistics…..
With the information gathered from the focus groups, we set about designing some PowerPoint (PP) presentations. We did some cursory research into disability awareness training provided by organisations and consultancies, but they seemed to be overly medical and technical. It appeared that they were geared towards professionals or people working in the area. As our target audience was secondary students and the general public, we used plain English and did not make the presentations too technical.

The first presentation is a very general overview of various disabilities, with a little information from the World Health Organization (WHO) on how most of us, at some stage in our lives, will experience disability. It also includes slides on human rights, treating people fairly and respect and dignity. This presentation is usually delivered by a member of staff. After that we show a DVD featuring some of the service users at Sunbeam House Services, who talk about their everyday lives.

Finally, two service users present a PP about their lives. This includes slides on their education, employment, relationships, hobbies...
and interests and their goals for the future. This is by far the most effective section of the programme and it is most commented on feedback sheets.

Feedback
For the past three years, in conjunction with Bray Partnership, we have been delivering the programme to secondary schools in the Bray and Greystones area. We have also delivered it to County Wicklow staff, Wicklow VEC staff and staff from our local leisure centre Shoreline. At the end of the programme, which takes approximately one hour, we ask the audience to write some brief feedback comments on what they thought of the programme, and what they thought was the best part of the presentation. The vast majority of the hundreds of comments we got back said that the best part of the programme was meeting the service users and listening to them talk about their lives.

‘I loved this talk. It was definitely the best seminar we had this year. I learned a lot about Gerry and Dan and how their lives are not that different from ours.’

‘I thought it was all very good. Having a learning disability myself I know what it is like to be mocked for being dyslexic.’

(Transition year students at St David’s Secondary School, Greystones, Oct 2012)

What we learned from delivering the programme
A couple of things became clear to us from delivering the seminar and looking at the feedback comments. It seems that many of those who attended the sessions had little or no personal interaction with people with ID. It was also apparent that despite the raised awareness of disabilities and more positive media attention, people with ID are still considered to be ‘other’ and intrinsically different from the majority of society.

THinking IN DisABIlity ORGANISATIOnS

by Angelina Veiga, Disability Psychotherapist

DISABILITY ORGANISATIONS TEND to promote the concepts of advocacy, self-choice and self-determination under the guise of a person-centred ethos and subscribing to the UN Declaration of Human Rights and the UN Convention on the Rights of People with Disabilities. However, in practice some organisations are not actualising what they promote. Instead, and increasingly we are faced with organisations operating in states of anxiety and crisis, where systemic despair envelops those being supported by the disability service. This creates an anxiety felt by all those within the system. The trauma of disability becomes further traumatising for those not adequately being contained at a psychic level due to increased anxiety in the organisation.

While it is acknowledged that many agencies are excelling at service delivery to enable people to live as independent and self-actualised lives as possible, it is this author’s experience that there are exist agencies that are unable to provide a thinking space for all levels of staff to reflect on the experience of a disabled organisation. A disabled organisation is an organisation that finds themselves unable to think. They lose the ability to think about the effects of disability on people whom they support. This non-thinking state vibrates through and paralyses the organisation’s capacity to think and reflect. The organisation becomes traumatised.

In disabled organisations a culture develops that consists of crisis management and scapegoating. Dissociation in service provision develops. Management teams dissociate from the experience of lower-ranking staff, who in turn dissociate from the disabled people they are supporting.

Disability by its nature draws a projection of societal hate and fear; these states are projected onto the disabled person. In disabled organisations this is mirrored within staff teams and through organisational dynamics and modes of relating. Furthermore, a hierarchy of projected disability can exist amongst people with disabilities themselves.

The demand for organisational advocacy is infused by the hate of the advocate for challenging longstanding organisational culture and beliefs necessary for introducing change. The advocate must become creative and strategic in their approach to encourage, empower and influence thinking and unconscious belief systems to explore and implement lateral thinking among resistance by those who hold power, whether through organisational dynamics or employment contracts. The advocate finds themselves a lone voice and bearing witness to the projections of disabled thinking and non-thinking states that see the hate of disability seeking to find containment in the advocate. The system is not set up to support the advocate to complete the organisational tasks set. The advocate takes refuge in small victories and thinks about the internal world and experience of the person with disabilities.

Disabled organisations lose the ability to work relationally—i.e. to consider self with other (De Young 2003). They also lose the ability to mentalise (Fonagy, Gergely et al 2004). Human beings are essentially meaning making and relational beings that seek to understand relational experiences. Disability can be experienced as continuous trauma that contains losses, abuses and the infringements of human rights. It is extremely painful to think about the losses and infringements that people are experiencing on a daily basis as they access services. These losses can include the loss of relationships, sexual lives, financial control, privacy and health, amongst others.

Organisations struggle to contain the anxiety inherent in the attempt to deliver a service with fewer resources. This is a real and traumatising reality in this current climate of cutbacks. These cutbacks result in reducing quality of life of those most vulnerable and those who are less able to advocate for themselves. The emotional and practical effects of these cutbacks are enormous.

Disability service provision calls for the examination of the emotional impact of the disability. Examination of impact of disability can occur in reflective meetings, where open and honest discussion of all aspects of work is encouraged. These types of meetings promote insight and lead to healthy organisational functioning (Hopper 2011). When agencies struggle to provide thinking spaces and contain the anxiety and pain of disability, there cannot be a culture of advocacy, self-determination or choice. The anxiety of the current financial experience for disability organisations moves managers away from thinking about the lived experience of disability to ‘managing the books’. There needs to be space for people to bear that which is most unthinkable—the pain of a life unlived and the pressures to exist against societal repulsion and financial constraints. Without thought, trauma paralyses the thinker; with thought there is some respite and a capacity to hope that things can be made better or at least survived.

References available upon request from the editor
Jonathan Egan shares his tips on how fellow psychologists can keep the stresses of the job at bay.

AS A PSYCHOLOGIST, I suppose I should have a lot to say about wellbeing, although it is sometimes difficult to practice what I preach, particularly with two very small sons (Ted aged 2 years, 3 months, and Leo, a sparking 7 month old). I have, however, come across some bits of wisdom from the behavioural and medical sciences, and here are my top nine suggestions toward fostering your wellbeing:

1. Sleep well
A good night’s sleep is probably one of the most underrated aspects of wellbeing. Poor sleep is related to worsening anxiety, depression, pain and a multitude of other unwanted side effects. Marital satisfaction slips, simple mistakes of memory and planning occur. For example, during long periods of night baby-feeding (an attachment behaviour akin to the torture technique of waterboarding), I have found myself putting the kettle in the fridge, forgetting appointments, thinking I had written things in my diary which I hadn’t, yawning rudely during telephone calls and being irritable with my wife. So here are some tips: exercise early in the evening, allowing your body to warm up and then cool down. Have the bedroom slightly cooler than the rest of the house. Do not bring your laptop to bed. Throw out any clocks or at least have the alarm out of arm’s reach, and never look at the time—you’ll just end up calculating how many minutes or hours are left before you have to get up and an adrenaline cascade will have you awake until 20 minutes before the alarm goes off. I write from hard learned experience. Next, for me at least, no caffeine, which means tea, chocolate or coffee after four pm. Coffee has a half-life of 2.5 hours, so that a coffee at 10.00 pm will still be at half strength at 12.30am and at quarter strength at 3am!

If you have a problem with sleeping (insomnia), then do not go to bed earlier. The best way to return to a normal sleeping routine is to anchor your sleep by your wake-up time, and (this is the difficult bit), try to keep to a similar routine at the weekends. It may take them until Wednesday to get back to a normal routine, after a few weekend late nights or lie-ins. (But, obviously I do not have the luxury of lie-ins anymore, anyway.)

2. Don’t prejudge events
Try not to catastrophize or personalise events. Psychologists have consistently found if one jumps to the conclusion, from a small piece of evidence, that something awful is going to happen, it is then very difficult to stop the ‘awfulisation’ process; mountains are truly made of molehills. Where I work, in the Mater Hospital, patients coming in for test results often misperceive the mood of a nurse or doctor as evidence of dire awaited results, anxiously examining the professional’s face for signs of impending bad news.

3. Talk
A problem shared truly can be a problem halved. In cardiac research we refer to some people as having ‘a Type D personality’: those who are experiencing emotional distress, but who do not feel inclined to share or be relaxed socially. They are far more likely to have another heart event or procedure than those who share their problems. Interestingly, when you look at most physical illnesses, those with a wider, accessible social support network tend to live longer and have a better health prognosis. Illness is really a social thing—if one’s husband or wife is sick, it also makes the couple and family sick. (We have learned to invite partners to training events, as it seriously improves outcomes.)

4. Relax
Relax/be mindful: Learn some form of relaxation or mindfulness technique, or pray for fifteen minutes every day. Fifteen minutes has been shown to be the magic figure. People who practise the relaxation response on a daily basis have lower levels of stress and their wounds (such as ulcers) heal more quickly. At a physical level, the alarm system which produces cortisol and stress hormones (e.g. adrenaline and nor-adrenaline) is less active. In addition, pro-inflammatory cytokines in the body are reduced and people with painful conditions report that they feel better. I have just taken part in a study using an online mindfulness and stress management programme with fellow researchers, Angeline Traynor and Brian McGuire in Galway. We found that six weeks of relaxation reduces pain ratings in chronic headache and migraine sufferers, and that their quality of life improved, they had fewer headaches and were taking fewer pain medications. Pain medication overuse has been linked to the body developing rebound headaches, just to get the user to take more pain medication. (You can check our website, www.headachemanagement.org, or look at additional information on the International Association for Pain website www.iasp-pain.org. Dr Tony Bates has a number of good books (available in Easons) which contain excellent CDs on mindfulness. He also addresses low mood and depression.)

5. Walk or swim
As we get older, many of us develop aches and pains. Our natural response is to reduce our level of activity when we feel pain, but this is the wrong thing to do. A friend of mine with back pain was told he could have an operation, or he could just walk. When he had stopped walking, he was told to ‘walk some more’. Looking back at the paragraph on sleep, I am reminded of my own recent knee pain. Many analgesics contain caffeine, so the result of using them was less knee pain, but being wired and awake all night! Something else I’ve learned from ‘painful experience’.
6. Water, fibre and wine
Drink water, eat fibre and have a couple of glasses of red wine. Red wine is full of resveratrol which is good for antioxidants and helps to prevent clotting. Most of us do not drink enough water and we eat insufficient fibre, which does not help in the stomach department or further down. Make sure you have at least two days a week without alcohol. Never ever drink and drive, it will cost you a fortune in dry cleaning.

7. Laugh
In general, a mood last from 2 to 2½ hours, and they are contagious. In a previous life, when I worked as a director of counseling in the HSE for adult survivors of childhood abuse, between counseling sessions, I often watched a You Tube clip of quadruplets laughing at their father. No matter what had just happened in the treatment room, this clip would bring me back to my normal mood, after a minute of gleeful laughter. (Go on, check it out: http://www.youtube.com/watch?v=WxUulGkLu4I. If you do not smile at the clip, you definitely need to talk to somebody!)

Laughter and humour allow us to observe the unobservable in our lives. We tend as Irish people to be good at humour: ‘You know, he never looked so well’—a comment I overheard between two men having a fag outside a house after a funeral.

8. Use your employee assistance programme
If your mood is low persistently or you cannot shake off your worries, use your free employee assistance programme. They are great and many organisations allow up to six free counseling sessions. The American Psychological Association declared last year that therapy and counseling have been scientifically shown to be effective for approximately 80 percent of people; the National Institute for Health and Clinical Excellence in the UK recommends therapy before most antidepressant treatments.

9. Breathe
You would be amazed at the number of people who breathe shallowly. Place one hand on your sternum and the other on your belly. Take a deep breath in. If your belly fills like a balloon, then you are breathing correctly, if your chest rises and your belly stays flat, then you are breathing shallowly. Most good yoga teachers and relaxation and stress management courses cover this. Put little stationery notes around the house to remind you to check your breathing. The trick is to breathe in this new manner forevermore!!! Breathe out for six, then breathe in for four, and then hold this breath for a further four and repeat. Interestingly people who breathe shallowly often also report dizziness, numbness or tingly fingers. Some people worry that this is a sign of an impending tumour. (Of course, always get things checked out by your GP—I have to say this because my wife is a GP in Galway!)

And so, that’s my top-nine. I personally would also include buying a season ticket to Connacht Rugby, but that may not appeal to everyone. Every Christmas and birthday I ask for presents of deep tissue or hot stone massages. (This does not appeal to many men and it’s not as macho as the rugby season ticket.) Finally, I am firm believer in Rioja, and I was also an avid fan of delicatessen cheeses until I saw the results of my cholesterol test (8.2). Now I believe in a dairy-free diet and a daily dose of Lipitor!

RESEARCH ACTIVE PROGRAMME: IDS@UL
‘NOTHING ABOUT US WITHOUT US’ is a call for academics and policy makers to include people with disabilities in all stages of the research process. The Research Active Programme (RAP), recently piloted by the University of Limerick and grounded in the UN Convention on the Rights of People with Disabilities, was designed to:
1. Enable people with intellectual disabilities to become critical consumers and co-producers of research,
2. Establish a core group of co-researchers to work alongside members of Intellectual Disability Studies @UL, and
3. Create an opportunity for people with intellectual disabilities to participate in third-level education.

RAP is an initiative emerging from Intellectual Disability Studies @UL (comprised of colleagues in clinical therapies, nursing, clinical psychology and health psychology). Nancy Salmon and Eileen Carey developed and piloted the 8-week RAP curriculum with disability advocate Martina Neylon and peer mentor Joe McGrath. Before joining RAP, each student was interviewed about their learning style, communication strengths and research awareness. That information shaped the structure and content of sessions, enabling everyone to engage equitably in the learning process. Fourteen lifelong learners participated in the RAP sessions, which included: Making Research Work for You, Being a Co-researcher, Your Rights in Research, and Telling People What You Learned.

Each week, students highlighted what they enjoyed and what could be improved, ensuring that their perspectives continued to inform curriculum development. In the final week, students showcased their work in a group presentation to over 40 family and friends. RAP far exceeded its aims, given the pride and sense of accomplishment expressed by the people with intellectual disabilities, who were by then comfortable and confident UL students. Graduates co-presented at the Intellectual Disability Studies Conference held at UL in June—another terrific outcome.

We are excited about extending RAP to a full module where people with intellectual disabilities, students in the health professions and service providers can learn together and practice socially responsible, inclusive research. Nancy Salmon, PhD, Lecturer, Department of Clinical Therapies Eileen Carey, Lecturer, Department of Nursing and Midwifery, University of Limerick

RHYTHM ROOM
An Integrated Theatre Company, is committed to making art accessible to everyone (in our case - music, dance and movement) and to take this a step further by creating unique productions. The Theatre Company is in rehearsals with an exciting new production CAN I FIT INTO THIS? Keep up to date with their progress by following their blog at: rhythmroom.tumblr.com. You can also track the company on: www.rhythmroomdublin.com.
Disability in the published articles on men’s health in intellectual disability.

Based primarily on generalisations from clinical and research findings of our knowledge on health issues for people with intellectual disability is medication as three significant risk factors for ill-health for people with nutrition, lack of exercise or inactivity and inappropriate or overused why there is a shorter life-expediency for people (and specifically for men) 46 years. The average age of death in Ireland for individuals with intellectual disability is from all the leading causes of death (McEvoy and Richardson 2004). Disability, who remain a marginalised group.

In the wider population men die younger than women and suffer more from all the leading causes of death (McEvoy and Richardson 2004). While male life expectancy in Ireland is currently 78 years for men, the average age of death in Ireland for individuals with intellectual disability is 46 years. There is no difference in lifespan between men and women with intellectual disability or within the levels of disability (Lavin et al 2006). Men with intellectual disability die approximately 31 years earlier than men in the general population.

Morbidity can provide a better explanation and health indicator as to why there is a shorter life-expectancy for people (and specifically for men) with intellectual disability. Prasher and Janicki (2002) identified poor nutrition, lack of exercise or inactivity and inappropriate or overused medication as three significant risk factors for ill-health for people with intellectual disability. According to Prasher and Janicki (2002), much of our knowledge on health issues for people with intellectual disability is based primarily on generalisations from clinical and research findings of the general population. There is limited health research and very few published articles on men’s health in intellectual disability. While no argument is made for a specific focus on men with an intellectual disability in the National Men’s Health Policy (2008), there are appalling statistics of mortality and morbidity in men in the general population, and in a number of barriers that men face in achieving optimal health. More research is needed to understand the differences which may exist between the statistics for men with intellectual disability?? (Prashe and Janicki 2002). Health research on men with intellectual disability can lead to a clearer picture of their health, the barriers they face to prevent illness and how to promote high-quality health practices.

People with intellectual disability face many barriers to achieving good health and men with intellectual disability face their own unique barriers. The barriers to achieving good health for men with intellectual disability are specific to their peer group and vary in many indistinct ways. Many of the barriers to health are directly related to gender values, while others are barriers directly related to intellectual disability.

Gender neutrality and obscurity

Umb-Carlson and Sonnander (2006) looked at the living conditions of people with intellectual disability from a gender perspective. They found that people with intellectual disability were treated as gender-neutral, rather than as men and women with individual preferences and needs. The study found that having an intellectual disability was a more important determinant than gender in regard to living conditions for people with intellectual disability. People with intellectual disability were treated as a standardised group categorised by their level of disability and general service needs. Health issues for men and women with intellectual disability can be disregarded because of the lack of gender identity in the gender-neutral world of intellectual disability. In Ireland, an example of this approach can be found in the National Intellectual Disability Database (NIDD). In the NIDD, which provides information to plan services for the population of people with intellectual disability, gender is recorded and noted, but it is not planned for (Kelly et al 2008).

People with intellectual disability seem to face a gender-neutral wall where, although gender is noted, it is not referred to or considered in service planning. Arrangements are made based on the whole intellectual disability group and not referring to or any gender difference. Society appears to be blind to the significance of gender in planning for individuals with intellectual disability—whether they are girls or boys, men or women. Frey et al (2008) argued that the combined gender groups used in studies obscure unique physical activity patterns associated with health determinants. Many research studies in intellectual disability can produce ambiguous patterns in results because specific gender is not reported or discussed. An Irish survey on health behaviours by Maguire et al (2007) found no significant gender difference in five health domains of diet, physical activity, smoking and alcohol, medical appointments, and level of choice. Although they found no gender difference in the results for individuals who smoked, a further look at the study showed that of the 4 people within the study who smoked, all were male.

Health promotion of homogeneous men’s health

Richardson (2004) carried out a comprehensive and influential study on men’s health in Ireland, entitled ‘Getting inside men’s health’. The study highlighted that men’s health can be viewed simplistically as a single homogeneous set of men’s health issues. Problems in men’s health, such as cardiovascular disease, overweight, prostate cancer, erectile dysfunction, are all treated individually, with no attempt to deal with the influence of cause and effect—in numerous cases due to male behaviour. Richardson (2004) argues that men’s health should be defined in its own right, while taking into account all the wider factors such as age, social class, race, marital status, disability, and living settings—all of which have a significant bearing on health status. Williams (2006) argued that men’s preventive health needs can be effectively met in primary care, but that a ‘one-size-fits-all’ approach to men’s health is unlikely to be effective. They suggest that a specific approach is needed for particular groups of men. This is especially relevant for men with an intellectual disability. In looking at the health of men with intellectual disability it is necessary to consider the different sub groups, and levels of disability which can affect health demands over a lifespan. Wass (2000) argued that people with intellectual disability do not fit neatly into the continuum of health promotion and disease prevention agendas. The causes of health problems and associated risk factors are confounding aspects that make it very difficult to understand and manage health issues for people with intellectual disability.

Nursing and women as a barrier to men’s health

Women are found to be a potential barrier in the treatment of men’s health, particularly in nursing and the caring professions where there is a
Back to Ballymun
by Máiréad Woods

I WENT FOR an uncomfortable trip down memory lane last night. It led me past a clinic where I had brought my four-year-old daughter in 1975, to a school hall in Ballymun where about one hundred people were sitting under children’s art work. Waiting for bad news.

Many of them had white hair, a few walked with sticks. Many had been through the pre-HSE versions of this movie when disability services were cut in the eighties. In those days I had been one of them.

My daughter had Rett Syndrome—the type of disability where you need support for everything; every piece of food that goes in your mouth; every soap-sud that runs down your back. If she were alive today, she’d be 41. I’m in my sixties and I’d come to support the service she had when she was alive. The service had been started by a determined mother in the 1950s and it’s a good service: dedicated staff, flexible, innovative. Like all HSE-funded services, it’s threatened by cutbacks. I miss my daughter, but tonight I think maybe she’s better out of it. I’m near the end of my capacity to care for a person with her needs and the HSE has intimated to St Michael’s House that people with disabilities cannot continue to have a ‘gold-plated service’.

Notice that word ‘gold-plated’. It suggests luxury, extravagance … but the day centres my daughter attended were located in ordinary houses in unpretentious suburbs— as are St Michael’s House’s residential houses. Staff are not overly medicalised or expensive. ‘Normal’ is what they’re aiming at. ‘Gold-plated’ is part of the ideological speak which seeks to shift responsibility for costs from the state to the vulnerable.

There’s nothing of Versailles about a good disability service—the gold lies in the people, the social care workers, the Link girls, the house parents, the nurses who open up the world for those who can’t do it for themselves. People pay money, but in this area they can’t be replaced by robots. The cuts have shaved about €11 million off the St Michael’s House budget in the last four years, but more difficult has been the moratorium on staff recruitment. Worse still is promised in the next Budget. Services are faced with various Catch 22s. Under ‘Section 38’ they can’t recruit staff; agency replacements are being cut; HSE agreements tie them to a certain level of service; yet HIQA standards (which have staff-client ratios) are being introduced.

And St Michael’s House has particular problems. On the one hand its original service-users are getting old and losing their parents—that invisible night shift who have to be replaced by waged workers. On the other hand, its catchment area is mainly North Dublin, an area with the highest birthrate in Europe. Should St Michael’s House withdraw from its elderly residents? Or refuse parents with newly diagnosed babies. Or turn its back on school leavers?

It’s not as if the organisation’s costs are average: the opposite in fact, according to the new Bible Value for Money. But that doesn’t seem to gain them any brownie points. And when your funding is cut and you can’t employ staff, what option do you have but to reduce services? St Michael’s House is trying not to do this, but there is only so much elastic in any system and the innovative and personalised extras are beginning to suffer. Parents were asked to volunteer their help for outings and hospital visits, and most are happy to do so. But not every client has an able-bodied parent.

The Department of Health and the HSE keep repeating: No more money. Yet there is money for TDs’ allowances, for ‘special’ advisors, for tribunal lawyers, for a referendum. How many social care assistants would that money fund? The policy-makers talk about a new model of ‘individualised service’, as if there was a magic formula to provide ‘better’ services at a reduced cost. I’m very glad I’m not negotiating alone for an ‘individualised’ service for my daughter. In my time I’ve seen a lot of models of disability provision strut and fret their hour on the stage—but a good service for people with significant disabilities always depends on the same things: enough kind, dedicated and imaginative people on the ground and an efficient system behind them.

I felt pretty sad listening to the parents in Ballymun. We’ll march, they said. Like the farmers. We’ve made Reilly listen, they said. Lobby, said the politicians (the younger, less secure variety). Eighty-year-old parents spoke. They had thought their middle-aged sons and daughters were secure and happy in a community house; now they didn’t know. Younger parents were worried about the post-school scenario. There was a mother who wanted to volunteer for outings, but she didn’t have the energy; her child hardly ever slept.

It isn’t nice to have to disclose sad stories in order to get supports for an ordinary life. It isn’t nice to hear well-dressed people who hold the purse-strings squabble over what the bare minimum is for the likes of people with disabilities. Health cuts hurt the old, the sick and the handicapped—that was one of our slogans in the 1980s. The terminology may have changed, but I fear not much else has.

---

Memory Lane

It isn’t nice to have to disclose sad stories in order to get supports for an ordinary life. It isn’t nice to hear well-dressed people who hold the purse-strings squabble over what the bare minimum is for the likes of people with disabilities. Health cuts hurt the old, the sick and the handicapped—that was one of our slogans in the 1980s. The terminology may have changed, but I fear not much else has.
‘FORENSIC DISABILITIES’, a morning seminar led by Tamsin Cottis and Richard Curen of Respond, London, brought us into the world of intellectual disability, trauma and sexual harmful behaviour. Respond has pioneered the use of psychotherapy as a treatment choice for those who have experienced abuse and trauma, and for those who have abused others. Besides psychotherapy, Respond also has a range of other supportive services which they provide for those most vulnerable.

The Respond model is based on attachment theory, neuroscience, object relations and using a relational psychotherapeutic relationship to attribute meaning to thoughts, behaviours and expressions. The notion of thinking, reflective functioning and developing and increasing the ability to mentalise as a means of understanding trauma was explored during the seminar. We considered how early trauma—in particular, domestic and sexual violence—can affect the developing brain.

Richard, a forensic psychotherapist, briefly introduced the services of Respond. Tamsin, an integrative child psychotherapist, then spoke about her work with adolescents and young adults. She offered the thought that ‘what goes around comes around’, in that the past is always present in one’s experience. This is a chilling thought, as we considered the effects of trauma and violence on the developing mind. She promoted psychotherapy for this group to be chiefly concerned with providing a high quality thoughtful relationship with very damaged people. She stressed that a child needs assistance to make sense of the experience of sexual abuse. Play and expression are helpful therapeutic techniques, as they put outside the child what is inside him in a contained way. The therapist needs to be aware of the child’s attachment styles as it affects the child’s attachment behaviour. She highlighted that children from age 5-8 years have harsh superegos and that we should never underestimate the child’s desire to stay out of trouble. Children learn to shut down and the provision of therapy allows for a safe expression of feelings.

We learnt that a frightened child’s brain floods with cortisol and this affects brain development at the expense of thinking and developing. Therapy can become a place to experience regulation. Children who cannot regulate their feelings need an opportunity to do so, and this can happen through play. In play, a child can do violent things, which allow them to get the violent images out of their head for someone else to see and make sense of. She spoke about the impact of witnessing domestic abuse on young minds and its links between sexual abuses between children as a way of making sense of the experience. She also highlighted the early experience of being loved for who you are and how negative attachment experiences impact on a young mind. Again and again she returned to the idea of creating a thinking space in the relational experience between child and therapist.

Richard spoke about his work with young adults and adults who display sexually harmful behaviour.

With forensic clients, a thorough risk assessment phase is part of any Respond treatment. The risk assessment is therapeutic and focuses on the behaviour and what it feels like to be that person. Adults were once children and their early experiences are considered. He outlined factors affecting sexual development that include poor attachment and being victims of sexual abuse and violence, lack of ‘normal’ sexual development such as experimenting with peers, and parental denial of sexual development, or their anxiety towards it. This is then linked with limited sexual knowledge, supervision, lack of privacy, being impulsive with fewer inhibitions, lack of opportunity to purchase items with an erotic charge and difficulties making peer relations. Intellectual disability and paraphilia were considered and he suggested that for some, intellectual disability could be a paraphilia.

Richard introduced the idea that paraphilia could be a defense—against unstable sexual identity, loneliness, anxiety, shame, anger or the demands of life. He also suggested, based on Stanley Ruszczynski’s work, that paraphilia could be a result of loss. Loss can be the result of the experience of not being contained or not having learnt to mentalise. The core clinical issues with this population include guilt, rage, shame, ‘damage goods syndrome’, fear, sexualisation of anxiety, disability, dissociation and denial and confusion.

Sheila Hollin’s ‘Three Secrets of Disability’ are considered in treatment. These secrets are Sex, Death and the Disability itself. Treatment hopes to increase the capacity for reflection, in order to support difficulties in managing compulsions. Treatment also focuses on the positive in people’s lives and the therapist retains hope that things can be made better. For the therapist this can seem, at times, unsatisfactory. Supervision and team meetings are seen as invaluable as they involve in their inherent nature a thinking space with another.

There was a short question and answer period at the end of the seminar. Participants were interested in the ideas of infantile containment as advocated by W.B Bion and D.W Winnicott, the capacity for reflection, play, the systemic approach to delivering psychotherapeutic treatment utilising a case manager who acts as a bridge between the therapist and outside supporters, and who provides consultation with staff and services to assist them to think psychodynamically so that treatment is not sabotaged by those who do not understand why it is so important and more than just sexually harmful behaviours. The seminar presenters then answered individual questions and distributed literature about Respond and Books beyond Words.

The seminar proved to be a thoughtful and thought provoking experience. It highlighted how thinking about one’s early experience and behaviour and the ability to think and be thought about play a significant developmental role. Most importantly, the seminar provided an opportunity for participants to come and think together, so that those most vulnerable are thought about and understood. Without thinking and understanding together, the experience and perpetration of trauma continues in isolation.
DESPITE THE FACT that over 9,000 people are availing of residential disability services in this country, there is no oversight of the standard of care being provided to any person. With this in mind, on 17 October, the Health Information and Quality Authority launched the draft national standards for residential centres for people with disabilities. These standards describe the essential elements of quality and safety that both children and adults who use these services have a right to expect. This article explores the impact that the draft standards will have on the provision of appropriate and high-quality residential care for people with a disability.

Why standards?
It is important to put the issue of regulation and standard-setting in healthcare in context. In the last decade alone in Ireland there have been numerous examples of bad practice, resulting in enquiries or reports that have raised serious concerns regarding the workings of the healthcare sector (e.g. the Clark enquiry into peripartum hysterectomy at Our Lady of Lourdes Hospital and reports into aspects of care in Mallow and Tallaght Hospitals (Clark 2006; HIQA 2011b, 2012b).

In relation to the disability sector, a recent shocking case occurred in the UK when eleven former staff at the Winterbourne View hospital in Bristol (for adults with autism and learning difficulties) pleaded guilty to beating patients, dousing them in water and encouraging some to consider suicide (Hennessy 2012). Following the concerns highlighted at Winterbourne (an English private hospital group owned by Irish investors), the Care Quality Commission carried out a programme of unannounced inspections of services providing care for people with learning disabilities and challenging behaviours. The results from the 150 inspections showed that 69 failed to meet standards relating to care and personal safety. Many of the shortcomings were a direct result of care that was not centred on the individual or tailored to their needs (Care Quality Commission 2011).

These examples from the Irish healthcare system and disability sector itself highlight the need for a regulatory environment of quality and safety standards designed to protect the rights of people who use services, particularly the most vulnerable and disadvantaged (Adil 2008).

What are these new standards?
The Draft National Standards for Residential Centres for People with Disabilities (the Standards) are standards to be applied by HIQA (2012a). The standards consist of eight main components, known as themes. Each theme identifies the key topics for quality and safety which are addressed by the standards. The eight themes are person-centred services/child-centred services, effective services, safe services, health and development, leadership, governance and management, use of resources, workforce, use of information.

These themes are divided into 31 individual standards for children and 31 individual standards for adults. Each standard consists of:

- **standard statement** which describes the high-level outcome required to deliver quality residential services and residential respite services for adults and children
- **criteria** that, taken together, will enable progress towards achieving the standard
- **features** under each standard statement which give examples of what the residential centre may consider in order to meet the standard and achieve the required outcome.

Who or what is HIQA?
HIQA was established by the Health Act of 2007, with the object of promoting safety and quality in the provision of health and personal social services for the benefit of the health and welfare of the public. HIQA has a number of statutory functions including:

- to set standards on safety and quality in relation to services provided by the Health Services Executive,
- to monitor compliance with the standards,
- to undertake investigations,
- to operate accreditation programmes, and
- to evaluate the clinical and cost effectiveness of health technologies.

HIQA is perhaps best known for its thematic reviews of particular kinds of healthcare and service provision in nursing homes and also for its unannounced visits in relation to hygiene in acute public hospitals. However, HIQA’s remit also extends to investigations of services.
where there are reasonable grounds for believing there is a serious risk to the health and welfare of a person receiving those services (under Section 9 of the Health Act 2007). The investigation related to the care given to Mrs Rebecca O’ Malley and the pathology services in CUH and Limerick Regional Hospital are an example (HIQA 2008).

To whom will these standards apply?
The HIQA standards will apply to services provided by all types of service providers whether public bodies, private organisations or voluntary agencies. They will apply to all residential care services for children and adults with disabilities, including:
- congregated services and institutions,
- group homes, and
- community houses.

HIQA as regulator
A HIQA inspection in relation to these standards will most likely consist of:
- meeting with residents and relatives,
- observing the day-to-day routines and activities,
- talking to staff about their understanding of the care they deliver,
- checking premises and equipment to ensure they are safe and promote the wellbeing of residents, and
- reviewing key records and relevant documentation.

HIQA will also have enforcement powers following an inspection, so the implications for healthcare providers are significant. For example, in relation to other designated centres there are two main enforcement measures:

1. Non-statutory enforcement action which can consist of

   Inspection report: The inspection report will clearly set out any improvements required, and timescales for compliance.

   Agreed action plan: The registered provider may be requested to submit an action plan with timescales. The action plan will address the improvements required in the inspection report.

   Warning letter: A warning letter outlining the issues that the registered provider needs to address. It will give a set date by which the issues must be addressed if statutory enforcement is not to be pursued.

2. Statutory enforcement action which can include:

   Prosecution (Health Act 2007 section 59)
   Cancellation of registration (Health Act 2007 section 51(1)).

During 2011, HIQA inspectors carried out 769 inspection visits to designated residential centres for older people to assess whether the level of service met the needs of the residents. Six centres were closed as a result of enforcement action taken by the Authority (HIQA 2011a). They were closed because inspectors had reasonable grounds to believe that there were serious risks to the health and welfare of residents, or that there was a substantial and significant breach of the regulations as a result of a provider failing in its duty to safeguard residents.

A number of features of HIQA as regulator are worth comment (Hamblin 2008). First of all, its reporting arrangements are designed to ensure independence because it reports directly to the Minister for Health, and not to the Department of Health or the HSE. The second feature is that unlike private accreditation systems (e.g. Joint Commission International (JCI)), HIQA does not have any commercial imperative to implement the standards and is not reliant on the services it is monitoring to provide an income stream. The third feature is that HIQA will have a dual role, in that it has responsibility for setting the standards and it is also the organisation that will inspect against the standards. It has been observed that this dual role may risk a conflict of interest by, for example, influencing decisions about standards compliance (Australian Commission on Quality and Safety in Health Care, 2007).

Implications for service providers
Although services for people with disabilities are not as yet regulated or inspected by the HIQA, the Authority received 22 concerns in relation to services for people with disabilities in 2011. This would re-enforce the need for standards and regulation of this area.

Voluntary (or not-for-profit) disability service providers provide the majority of Irish disability services (90% of intellectual disability and 60% of physical/sensory disability services), with the remainder largely provided directly by the HSE. Of the approximately 53,000 people availing of, or waiting for, specialist disability services, just under 9000 (17%) are in disability residential services. If the HIQA standards are finalised, the practical implication is that these service providers will have to provide real evidence to show compliance with the standards. For each of the eight themes in the standards, illustrative examples of steps service providers may take towards meeting the standard are provided, but it will be very much left up to each organisation to provide the evidence of compliance with the standard. In practical terms, this will require the service to provide reviewing and articulating:
- what structures they have in place,
- what processes they have in place (policies, procedures and guidelines etc), and
- outcome indicators (audits, annual reviews, implementing reports, best practice).

How will service providers do this? There is no set methodology of reviewing structures, processes and outcomes. Depending on the size of the residential centre each ‘theme’ of the standards could be reviewed by a multidisciplinary team representative of all staff and service users. Alternatively, the themes could be assigned to smaller subgroups within the service who could feed back to an overall supervisory group who would coordinate the review of the service. What can be said for certain is that this will generate large amounts of data to be collated, compiled and reviewed with associated time and resource implications for service providers. For the moment, the standards are in draft format with feedback being requested from HIQA. It is recommended that the standards are studied carefully by service providers, staff and service users and any comments sent to HIQA. Service providers are caring for the most vulnerable individuals in our society and there is an ongoing responsibility on them to make sure that quality assurance systems are in place.

References available upon request from the editor
HOW TO BREAK BAD NEWS TO PEOPLE WITH INTELLECTUAL DISABILITIES: A guide for carers and professionals,
by Irene Tuffrey-Wijne.
ISBN: 978184905 280 1;
E ISBN: 978085700 583 0

It is likely that anybody working with people with intellectual disabilities, at some time or another, has had to break bad news to them, sometimes perhaps in an unhelpful way. For some people with the intellectual disability, the comprehension of what they have been told may not be readily observable. Understanding is sometimes inferred. At other times, it is clear that the news has had a profound impact. Is there a right or wrong way of breaking bad news? Clearly certain approaches should be avoided at all costs.

What is refreshing about this book is the ever-present understanding that relationship is at the core. Relationship may not always be readily apparent, given the level and extent of some people’s individual disability, but it is nonetheless present. Implicit in relationship is knowing and understanding the person. This knowledge and understanding is central to how the bad news is given. A person with an intellectual disability does not easily understand information and its consequences. Information has to be broken down in ‘chunks’ that the person can understand. The author deals very well with timing and the right amount of information to give.

The guidelines the author puts forward are very helpful, as are the examples throughout. She also sensitively addresses the tensions which can exist between staff, family and friends about breaking bad news. Examples are given of breaking bad news of a serious illness; that a friend has dementia, staff leaving or a well-planned activity will not now take place (e.g. moving house). At the heart of all the examples is relationship and knowledge and understanding of the person and their right to know.

At the end of each chapter there are very helpful reflective thinking points, often linking back to the networks around the person; important people in a person’s life and their involvement in the process. The author deals effectively with the challenge of a person’s limited or non-existent communication skills and reminds the reader not to make assumptions about how individuals, regardless of their level of intellectual disability, react to loss and disappointment. The author gently reminds the reader not to forget the person and the importance of a respectful engagement.

This book is timely and the offered guidelines are relevant to the daily lives of people with intellectual disabilities and their supporters.

Stephen Kealy

THE ART AND SCIENCE OF MOTIVATION: A THERAPIST’S GUIDE TO WORKING WITH CHILDREN
edited by Jenny Ziviani, Anne E. Poulsen and Monica Cuskey.
ISBN 9781849051255

The Art and Science of Motivation is a guide for therapists and practitioners who work with children in health and educational settings. Its specific focus is on children at risk of developmental disadvantage as a result of physical, developmental or social disabilities. The central aim of this book is to guide practitioners in their attempts to motivate children to engage with therapy. The target audience is practitioners in all professional disciplines involved in early intervention and school-age disability services. As the name of the book suggests, both practical advice and scientific evidence are provided for therapists, and it is in the former area that this book’s particular strengths lie.

The editors adopt self-determination theory (Deci and Ryan 1985, 2000) as a model within which to frame their exploration of practice issues related to motivating children. This theory posits that three basic psychological needs of children and their families must be met in order for successful engagement with therapy to be achieved. Firstly, children must have a sense of autonomy or control over the goals of therapy. Secondly, children’s feelings of relatedness or connectedness to their therapists and to others in their environment must be facilitated. Thirdly, children’s self-evaluation of their own competence and mastery over age-appropriate tasks should be strengthened. The book provides an overview of the research suggesting that the motivation of children to engage with therapy increases when these three needs are met by practitioners.

The book includes a plethora of therapeutic techniques which may assist practitioners in enhancing motivation, through the facilitation of the child’s need for autonomy, relatedness, and competence. These techniques are then brought to life by the useful inclusion of numerous clinical vignettes which explore the application of these techniques.

I found the structure of this book to be more coherent than many edited volumes I have come across. Many such volumes contain stand-alone chapters written by a number of authors which lack the flow required to convey a coherent overall message. However, each of the chapters in this volume involves at least one of the three editors as co-author. This ensures the maintenance of a coherent focus and a logical structure throughout.

My main criticism of this book is that the model of self-determination theory is given a large amount of attention, without sufficiently exploring the usefulness of other models and factors which might contribute to the motivation of children in therapy. However, self-determination theory does represent a broad model covering a range of factors which contribute to motivation. The many associated practical techniques provided in this handbook will certainly provide a useful starting-point for practitioners who wish to enhance their skills related to engaging children in their therapeutic work.

Seamus Ryan, PhD, Psychologist in Clinical Training, NUI Galway.
To subscribe, please email Frontline at secretary@frontline-ireland.net or fill in the form across and send to:

Unit C2
The Steelworks
Foley Street
Dublin 1

Frontline has been published since 1989 and deals with issues of interest to frontline workers, those with a learning disability and their families.