

FRONTLINE



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IMAGINING A BETTER LIFE

The cover of this issue features Cillian having fun—and that is a large component of a good life.

The summer paralympians reminded us what can be achieved in spite of what appear to be significant obstacles—achievements that reflected their interest, determination, motivation and desire to succeed—a real demonstration of the art of the possible.

Celebrating change, achievement and movement is captured by articles in this issue, particularly those that follow the movement of people from a stark Victorian psychiatric hospital to live in small more personalised settings in the community. There is, thankfully, an emerging understanding of the trauma people with an intellectual disability suffered following their wrench from their family home as young children and adults, to be placed in huge settings which often lacked the capacity for tenderness, closeness, and a close personal experience, regardless of how well motivated their carers may have been. Noise – confusion – disagreements – herding, all were raw experiences with no opportunity for many to receive an unconditional helping hand. It is to the great credit of staff of the HSE that their congregated settings are now closed. This issue looks at the journey of some of the people from one of those settings—Alvernia House. It should be no surprise that anecdotal feedback suggests that people are happier, less 'challenging' and more at peace. That is not to say that there are no challenges in trying to have in place the best personal fit. The biggest challenge of all may be the inability of able-bodied people to imagine that it is possible for these new neighbours to live a better life.

Often it is difficult to receive copy for *Frontline*, but for this issue there were many people who wanted to share the achievements of people they know or to whom they are close.

Joe Wolfe completes his series on Standards. While the draft standards are linked to congregated settings, it would be imprudent for service providers not to apply them also to community settings.

As *Frontline* goes to press there continues to be uncertainty as to whether there will be a further cut to the disability budget, possibly as much as 3.7%. These cuts, like all the previous ones, will have an impact on the quality of services for people who want and deserve a better life. The more the disability budget is cut, the greater likelihood there is of a creeping movement back to larger settings—maybe not as large as those cited in this issue, but still large enough to traumatise people with intellectual disabilities.

Aiming high—dreaming of and achieving a better life is reasonable, normal, pleasurable and possible—and this movement needs to continue and strengthen.

Stephen Kealy

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.

Stephen Kealy, Editor

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Joe Wolfe

Introduction to this issue of *Frontline* Celebrating People with Disability by Minister of State Kathleen Lynch



I am delighted to contribute to Frontline's issue on celebrating Disability.

Just a few months ago we watched the London Paralympic Games and marvelled at the bravery and skill of each competitor in the games. The team from Ireland scored a number of successes and this undoubtedly lifted the mood of the whole country. The tremendous effort and dedication of all of the athletes proudly representing their nation has to be acknowledged.

We all remember the Special Olympics hosted in Ireland in 2003 as a great event. As a country, we celebrated the success of those games. The Special Olympics is not only for great occasions. It's about people with intellectual disabilities attending sporting clubs each week, participating in training and enjoying the company of fellow athletes.

Sport is not the only area in which we should celebrate disability. Huge advances are being made in education where people with disabilities are excelling. There are a number of third-level courses for people with intellectual disabilities. One in particular that I am familiar with is the Certificate in Contemporary Living in the National Institute for Intellectual Disability in Trinity College Dublin. I recall seeing the pictures of the students celebrating outside Trinity after graduation. The inclusiveness captured by this image is a model for all education providers to follow.

In the arts, people with disabilities are making great strides. I was particularly heartened to see the great work of Orla O'Sullivan recognised recently when she won the Hidden Hearing Heroes workplace award. Orla is a deaf and blind pianist and music teacher. She uses her great musical talent to teach deaf children music. Her words on winning this award are an inspiration to all of us: 'Disability is an obstacle, not a barrier. People with a disability should never give up doing what they want to do. They might have to work harder like me, but it is worth the effort.'

Kathleen Lynch, TD, Minister of State with responsibility for Disability, Older People, Equality & Mental Health



Above: Lynn Conroy (left) and Carol Nairn (right) of the Special Olympics, with Minister of State Kathleen Lynch.

RE-MAPPING SPECIAL EDUCATION NEEDS

(Extracts from a paper given at the 11th World Down Syndrome Congress in Cape Town, August 2012)

The governments of the world have given special needs education an exacting challenge for the 21st Century. The United Nations Convention of Rights of Persons with Disabilities spells out the aspirations for enabling disabled people to lead happy, fulfilled and self-determined lives. Of course, these rights are the same as for all citizens, but this convention recognises the extra support required by persons who either are born with impairments or who acquire them later in life.

Education is a vital means for preparing our children and youth to gain a lifestyle that fulfils their aspirations and talents. Is the same true for pupils with special educational needs? I suspect not. The reason, I fear, is simple: their disabilities—what they can't do or what they struggle to do—so that we devote little attention to the conditions that help these young people obtain fulfilled lives.

Martin Segilman, the father of Positive Psychology, in his recent book *Flourish*, writes this: 'Removing disabling conditions is not remotely the same as building the enabling conditions of life.' In the past two decades, big businesses have harnessed the insights from positive psychology to refocus their efforts on creating and sustaining a fulfilling lifestyle for their workforces. Likewise, educators in the USA and the UK are reshaping their curricula and school communities to better prepare their pupils to lead happy, fulfilled lives. Segilman's book is replete with examples of how these ideas have been put into practice.

To date this thinking has had little impact on special education, whose pupils ironically stand to benefit most from it. Segilman identified five enabling influences to transform people's lives for the better. Together they provide a RE-MAP for teachers and families to follow.

R is for Relationships. A lack of peer friendships is common for many students with disabilities. They spend many hours after school and at weekends alone. Giving them the skills of making and keeping friends is vital to their future wellbeing. Friendships may lead to more intimate relationships and, for some, even marriage. Is your school a community in which friendships are nurtured and extended beyond the school day?

E is for Engagement. Personal fulfilment comes from pursuing the things that fascinate and intrigue us and on which we will happily spend hours of concentrated effort. Paradoxically we often refer to these pursuits as 'hobbies', to distinguish them from real work! The creative arts of music, drama, art and dance are all ways of engaging students and giving them a sense of personal fulfilment in ways that academic subjects may never do. How much are they a valued part of your school curriculum?

M is for Meaning. We all need a purpose in life. It gives us an identity and a reason for living. Disabled young people face extra challenges in this regard as they struggle to make sense of their difference, while being all too aware of the burden they can be to others. Often families, schools and even professionals shy away from helping young people to make sense of the impact which disability has on all aspects of their lives. Also they need to feel valued for their

contributions and opportunities to make them, for example, through being given specific responsibilities in school, at home and in local community groups.

A is for Accomplishments. Positive psychologists strongly advise us to savour our daily accomplishments, no matter how small they may be. Growing children need our help to appreciate what they have accomplished, yet too often as teachers we stress their failures. It is a question of balance. Nor should it be empty praise. As pupils' competence grows we should expect more from them. The old saying is true, 'success breeds success.' However, for disabled students a sense of achievement may come more readily through non-academic subjects such as sports. How well does your school applaud and celebrate students' accomplishments?

P is for Positive Emotions. Disability is replete with negative connotations—despair, disappointment, distress—to name but three. But dwelling on negative emotions is a known trigger for mental ill-health. The antidote is expressed beautifully in the Disney song: you've got to accentuate the positive! So what helps you feel good about yourself and about life in general? Answering questions like these should help you recreate the conditions in which positive emotions (such as contentment, excitement and joy) outweigh the inevitable negative ones to which we are all prone. Equally, exercises like these can enlighten every school day and help students gain an insight into how they can experience more positive emotions.

RE-MAP is for everyone. Remember too that these five conditions will help us all to flourish so that we fully realise our full potential as creative teachers, as effective therapists, and as loving parents. And in so doing we stand to rejuvenate our schools and communities to everyone's benefit.

A final thought: this RE-MAP for special needs education is as much a shift in attitude as it is a change in practice. The UN Convention is a reminder that disability does not make our fellow citizens any less human, yet it dramatically reduces their chances to live happy, fulfilled and self-determined lives. Of course, we must strive to reduce the impact of disabling conditions, but equally we cannot ignore the conditions that will enable these young people to flourish as contributing citizens.

Roy McConkey

Roy is Professor of Developmental Disabilities at the University of Ulster in Jordanstown. He is co-author of *Shared lives: Building relationships and community for people with intellectual disabilities*, published by Sense Publishers, Amsterdam (available through Amazon.co.uk).

References

- Segilman, M. 2012 *Flourish: A Visionary New Understanding of Happiness and Well-being*. New York. Free Press.
- United Nations Convention of Rights of Persons with Disabilities. Available at: <http://www.un.org/disabilities/convention/conventionfull.shtml>



NEWS from INCLUSION IRELAND

YES VOTE IN CHILDREN'S REFERENDUM

Inclusion Ireland was one of many not-for-profit organisations that supported a yes vote in the recent Children's Referendum. The Referendum was passed by a majority of 58 per cent on 10 November. Paddy Connolly, Inclusion Ireland CEO spoke in support of the referendum saying: 'The rights of children with an intellectual disability and autism have been disregarded by successive governments.... A yes vote will be a clear message to this government that the Irish people expect them to act on the wishes of the people to protect and cherish all the children of the state equally, including children with disabilities. Inclusion Ireland believes that the proposed change to the Irish Constitution is another step towards embedding a culture in Ireland of respect for human rights A Yes vote will place further expectation on the Irish government to vindicate these rights in Irish law.'

13% OF POPULATION HAVE A DISABILITY

New figures from the Central Statistics Office (CSO) show that almost 600,000 people in Ireland, equalling 13 per cent of the population, have a disability. The figures are published in the CSO's Bill of Health, which is a profile of the health of the Irish population. It shows the following:

- Going outside the home was difficult for 22,989 people, while 21,844 found it hard to participate in other activities.
- Among disabled people aged 15-49, 16.3% had not gone beyond primary-level education, compared with 5% of the general population.
- Secondary school was the highest level attained by 22.3% of disabled people, compared to 15% of those without a disability.
- There were 162,681 people with a disability in the labour force—a participation rate of 30%, compared to almost 62% of the overall population.
- There were 57,709 people (1.3%) with an intellectual disability and the greatest incidence was among 10-14-year-old boys at almost 4,000—more than double that of girls at 1,900.
- The census showed that 187,112 persons, or 4.1% of the total population, were providing unpaid assistance to another last year.
- Of the carers, 114,113 (61%) were women and 72,999 (39%) men. Some 4,228 children aged under 15 were providing care—2.3% of all carers.

HIQA PUBLISHES DRAFT STANDARDS

The Health Information and Quality Authority (HIQA) are due to begin independent inspections of residential centres for children and adults with disabilities next year. HIQA launched a consultation document on draft national standards in October. HIQA Deputy Director of the Social Services Inspectorate Niall Byrne said the standards set out a 'vision as to what people can expect from good-quality residential care services'. There are an estimated 1,700 residential services for people with disabilities. (To download the draft standards visit www.hiqa.ie). Inclusion Ireland welcomed the publication of the draft standards, and that time

has been given over to public consultation, saying 'Inclusion Ireland has been campaigning for nearly 20 years for independent inspection of disability services, and we hope inspections will finally start as early as possible next year. We encourage people with disabilities and their families to feed into the process and get their voice heard.'

WELFARE APPEALS SYSTEM 'NEEDS RADICAL OVERHAUL'

Legal rights group FLAC launched a legal analysis of the social welfare appeals system in October. Their report, entitled 'Not Fair Enough', shows that the social welfare appeals system does not measure up to basic human rights standards in several areas, such as independence, transparency, access to information and fair procedures. FLAC called for a root-and-branch reform of the appeals system and outlined a list of concerns about the process, including lengthy delays in decisions and the Appeals Office's lack of independence.

In 2011 the average time to process appeals by the Appeals Office was more than 32 weeks. The department itself took an average of 12.9 weeks to pass requested information on to the Appeals Office, while the average processing time for an appeal which required an oral hearing was 52.5 weeks. FLAC also highlighted inadequate consistency and transparency in decision-making and access to legal advice and representation for those appealing decisions. The Report was launched by Ombudsman Emily O'Reilly, who said those appealing decisions must have the chance to put their case at an oral appeal hearing. FLAC also launched three guides to help people accessing social welfare:

- a checklist for applying for a Social Welfare payment;
- a guide to making a Social Welfare appeal;
- and a guide to the Habitual Residence Condition.

(The report and guides are free to download from the FLAC website at www.flac.ie.)

OMBUDSMAN CRITICISES GOVERNMENT OVER AGE LIMIT ON MOBILITY ALLOWANCE

The government is to take legal advice on the mobility allowance, following a report from Ombudsman Emily O'Reilly that shows the state has acted illegally in refusing the allowance to people over 66 years of age. The Mobility Allowance is a means-tested monthly payment from the HSE, to people who have a disability and are unable to walk or use public transport. It can be used, for example, to finance taxi journeys. The payment is made to approximately 45,000 people, and is worth a maximum of €208.50 a month.

Emily O'Reilly published a report in late October that said the Minister for Health James Reilly was breaking the law and rejecting international human rights principles by failing to remove the upper age limit on the allowance. She said limiting the allowance to people aged under 66 'raises fundamental questions about the strength of our commitment to international human rights norms', and 'the continued failure of the department to tackle this issue suggests ... a very weak sense of the rule of law and of its

obligation to act in accordance with the law.’ Ms O’Reilly said when the scheme was introduced in 1979 the upper age limit was legal, however once the Equal Status Act became legislation in 2000 the state could no longer discriminate on grounds of age.

The report says the department has been operating the scheme for the past 12 years on the basis of a condition that is illegal, and that it has known it to be illegal for the past four years. The Department of Health originally promised last year to review the mobility allowance scheme, but it now says it cannot afford to make the changes recommended by the ombudsman. Department Secretary General Ambrose McLoughlin said allowing those aged over 66 to avail of the allowance would ‘ignore the very serious financial constraints’ on the state and ‘create liabilities that the state could not afford’. Tánaiste Eamon Gilmore said the government will seek further legal advice on the issue and they want to resolve it in a way that is ‘reasonable, sustainable and does not cause undue distress’ to people receiving the allowance.

INCLUSION IRELAND SAYS ADVOCATES MUST HAVE STATUTORY POWERS

Inclusion Ireland has called for statutory powers for advocates working in the National Advocacy Service (NAS), following reports published in the media in early November that show a lack of cooperation from state agencies on important issues relating to people with disabilities.

Inclusion Ireland CEO Paddy Connolly said that media reports showing resistance and a lack of cooperation from the HSE and disability service providers towards state-funded advocates supporting people with disabilities mirror Inclusion Ireland’s own experience of providing advocacy for people with an intellectual disability and their families.

He said this experience could be very different for NAS advocates if government were to enact the 2007 Citizens Information Act: ‘Establishing the National Advocacy Service is part of the Citizens Information Act, and NAS was launched in 2011. However, providing advocates with statutory powers was also in the Act, and this has not happened. These statutory powers would enable advocates to enter residential services and request information. Currently, advocates have no power to obtain information or attend meetings or consultations, and can only operate on the basis of voluntary cooperation of service providers. The Citizens Information Act 2007 is a cornerstone of

the much-vaunted 2004 National Disability Strategy. We are aware from the work of NAS that cooperation from service providers and some professional groups is not always forthcoming. This is an experience shared by Inclusion Ireland advocates. The NAS reports show that people with disabilities continue to be abused and have their rights ignored. Some of these reports were made public in the media (*Irish Times*, 30 October 2012, 31 October 2012). Inclusion Ireland believes these reports should be made publicly available, with appropriate protection of people’s confidentiality.’

‘Inclusion Ireland calls for the full implementation of the Citizens Information Act so that NAS advocates are statutorily empowered. There is no reason, of which we are aware, why this fundamental piece of legislation is not yet fully enacted.’

INCLUSION IRELAND WELCOMES €7 MILLION INVESTMENT IN EMPLOYMENT PROGRAMMES FOR PEOPLE WITH A DISABILITY

Inclusion Ireland welcomed Social Protection Minister Joan Burton’s announcement in late October, that €7 million will be invested in employment programmes targeted for people with disabilities under the Disability Activation Project (DACT). ‘People with disabilities face great barriers in accessing employment, and the government’s decision to target funding at this area is very welcome,’ said Inclusion Ireland CEO Paddy Connolly.

People with disabilities did not experience the boom period in the same way as people without a disability, and the unemployment rate among people with a disability continues to be far higher than in the general population. The 2006 CSO Equality in Ireland report found that only 16% of women with a disability and 26.8% of men with a disability were in employment.

Mr. Connolly said, ‘Minister Burton’s comment on the untapped potential of people with disabilities is very true—for many people with a disability, their own ambitions are often stalled by societal attitudes of low expectation. People with an intellectual disability, in particular, are rarely asked what their ambitions and plans are for future employment. While today’s announcement is welcome, the projects will only continue until 2015, and are specifically targeted at the Borders, Midlands and Western regions. We need a broader strategy that looks at supporting people with a disability to both enter the workplace and stay employed.’

Siobhan Kane,
Inclusion Ireland

THANK YOU, NIAMH!

Frontline has benefitted from Niamh Power’s talents for more than ten years. Her work may have been taken for granted a bit by our readers, but not by the editorial board. She has designed and produced the magazine for three successive editors, and she has given the magazine design three ‘facelifts’.

Niamh agreed to continue working with us when *Frontline* moved from its previous publishing home in Wordwell, in 2008-2009. We editorial board volunteers have heavily relied on her knowledge of the print/publishing world over the past three years.

Because of her decision to make a career change now, Niamh will no longer be our guru. But she isn’t leaving us in a lurch, bless her. From our next issue, March 2013, Niall Ó Laoghaire (Guilder Design) will assume the design and production mantle, the role that we editorial volunteers rely on so much.

We are indebted to you, Niamh, with our best wishes for you in your future endeavours!

ABILITY WEST SERVICE USER COUNCIL



Ability West has a Service User Council in place which is representative of service users throughout the organisation. The Council has been in place since June 2010. The Chairperson of the Council is Jimmy

Sweeney. The Council is facilitated by Eileen Costello-Conneely, staff member of Ability West. The Council has fourteen members and meets regularly (at least six meetings a year) with the main purpose of being a representative voice for service users and having a meaningful forum by which issues of common interest are discussed. Council members regularly meet with the Senior Management Team and other groups within the organisation. The Chairperson of the Council also meets regularly with Breda Crehan-Roche, Chief Executive of Ability West, and also with the Chairperson of the Board of Directors. The Council very much appreciates the support it gets from the organisation in doing its work.

The Council works under a code of practice with the main core elements of respect, confidentiality and everyone having an opportunity to share ideas. It has taken as its main theme of work the well known mantra in advocacy circles – ‘Nothing about us without us’. The Council is involved in a good deal of developments in the organisation, some examples are as follows:

- Development of Ability West’s Strategic Plan
- Drawing up Anti-Bullying Procedures for service users
- Helping the Human Resources Department with job descriptions, newspaper ads for jobs and the Code of Practice for staff
- Suggestions to the Senior Management Team about cutbacks
- Feedback to Senior Management Team on the draft Disability Policy Document
- Major Consultation Sessions (over 100 service users) for the past three years
- Various other consultations with groups and people, such as Human Rights Committee, Social Media, Fundraising
- Consultation and feedback on policies and procedures under development.

Since 2010 the Service User Council has held three very successful ‘Consultation Session Days’ which involve representatives from our services throughout the county. In 2012 this was held in the Claregalway Hotel on the 24th July. Approximately 120 service users attended. The day started with a presentation from the Service User Council Chairperson on the work done to date. The second edition of the Service User Council Newsletter was presented. This was followed by group consultation sessions, facilitated and supported by volunteers and staff members. A number of topics were discussed and feedback given, including overall services and what service users like, do not like, any improvements, person centred planning, e-learning, social media, Human Resources standards and communication. The feedback was presented to the Chief Executive and Senior Management Team.

This year the consultation day was a great success, particularly as it was almost fully organised by the Service User Council members and presentations were given by the Council members. Previous to this, a good deal of the work involved was undertaken by staff, but in 2012 the staff took a ‘back seat’ and the service users were to the forefront!

For the coming year, the Council will be continuing its work in terms of consultation and feedback on developments and important aspects of the organisation. Another development that the Council is looking at is facilitation of the group; this is currently undertaken by a staff member, and appears to be fine for the early stages of development. However, the Council is looking at the idea of independent facilitation, for example, through an independent volunteer.

In conclusion, we feel that the Council has made an impact on the organisation and feel that moving forward ‘nothing about us without us’ is of crucial importance, particularly taking the current economic climate into account.

Jimmy Sweeney, Service User Council Chairperson.
Eileen Costello-Conneely, Facilitator/Service Quality Manager.

PLOUGHING NEW FURROWS IN RURAL COMMUNITIES

Shiny new machinery, showers and mud, food stands and coffee bars with laughter and banter are all part of the spirit of the gathering which is the ‘National Ploughing Championships’. An abiding feature of this event, year in and out, in good times and tough times, is the celebration and camaraderie which characterise the people and way of life of rural Ireland. Despite the advance of technology and modern communications—even down to the sight of a man following a horse-drawn plough with reins in one hand and mobile phone in the other—rural communities still have something of people, place and values which define them. Our current President, Michael D. Higgins, and his predecessor Mary McAleese often referenced this strength of community, neighbourliness and the collective efforts which are evident outside more urbanised settings—a living link to the meitheal as a task and social gathering of community around the shared seasonal activities, such as saving the harvest.

In the UCD tent at this year’s ploughing event in Wexford was a stand promoting a new rural initiative focused on inclusion and participation opportunities for people marginalised in society for reasons of health, social, economic disadvantage or disability. The project ‘Social Farming Across Borders’ had already visited other agricultural shows earlier in the summer, with a focus on getting information on this new initiative to those most marginalised in society.

The project is preparing to offer new and exciting opportunities for people to experience real farming and rural life with farm families in their local communities. The partnerships that evolve in this pilot venture may be of people who already have a ‘preferred choice’ of being involved in rural, farming and outdoor activities, or those who wish to experience farming as a potential life option. One of the best parts of rural life is the quality of friendships and the diversity of interests that are to be found in rural Ireland. Even better are the social gatherings, often around a welcoming kitchen table, which provide opportunities to share ideas and experiences or to plan the work and activities of the day over a cup of tea.

The roots of this project (which runs from late 2011 to September 2014) were the interest and wish of a strong cohort of people from diverse support backgrounds to have the opportunity to learn, train, work or merely engage and be part of the everyday life within the farming community. The project offers the opportunity of 30 days of experience to 60 people across 20 farms from within its catchment area of the 6 counties of Northern Ireland and 6 northern counties of the Republic of Ireland. While pilot supports can only be offered within that catchment area, the project is open to all interested parties who want to learn and share in the experience as it evolves. There will be a number of information-sharing events and the website (www.socialfarmingcrossborders.org) will be kept updated with news and resources. The project aims to have partnerships in place and to offer experiences to people from early 2013. Leadership of the project is through Leitrim Development Company, the UCD Faculty of Agriculture Food and Veterinary Medicine and Queens University Belfast. (www.socialfarmingcrossborders.org).

Paul Henry

People's Pages

ME, MY TALENT, MY MUSIC

If there is something that Kathleen McDonagh truly enjoys, it is her mouth organ. Because music plays such a big role in Kathleen's life, an idea emerged amongst the team that supports her: developing a project that involved recording Kathleen playing her mouth organ and compiling these songs into an album. This was seen as a great opportunity for celebrating Kathleen's special talent and for sharing it with her family and friends.

And so the project began. Every week, Rasa Savickaite, a Daughters of Charity (DOC) volunteer, met Kathleen in her home and recorded her playing some beautiful Irish and other international tunes. After this, CDs were created, a CD cover and a label were designed and a launch party was arranged. Kathleen sent out invitations to all her friends and happily waited for the big day.

On July 18th, on a bright summer evening, Kathleen's house quickly filled up with friends! Everyone was excited to hear the tunes that had been recorded as part of an album entitled 'The fields of Athenry and other songs' by Kathleen McDonagh. After a few introductory words and the opportunity for Kathleen to thank everyone for their presence, songs such as The Fields of Athenry, Wooden Heart and The Wild Colonial Boy vibrantly echoed in the room, and while some people were singing along, others were busy trying to take a picture with the artist or get a signed copy of the CD!

It was an evening full of joy for Kathleen and everyone present. Hearing Kathleen playing these beautiful songs is something that her friends are well used to, but what made this event so special was being able to leave the party with a copy of Kathleen's album in our hands. Not only did Kathleen share her musical talent with all the special people in her life, her music can now reach out at and inspire other people, perhaps motivating them to also share their unique talents within the community where they live.

**Sofia Laureano-Schelten, Clinical Psychologist,
Daughters of Charity Services, Dublin**



Advocacy and leadership course, DIT 2011–2012



On 4 November 2012, I and my friends graduated from the Advocacy and Leadership Course at the DIT Mountjoy Square. All our family and friends attended the graduation ceremony. It was lovely.

I had to do an interview to get a place on the course and was delighted when I got the news that I had been successful. The course started on 21 October 2011. The students came from St Michael's House, St John of God Services Kildare and Menni Service.

As part of the course we had to learn about the:

- ◆ History of disability
- ◆ Social inclusion
- ◆ How we are governed
- ◆ Voter education
- ◆ Standards awareness
- ◆ Communication and teamwork

At the end of the course I had to do a presentation with a folder on what my interests are and what I had learned on the course in front the staff members of St Michael's House, at the Omni Employment Centre (where I attend). I was very nervous. The folder was sent with a report of how my presentation went to my tutors for them to decide if I could graduate.

It was hard work. We students were involved in all the activities of student life in DIT—we mixed with the other students in the college and made many friendships. This could be seen at the graduation ceremony, as many of the other students came in especially to wish us well.

I enjoyed the course and feel that I am better able to speak out on behalf of people with intellectual disability. This is where the course helped me.

I would like to thank St Michael's House staff for helping me during the course, my tutors on the course, the DIT staff and all my friends.

Deirdre Spain

People's Pages

STEPHEN'S TUNNEL

My friend Greg and I started a project three years ago that we were passionate about. Our passion is gardening and Greg and I have a medium-size garden in a polytunnel. Our polytunnel is at the back of the house where I live, which is called Cara Cheshire Home in the Phoenix Park. The first task we did was to go and get the seeds that we decided on—potatoes, parsnips, cauliflower, carrots, onions, tomatoes, spinach, radishes, lettuce, grapes and peppers (which were very hot!). Greg and I also decided to get some flower seeds for a different section of the garden, which we got from Greg's mother. We got the rest of the seeds from Robert, the gardener, and from B&Q, Aldi and Lidl.

After we had decided what to grow we had to prepare the garden by removing all the weeds and turning over the soil. Greg and I then decided to plant our seeds in different sections along each side of the tunnel. After we decided what should go in each section, Greg and I dug the soil and put in fertiliser, then sowed the seeds, about a half-inch below the surface in rows about a foot apart and then we watered them in. Some seedlings appeared after two weeks and others grew a lot slower. Spinach grows like a jungle and needed to be cut back all the time. The spuds, lettuce and cherry tomatoes did very well this year, but parsnips, beetroot and carrots didn't grow this year.

Greg and I harvest the spinach every week, even into winter. We harvest the spuds a few months after planting, a few every week so they are staggered. After everything was harvested, we

brought all our vegetables to Chapelizod village, into Kelly's Shop, when it was opened, and into O'Connell Bridge with Leon, the German volunteer. I then went to a very close friend of mine to sell some of my best tomatoes. My friend's name is Colin and he works in Trinity College. So, one Friday my friend David and I went into Trinity College and met up with my friend Colin and showed him some of the best tomatoes. We had a fantastic time together and went home with our pockets full of money. It is a great feeling to do something you love (gardening) and get paid well for it. Greg and I look forward to working in the garden whether it's weeding, sweeping or watering our garden and we can't wait till we start the next batch of vegetables.

Stephen Conlon



OUR BOOK OF RIGHTS



In April 2011 we got together with the help of Pat Maloney and Audrey Ryan and formed an advocacy group which talked about our rights. This group met once a week for six weeks. At the end of the 6 weeks a working group was set up, who worked on the signs and how we would tell everyone about our book of rights. We got the rights printed on a poster, one big and one small.

St Christopher's AGM was on 8 November 2011 and we told everybody about our book of rights. James McWeeney opened the book of rights with his introduction and presented the right to make choices about my life and the right to speak up. Adrian Hand then presented the right to be listened to, and the right to have my say in service planning. The right to make a complaint and the right to have control over my money was presented by John O'Reilly.

James Baxter presented the right to be treated as an adult and the right to be treated with dignity. The right to privacy and the right to have an advocate to help me were presented by Frances Tynan. Kevin Brady presented the right to be safe and the right to protection under the law.

Stephen Brown presented the right to have information in a way that I understand, the right to try new things and the right to form relationships. Stephen finished by thanking everybody for listening.

Sadie Sorohan then unveiled our book of rights to all present, who gave us a big round of applause.

It was a very good achievement for all of us because we did not do something like this before. THE RIGHTS ARE IMPORTANT BECAUSE THEY HELP US STAND UP FOR OURSELVES. We will keep working on improving our rights.

Stephen Brown, Adrian Hand, Frances Tynan, James Baxter, James McWeeney,
St Christopher's Services, Co. Longford.

When I have a goal!



My name is Áine Lawlor and I am 28 years old. I did a course in Killester College. I did a Special Needs Assistant (SNA) course for two years. The course was a year-long, but they let me do it over two years, so the pressure was taken off me that way. Also I got a disability worker to help me. She helped me with my assignments and the homework that I got. The assignments were tough, so I needed someone to sit down with me and break the assignments down bit by bit. Once I did that I flew along with the work. It was pretty intense work and I wanted to throw assignments out the fecking window. But yeah, I did not give up and I kept going.

My friends and my family were a huge support to me when I felt down or depressed about my work, they stood by me. There would be days when I did not want to go to college at all, but I did so. The only thing that kept me going was the vision in my head: I would walk into the head teacher's office in St Michael's House School and she would give me a job. I kept that rolling around in my head and that's how I kept going through the tough days, for all I ever wanted to be is an SNA in the school. I would be the first to ever attend there and to work there. I would be

making history. So I got work experience up in the school during those two years and it was my favourite day of the week. The schoolkids were the only things that kept me going. If I was tired or stressed out about college they would cheer me up when I went in to help. In the end I stuck with college and I passed the SNA course. I got merits and passes.

On my last day of work experience I asked the head teacher if there were any jobs out there for me to take. She said no, but she could put me on the sub list. (That means if someone is out sick I can fill in.)

The one question that I was asked in the interview was why do you want to work here? I said because I can relate to the children and I can help them in every way. I think that is how I got the job. So that is what I did after the exams. I was so excited for myself as I would be working in the school that I attended and now I am an SNA teacher assistant. I could not believe it when I was told that I would be working in the school. That was one of the highlights of my life. All the hard work that I put into the course was all worthwhile. All the dreams have come through and I feel so happy as I walk through the school doors. I take a deep breath and I say to myself. 'I made it, I am here and now I am an SNA teacher assistant.' It felt great to hear myself say that.

One day in work a queen from Africa came to visit the school. Lisa came into the classroom and said this is Áine Lawlor who used to go to school here, trained here as an SNA and now is an SNA and working for us. Well, something happened to me as I sat with the kids that day. A happy feeling came over me. It was like a blood rush. It went through my body and I felt so happy. That was another highlight of the day. I remember feeling nervous and not knowing if I will be as good as I was when I was doing the work experience, but I had nothing to fear. I learned a lot from those two years. I thought being an SNA the job would be a little easier. I thought wrong, but I am glad that I was able to think to myself that I am good. I am like the other teachers and I am like everyone else in the school.

I just want to be there to help the children. The head teacher saw that in me and she saw how good I was and that is why she took me on. I am ever so glad she did. I love going to the school and working with the kids. They are the reason I get up every morning and that is the best feeling ever. I do hope there will be a lot of working days where the kids can teach me and I can teach them. Up in the school I am treated well and I love that. I also work with teachers who are still there from when I was in the school. So it is a wonderful chance to work with them.

I am Áine Lawlor who has a disability and I don't let that disability get in my way of life. I think positive and not negative. I think forwards, not backwards. I just have a different way of living life than other people do. I am not letting it get in the way. I am Áine Lawlor. When I have a goal or a dream I go for it.

Áine Lawlor

DEVELOPING AN INDEPENDENT LIFE

My name is Mark Ahern and I live in Mullingar, Co. Westmeath. Independent living and the use of new technology have played a very significant role in my life. Independent living was an alien concept when I first heard about it, from a feisty female American wheelchair user who was determined to spread her message to Ireland. That was when I was approximately fifteen years old. I immediately realised that it could play an important role in my future and so it has proved to be. I have a disability called arthrogyriposis multiplex congenital (AMC) which I've had since birth. I am unable to walk or even stand and have only very limited use of my hands. Up till then it had always seemed like an impossible dream to go to college or live on my own. After that, my future no longer seemed so dark or certain.

After I completed my Leaving Certificate, I was accepted for a Bachelor of Commerce Degree in UCD. Fortunately and thanks to a great extent to my parents, who campaigned on my behalf, the Midland Health Board provided funding for a personal assistant (PA) service with more limited funding coming from the Department of Education.

I was provided with 70 weekly hours of PA service, coordinated through the IWA in Dublin. That not only helped me to complete my degree, and then a Masters, but it also helped me to experience real freedom and grow as a person. There are shops, restaurants and pubs on the campus and in a way it was like living in a town, rather than being part of the city. I stayed on campus from a Sunday evening to Friday and then went home at the weekend. One PA covered from Sunday evening to Tuesday evening and another took over until Friday morning.

As the campus would become largely deserted over the weekend, this never bothered me. During the week I could decide to go where I wanted without being answerable to anybody and could choose what would be made for dinner. I had a vibrant social life and I looked forward to each day—apart from the odd statistics lecture!

There were difficulties at times. For instance when a PA unexpectedly went sick. I was a long way from home; I couldn't expect my parents to drop everything and come to cover gaps—and they had their own lives to lead anyway. Therefore, I built up a back-up system of friends and extended family. Although they weren't able to help over extended periods, they did help in emergency situations.

It was during my time at college that I also began to think about how I would manage when I hopefully found employment in the future. I experimented with 'Dragon Dictate' at the time—a system which types from speech. However, it was one of the earliest versions and I never grew fond of it, due to the mistakes it would make. This was many years ago and I'd imagine newer versions have greatly improved.

It was a different computer programme I came across which was to have a much bigger impact—an on-screen keyboard. At the time it was novel and I immediately knew it would be a great help to me. It made it far easier to type. These days on-screen keyboards come as standard on the latest Windows, and I use them every day.

After I completed college I returned to live in Mullingar with my parents. The independent living service I had been getting ended with college. After a few months I applied for PA hours from both the local Irish Wheelchair Association and the Centre for Independent Living. I was given 25 hours, which was a great help to me in building for the future. I was able to get up when I wanted

to, go out for a walk and it helped me to look through papers when I was searching for employment. It only took a few weeks to find a PA and we got on so well together that she still works with me now.

The next major development in my life was when I was offered a permanent job as a Clerical Officer in Westmeath County Council. Before that, I had a part-time job working for the local Arts Centre, but this was what I really wanted—a fulltime job.

Independent living played a crucial role in helping me fulfil my ambition. It simply would not have been possible to work fulltime without it. Thanks to the services provided I could get into work, in time, and have the necessary toilet breaks and lunchtime.

I've now been working with Westmeath County Council for nearly ten years and I hope to continue doing so for many years to come. Apart from the important salary, it has also provided me with camaraderie and a sense of purpose. It is my longer-term goal to get a management position which I feel that I would easily have had the ability to do.

Recently I have taken independent living to the next level. About three years ago, taking advantage of the slump in house prices, I purchased my first home. It was situated in the ideal location for me—near the town centre and close to my place of work. I had spent a lot of time looking for a house in the correct location as I knew it would make a huge difference if I was able to get into town and to my place of work in my wheelchair. Many modifications were needed to the house—doors widened, a downstairs toilet added and ramps in various locations. One of the most interesting innovations was the use of swing doors so that I could go from room to room without assistance.

Fortunately I was able to apply for a grant from the Council, which helped cover some (but not all) of the costs involved. I considered it to be great personal achievement to purchase and modify a house appropriately for my needs.

Concurrent with the building works, I applied for an increased independent living service. The process had changed significantly from the last time I had applied for hours. This time I had to send in my form to a clearing house committee, rather than the individual companies which provided the service. Overall, however, I thought that this method was superior to the previous way, because it felt that I was being dealt with in a coordinated fashion.

I got enough hours to stay in my house for four nights of the week. Considering the recession in Ireland, I was pleased with that result. In the future I intend applying for more assistance, so that I can stay in my house fulltime—and become fully independent. I'm also looking into getting environmental controls put into my house, such as an automatic front door so that I will be able to spend some time on my own at the weekends, and require fewer PA hours.

It was great feeling to finally move in and I have thoroughly enjoyed my time since then. It is fantastic to have my own bit of space, be able to invite friends over to visit and even not have to argue with someone over what to watch on TV! Sometimes it's the small things that matter most.

Currently I have two PAs who help me to live independently. One does the mornings and the lunch hour, and the other one does from 5pm each evening until the morning. And that system has worked out well so far. **FL**

Mark Ahern

CILLIAN



Like in so many families, sporting activities, reading and indeed all hobbies are things that have been incorporated into my children's lives—often without realising the full rewards they bring. For my four eldest children, from when they started school (and sometimes before that, if they showed an interest), weekends in our home became absorbed into one long taxi ride, ferrying children to and from music lessons, sports and various other social outings.

When we learned (when he was three) that our youngest son Cillian had a moderate intellectual learning disability and he showed no interest in participation of any kind, let alone sport, I never dreamed of the possibilities that we have enjoyed with him in the last four years. For several years, our biggest goal as a family was to try and get a night's sleep as our insomniac Cillian roamed the corridors paying no heed to whether it was day or night. Although included in every family activity and outing, he never showed the least amount of interest in becoming involved or participating, preferring instead to take a disinterested sideline approach.

Four years ago I decided to take him to a soccer match in our home town of Dundalk, a local derby match between Dundalk and Drogheda, and a cup match in honour of Cillian's grandfather. It was as if a light went on! Cillian insisted on taking to the pitch at half time. This was a major feat in itself, as we have always found it hard to get him to walk any

distance, due to his very poor muscle tone. I was immediately struck by the warmth and encouragement of the young team-members who helped him score his first goal.

From that moment he was smitten. Week after week since then we travel to Oriel Park to support the Lillywhites. Although Cillian does not read in the traditional sense, it amazes me how he manages to identify every League of Ireland team, their home ground, manager and players without difficulty—something I would find too difficult!

Over the years I had unsuccessfully tried to enrol Cillian in various mainstream summer camps and had almost given up hope, until Dundalk FC agreed to allow Cillian to attend its youth summer camp. Cillian spent a week lining up alongside his peers and it was a real eye-opener for me and the rest of the family. His inclusion in the summer camp meant that Cillian was able to engage and make friends with children his own age with a shared passion—soccer. Cillian's siblings and I were delighted to attend the certificate presentation ceremony at the end of the summer camp and we were moved to see how proud Cillian was of his achievement, how confident he had become and how he had brought a little bit of fun and excitement into the lives of the other children. It was as positive an experience for Cillian, and for our family, as it was for the coaches and other children on the course.



Since then he never misses the opportunity to attend the camp and it is now part of his routine during the holidays from school. His admiration of Dundalk FC, especially goalkeeper Peter Cherrie, knows no bounds. He knows when they are playing and whether it's to Oriel Park or Terryland Park, the black and white jersey is out in force. Cillian is now one of the team. He regularly lines up with them as mascot, is known by everyone associated with the club and, indeed, I am continually struck by the genuine support and friendship shown to him by everyone in the club. Every week I watch in amazement at the relationships he has developed over the years with players and supporters alike, ranging in age from nine to ninety.

Inclusion in sport is so important. Soccer has made such a difference to the quality of life that Cillian enjoys and it has opened up a whole new world, not just for him but for our whole family.

Last year Cillian was delighted and very fortunate when FAI President John Delaney kindly invited him to be one of the flag bearers at an international match. To Cillian it was just another normal day, but to our family it was one of the most poignant of our lives. Cillian stood proudly for the National Anthem in the Aviva Stadium, chatted to the players and waved to the capacity crowd as if he was already an international player.

The lesson we have learned? Cillian expects to be included. His life is full of positivity. Whereas we might hesitate, or wonder if we will be included or accepted, thanks to Dundalk FC, Cillian has the confidence to take inclusion for granted. I am so grateful to all the people whom Cillian has met throughout his fourteen years, that they give him that confidence to take it all in his stride and to Dundalk FC for making it happen. **FL**

Mary Moran

‘BEHOLD THE TURTLE—HE ONLY MAKES PROGRESS WHEN HE STICKS HIS NECK OUT’

(James Bryant Conant, Past President of Harvard University)

SOS is a place where we encourage people to stick their necks out and we celebrate the effort it takes. Like many similar organisations, SOS was founded by a group of parents in Kilkenny and it has grown to support over 160 people with intellectual disabilities and their families. The SOS mission statement is to provide a lifetime commitment to people with a learning disability. This commitment includes the provision of a service based on Christian principles, which recognises:

The dignity and potential of the person with a learning disability
 The right of the person with a learning disability to be enabled to integrate as fully as possible into society.
 It is the small things that matter. The celebration of these small things, the ordinary life is what makes the difference. These ordinary things are the same things celebrated by people who do not have a disability and are not supported by an organisation like SOS.

As a preparation for this article I looked through the SOS quarterly magazine called *Rewind*. It told the story of a donation from a child of some of his Confirmation money. Ger, a person supported by services, wrote about his trip to Madrid. Trevor spoke about his trip to Cobh. The Mayor of Kilkenny visited the SOS radio station. There was an inclusive review of services ‘Is your door open or closed?’ John Waters had officially opened the *Dreamtime* radio station. A Job Shadow event was recounted. On his way home from work, Brian met about-to-be President Michael D. Higgins (who was canvassing for the presidency at the time) and most importantly, Sonny celebrated his 60th birthday and Derek his 40th birthday. This week Paul got great news that he is moving into his own two bedded apartment with his best friend, Lisa has started a course in WIT,

Ashley has started a part-time course in Ormonde College, and Joan is celebrating her 50th birthday—a

truly wonderful occasion because she has recently recovered from a serious illness.

My point is that when the disability world celebrates life’s special events—‘*Aren’t they great, considering!*’—they tend to celebrate in large gatherings of people with a disability together. A number of years ago as we were celebrating the graduation of group of people supported by SOS, I was asked to say a few words, and I said that the day we stop celebrating these special occasions will be the day of greatest celebration. I think my few words were lost in translation. What I meant was that the day when organisations like SOS are not involved in celebrating such events will be wonderful, because it will mean ordinary life has replaced special life; it will also mean that being truly supported in one’s own community will have taken over the need for ‘a service’.

I would like to tell you the story of Peter. He is a man in his sixties, supported by a service for many years. Peter uses a wheelchair and is in need of one-to-one support for lots of things in his life. In the mid-1990s he was asked to become involved in a project that would find him a job. It was a wonderful project and Peter got a job counting money from a vending machine in a large pub near his center. He made great friends there, and some of these friends helped celebrate his 40th birthday (organised by his center). His friends also celebrated his 50th birthday, organised by his family and friends, and his friends organised his 60th birthday and invited his family and friends from the center. The last I heard from Peter, he had just retired from the job, after a celebration with his work colleagues who were also retiring.

What I think is interesting about Peter’s celebrations over the years are the people he shared his birthdays with—starting with his center, then family and friends, and most recently with his work colleagues. He moved from a ‘special’ insular life, to the ordinary wider social circle of family and friends. Last week, as my own



Above: Official opening of the SOS radio station “Dreamtime” by John Waters and Jane Saunders.

father celebrated his 80th birthday, he was surrounded by friends and family. It was a normal ordinary special event—and great craic.

Last week a very wonderful and dear friend of mine passed away. Jane was a lady supported by services all her life. She attended special school, training services, and day service. She had a part-time job and was hugely into the Special Olympics, winning gold medals in the World Games in China. We celebrated all of her achievements; she was on the local paper and radio and even made it onto national TV. But what was striking at her funeral, a celebration of her life, were the ordinary things—the one-to-one friendships she had with her neighbours, her role in her local church, her support for her sick father—that everyone knew her, Jane.

If you cannot find life’s roses, go find the daisies sweet and revel in the common grass that sparkes at your feet.

In SOS we will continue to celebrate the large projects, such as the opening of eight two-bedroom apartments and the



refurbishment of our respite house. But we cannot lose sight of what really makes a difference in the people SOS supports: that the celebration of underpinning values and principles is the key to real celebration. For instance, an organisation that is focused on the individual citizen, the person's right to self-determination, is relationship-oriented, socially inclusive and person-centered. By celebrating these values, and the events which reflect these values, we have moved the focus of the service. This week we had first feedback from the external rights protection committee. This committee will allow the people we support to know and exercise their rights. SOS is half-way through a staff training programme called *Building Community Links*, to reskill staff to become community linkers, rather than community tourists. We have advertised for the first time for a housemate to support a person who wants to live a more independent life. Mary has a life-defining medical issue; she also has a mild learning disability and a child in care. She wants, and is entitled to lead, a self-determined life. She wants her supporting service to be a positive risk taker. The celebration of the success in this scenario will be when the supporting service is only a minor part in her circle of support.

I bring you back to the start of this article. The greatest day of celebration will be the day when supporting services are not part of the celebration. **FL**

Francis Coughlan,
CEO, SOS Kilkenny



Francis trained at the Daughters of Charity, Dublin as an RNID, and later completed a BBS in Business Administration.

He started his working life at Cheeverstown House in Dublin, and worked at Saint Aidan's in Gorey before being appointed as the CEO of SOS Kilkenny where he currently works. Francis was appointed to the Board of Directors of the National Federation of Voluntary Bodies this year and he is also the Chair on their Research Sub Committee. He has been involved in many international and national projects such as "A Seat at the Table" and the Genio project "Ordinary Lives".

ABILITY WEST: 2012 WINNERS OF THE DRAMA COMPETITION, IRISH PERFORMING ARTS FESTIVAL, CORK

Ability West's Team Adult Day Service, Tuam, took part in the Irish Performing Arts Festival (IPAF) in Cork this year for the fourth time. The IPAF is about creativity, inclusion, collective and individual experience and the arts. It provides opportunities for artists from all backgrounds to share skills and develop relationships. The IPAF showcases the outstanding talents and abilities of people with intellectual disability and autism. The competitions and street performances bring colour and vibrancy to Cork and Team has been proud to participate in this great festival for the past four years.

Ability West provides services and supports to over 500 children and adults with an intellectual disability throughout Galway City and County. Team is an adult day service in Tuam where 31 adults with an intellectual disability avail of a variety of programmes based around individual needs. There is heavy emphasis on personal development, basic care, social and personal skills and community involvement.

The Team drama group has worked tirelessly over the past months with the assistance of drama teacher Sylvia Nolan. In the past they have performed short comedy sketches, but this year they performed an interpretation of an old Irish legend, *The Children of Lir*. There was stiff competition from organisations all over Ireland, including entrants from COPE Foundation, Aisling Day Centre, Rehab Care, SOS Kilkenny, MIDWAY, Rosmini Resource Centre, Mullingar Resource Centre, Respite Support Project, Co-Action Cork and the Cloud Walkers (from Hungary).

When *The Children of Lir* was announced as the winner, the excitement was unbelievable and the celebrations have been going on since. The winning performers were Marie Roche, Tony Warde, David Warde, Breda Nicholson, Anthony Connolly, Rose Marie Martin, Kathleen Haran, Martin Douglas, Martin Shaughnessy, Noel Langan, Nicola Brennan, Teresa Mullins, Michael Feerick, Pat McDonagh and Mary Mullins. They were supported in Cork by Mary Margaret Garvey, Tony Goldrick, Susan Coady, Marie Miskell and Dominica Healy.

A great night of celebration and music was held in the Ard Ri Hotel, Tuam, to welcome home the Team performers and the All Ireland trophy! The play has also been performed to rapturous applause at Ability West's 50th Anniversary Gala Concert in the Black Box Theatre, Galway, in October.

Further information on Ability West can be found on www.abilitywest.ie or www.facebook.com/abilitywest. **FL**



BREWING UP SUCCESS!

For a theatre company, how can success be measured? Perhaps in the following ways:

- ◆ An original commissioned work by a nationally known playwright written for a specific company of actors
- ◆ A world premiere in a national theatre festival
- ◆ Sold-out performances at the festival with an extended run
- ◆ 128 individual philanthropic funders from all over the world contributing to produce the work
- ◆ Three inquiries (so far) to tour the new work
- ◆ One tour date already booked
- ◆ Recognition by a national theatre reviewer
- ◆ Inquiries by a film company into the success of the play.

Any one of these points would uplift any professional theatre company. All of these are the experience this autumn for Blue Teapot Theatre Company, a professional theatre company for men and women with intellectual disabilities (ID) based in Galway city. This year Blue Teapot commissioned and produced a new play, *Sanctuary*, by Christian O'Reilly, and the play was premiered in the Galway Theatre Festival in October. The press release said it all:

this poignant, funny and bittersweet play opens a window into the lives and relationships of people with intellectual disabilities and the obstacles they must overcome to be together.

The response of audiences was overwhelming. The final three nights of the nine-performance run were sold out, with waiting lists of 25 people hopeful to get tickets at the door. Audiences have asked Blue Teapot to bring the play back next year, and they will.

Critics have joined in with their opinion on this daring and funny piece of theatre. *Irish Theatre Magazine* said: '*Sanctuary* is a brilliant insightful piece of work that enlightens and entertains. It also brings to the fore the amazing talents of Pilley's first-rate cast.' 'In *Sanctuary* we are reminded that no subject is off limits to achieve brilliance in theatre when the ensemble is talented.' 'Blue Teapot have set the bar (and it's very high) for professional theatre productions with roles for and about people with intellectual disabilities.'

Charlie McBride of the *Galway Advertiser* remarked: 'O'Reilly and the gifted Teapot cast shine a welcome light on this issue which they illuminate with great tact, perceptiveness and, last but by no means least, a rich vein of humour.'

With *Sanctuary*, Blue Teapot chose to explore a subject that is often considered taboo, and managed to do so with humour and grace. Quoting the play's director Petal Pilley: 'My hope in commissioning this play was to present a living tragedy that demands discussion, awareness and a more enlightened response from our society towards the sexuality and relationships of adults with ID.'

To raise funds to create this professional theatrical production, Blue Teapot looked to the national fundraising site www.fundit.ie to add crucial support to their exciting new work. They met their goal of €4000 with five days to spare, creating new and avid Teapot supporters along the way. The first tour date for *Sanctuary* was to St Michael's Theatre in New Ross, Co. Wexford, on 21 November—hopefully the first in a long list of venues for this significant piece of theatre.

Blue Teapot is no stranger to this kind of success. Having worked with scriptwriter Len Collin on a short film script that premiered at Druid Theatre in 2011, producing a full production of *A Midsummer Night's Dream* in 2010 to sold-out houses, and



Above: Charlene Kelly (Sophie), Frank Butcher (William) and Patrick Becker (Andrew) in *Sanctuary*.

performing in the opening ceremonies of the Volvo Ocean Race in 2009 to an audience of over 50,000, this ensemble is used to being in the spotlight. It is a place they rightly deserve to be.

In the short space of sixteen years this talented group of individuals has blossomed into a professional theatre company with a three-year FETAC accredited Performing Arts School for school leavers with ID, and a drama-based community outreach project, Bright Soul.

The company's vision is to become the National Theatre for people with ID in Ireland, and it looks like they are well on their way of making that happen.

Led by Director Petal Pilley since 2006, their work has blossomed as the core company members have continued to take on more exciting and challenging productions. Six years ago Petal introduced the actors to the Meisner Technique, a well known acting technique that has proven a powerful methodology for the company members and students to access and express emotional, psychological and physical truth. The company regularly trains with the theatre industry's top professionals, recently working with world-renowned Meisner Maestro Scott Williams in two master class workshops, and periodically with Rod Goodall (founding member of Macnas, and former Artistic Director of the Galway Arts Festival).

Blue Teapot has also been represented on the international stage. Petal Pilley was invited and granted a full scholarship to attend an invitation-only International Convening of Thought Leaders in Theatre, Dance, Disability & Inclusion, hosted by the John F. Kennedy Center for the Performing Arts in Washington DC. Petal met with leaders in the field of arts and disability from around the world and created strong new ties for the Galway-based company.

This company is constantly training and stands ready for the challenges ahead. If success is what you make of it, Blue Teapot has built a strong foundation for their current achievements. Henry David Thoreau said 'Go confidently in the direction of your dreams! Live the life you've imagined.'

Blue Teapot Theatre Company is showing us how they make that possible. **FL**

Kathy Murphy

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**Special
Olympics**

MINISTER LAUNCHES SPECIAL OLYMPICS HEALTH REPORT

Ms Kathleen Lynch, TD, Minister of State at the Department of Health with responsibility for Disability, Equality, Mental Health and Older People, attended the launch of Special Olympics Ireland's research report on health promotion on Tuesday 2 October 2012. The report, *The development and evaluation of a health promotion programme for people with intellectual disabilities* detailed a pilot health promotion project which was created by Special Olympics Ireland.

Research has shown that 68% of people with an intellectual disability have a BMI in the overweight/obese category. The aim of this programme was to develop, pilot and evaluate a user-friendly health promotion resource pack which could be delivered in community-based Special Olympics clubs and intellectual disability services. The report details the findings of the programme which was initiated in 2008 to help address the lack of health promotion resources for people with an intellectual disability in Ireland.

The Resource Pack was developed in consultation with Special Olympics athletes, volunteers and family members. It covers the most pertinent health needs of people with intellectual disabilities, including nutrition, physical activity and heart and bone health.

Statutory and non-statutory organisations collaborated in the development of the resource. Health knowledge and behaviour questionnaires were administered to the 286 participants at the start of the pilot, in order to establish a baseline, and again on completion of the programme. The results showed a statistically significant increase in health knowledge and health behaviours—most notably a 48% increase in the numbers of participants meeting the recommended daily intake of five portions of fruit and vegetables.

Qualitative data were gathered through questionnaires and focus groups conducted with participants, volunteers, services staff and family members. The feedback from the participants indicated that the user-friendly nature of the pack ensured that the participants were more inclined to follow its direction. It was evident that by relating the importance of health to sport, the participants felt more encouraged to make a health change.

Speaking at the project report launch, Minister of State Kathleen Lynch said: 'I am delighted to hear such positive findings arising from this pilot programme. It is wonderful to hear how much of a difference it has already made to the participants in such a relatively short period of time. If this programme shows us anything, it is that health and sport go hand in hand and that positive lifestyle changes are important and beneficial to us all. I would like to congratulate everyone involved and encourage the participants to keep up the good work!'

Dr Nazih Eldin, Head of Health Promotion Dublin North East, Health Service Executive, said: 'The HSE welcomes this initiative which aims at reducing health inequalities for Special Olympics athletes in Ireland. It is great to see that an effective, evidence-based and targeted programme was developed in

collaboration and cooperation of so many different experts, parents and people with intellectual disability. The HSE is hoping that this model will achieve all its goals and that the benefit will be shared by everyone in Ireland.'

Matt English, CEO Special Olympics Ireland, said: 'The publication of this report is hugely significant for Special Olympics Ireland. We are delighted to see the positive impact that the introduction of this programme has made, not only to our athletes who participated in it, but also their families. The findings are hugely encouraging to us and once again affirm our promise of enriching and enhancing the lives of people with an intellectual disability in Ireland. I would like to take this opportunity to thank everyone who played a part in making the initial pilot programme such a success, particularly the HSE Dublin North East.'

Two Special Olympics athletes who participated in the pilot programme (Carol Nairn from Waterford and Lynn Conroy from Dublin) were interviewed at the launch, along with their mothers Carmel Nairn and Kay Conroy. During their interview the athletes spoke about how they used the resource to help them to keep a track on the types of food they eat and how much water they were consuming every day. They both said that they found the resource pack very easy to use and that making and adopting healthy choices was not too difficult. Their parents both agreed that being part of this pilot programme was very worthwhile, and not only did it have a positive effect on the athletes, but also on the rest of their families.

The full report is available www.specialolympics.ie. For further information about Special Olympics Ireland's Health Promotion Programme, please contact Carol Farrell, Health and Education Officer, Special Olympics Ireland (email: carol.farrell@specialolympics.ie). FL



Above: Mary Davis, Dr. Nazih Eldin, Lynn Conroy, Minister of State Kathleen Lynch, Carol Nairn and Matt English at the launch of the report.

HOW SPORT CAN END DISCRIMINATION OF PEOPLE WITH INTELLECTUAL DISABILITIES



**Special
Olympics**

Mary Davies, managing director of Special Olympics Europe Eurasia, outlines the aims and ambitions of the Special Olympics movement.



The thrill and excitement of sport is unique—and it should be available to everyone. In Special Olympics we promote sport as a vehicle for ending discrimination and stigma of people with intellectual disabilities—of whom there are more than 200 million people in the world. Sadly, a majority face a life of prejudice and discrimination, loneliness and limitation. Our number-one challenge in Special Olympics is to end that. For our mission to succeed, we have to be able to do two things. First, we must reach out to people with intellectual disabilities and their families and welcome them onto the field of sport. Secondly, we must be able to communicate the message of their abilities as a way of overturning stigma and prejudice. If we don't do both, we're not successful.

The way in which we create the sporting activities is one whole strand; the way in which we communicate and engage the public and the community in owning that relationship and owning that idea leads us into the world of social, community and political change.

People say sport is good for health, for confidence, for teamwork—and this is all so true. But we have a slightly sharper edge. We are confronting a massive social problem. It's not just about teamwork and confidence. That's nice and it's good. But this is about the world's oldest prejudice—against people who have a greater challenge learning and participating.

Access to and participation in sport and physical education provide an opportunity to experience social inclusion for people otherwise marginalised by social, cultural or

religious barriers caused by disability, gender or other forms of discrimination. Through sport, our athletes experience equality, freedom and a dignifying means for empowerment. Sport is a unique life-changing vehicle for this population because they have so many challenges with traditional educational environments and traditional pathways to full inclusion. Sport becomes an alternative that is almost unique in their lives.

Special Olympics

Special Olympics brings together more than 4 million people with intellectual disabilities across 175 countries. Special Olympics is not just about big sporting events; we provide year-round training and competition opportunities for children and adults with intellectual

disabilities in 32 different sports. We are a global movement dedicated to bringing tolerance and acceptance for all people with intellectual disabilities. In Ireland our 11,000 athletes are celebrated and admired; sadly this is not the case in every corner of the world. I work across 58 countries and stigma and discrimination of people with intellectual disabilities is common in many of them. Many still struggle for the opportunity to be integrated into society and in their communities, and even to receive proper medical care. They face discrimination, stigma and abuse that deny them their most basic human rights to health, education, and sometimes life itself.

We don't just support athletes, but their families too. The Special Olympics Family Support Programme recognises the isolation and exclusion that can be felt by family members and carers of people with an intellectual disability and drives to alleviate it. Families give their time willingly with no personal reward beyond the fulfilment that comes from giving and contributing to other family members.

Public health

In the area of public health, Special Olympics is the world's largest organisation working to address the persistent disparities in access to quality health care services for people with intellectual disabilities. We do this through our Healthy Athlete Programme. Last year alone, more than 13,000 volunteer healthcare professionals gave of their time and expertise to conduct 765 health screening clinics worldwide for our athletes. In many cases this screening provides an opportunity for athletes to see a doctor for the very first time. And in some cases the lives of our athletes have been saved through the detection and treatment of medical ailments the athletes and their families didn't even know they had.

Volunteerism

We promote volunteerism across borders—and of all ages—reinforcing active citizenship at a local and European level. Without the generosity of thousands of

Through sport, our athletes experience equality, freedom and a dignifying means for empowerment. Sport is a unique life-changing vehicle for this population because they have so many challenges with traditional educational environments and traditional pathways to full inclusion. Sport becomes an alternative that is almost unique in their lives.

volunteers, Special Olympics would not exist. In Ireland alone, 24,000 volunteers support the Special Olympics programme. Through our volunteers, we empower our athletes and provide an outlet for friendship and social development.

Athlete leadership programme

Off the playing field, we encourage our athletes to be leaders in their communities, in their schools and in their work places. We do this through our Athlete Leadership Programme which empowers athletes to develop leadership skills, to be advocates and to be fully integrated members of their community.

The oath which every Special Olympics athlete takes is 'Let me win, but if I cannot win, let me be brave in the attempt.' The common word is, of course, LET. December will again mark the International Day of Persons with Disabilities, so let us not forget the core tenants of the UN Convention on the Rights of Persons with Disabilities. They represent the most fundamental rights of all persons regardless of ability level: the right to healthcare services, the right to education, the right to an environment safe from exploitation and abuse, the right to sports activities, and (most importantly) the right to be included as an equal member of society.

Sport is a powerful vehicle. Special Olympics athletes show their strengths and abilities through their participation. Each

athlete has a different story, but each story has much in common. From the athletics track to the football field to the bowling alley to the basketball court, our athletes show their courage and the results of all their training and hard work.

Special Olympics is thriving proof of the commonality of the human spirit—that colour, creed, ability and background are irrelevant in the pursuit of a shared goal. Every day acts of inclusion have helped define our social fabric, where tolerance, acceptance, togetherness, helpfulness and advocacy have all become standard components of a past, present and future Europe.

Special Olympics inspires people in Europe and across the world to think beyond the normal bounds of possibility. People with intellectual disabilities are empowered to achieve their dreams and family members see loved ones grow in self-confidence and self-worth. With each athlete's experience, there comes a lasting legacy of attitudes changed and an ability to welcome and accept that which is different. The activities and programmes simply say to all, that people with an intellectual disability are real people, and rounded people. Yes, they need specific supports, but they have the same expectations, hopes and abilities as everyone else—the desire to contribute, participate, form relationships and friendships, and compete on the sports field. The power of sport is the vehicle that changes the lives of our athletes over and over again. **FL**

Donal Fitzsimons kicks off a series of articles about the recent closing of Alvernia House in Portlaoise and the impact it has had on former residents.



DOORS CLOSE FOR THE LAST TIME: THE END OF CONGREGATED-CARE IN ALVERNIA HOUSE, PORTLAOISE

Setting the context for de-designation

The development of services for people with intellectual disability in the latter half of the 20th century saw the beginning of a process of specialisation that led to the emergence of 'special' places for so called 'special' people. The Commission of Inquiry on Mental Handicap (1965) described the existing status of services for people with intellectual disability in Ireland; it called for greater equity and fairness for people with intellectual disability and inspired the development of local facilities across the country. Special centres and special schools were developed in the 1960s which also introduced the development of a range of specialised professions, which included registered mental handicap nurses (RNMH, now RNID), special education teachers and other professionals such as occupational therapists (OT), speech and language therapists (S<), physiotherapists, psychologists, psychiatrists and social workers.

A range of therapies were devised that required special equipment including hydro-therapy pools, multisensory rooms and snoezelen rooms. The underlying assumption in specialisation was that people with intellectual disability had special needs. The model was one that led to more sophisticated and varied specialisations, leading to a service that could respond to a broad range of special needs in a highly sophisticated and nuanced manner. Local parents and friends groups were guided by the zeal of the specialist movement, in that something special was better than something ordinary.

In order to promote full citizenship of people with intellectual disability, Irish

government policy began to acknowledge the importance of inclusion, participation in mainstream society and the significance of valued social roles for people with intellectual disability (Robins, 1986).

Government policy

Throughout the twentieth century in Ireland, home for many people in care with intellectual disability was in a large residential centre, institution or psychiatric hospital. These facilities were situated on the outskirts of large towns with the 'inmates' hidden away, protecting the community from the 'insane', 'mentally sick' and 'retarded' (Robins, 1992). By 1981, the census figures showed that there were approximately 1900 people with intellectual disability in the care of psychiatric services (Mulcahy and Reynolds 1984). Others were placed in the care of religious orders and, in later years, in the care of the health boards.

A report of the study group on the development of psychiatric services, *The psychiatric services: Planning for the future* (1984) recommended that people with intellectual disability would not in the future be admitted to psychiatric hospitals and that those with intellectual disability already living in a psychiatric hospital should be catered for separately from those with a mental illness. It also recommended that some of this cohort be considered for placement in specialised community services with adequate back-up facilities.

The report *Needs and abilities: A policy for the intellectually disabled* (1990) outlined the best approaches to meet the needs and realise the abilities of

people with intellectual disability (Department of Health 1990). The report recognised that people with intellectual disability have the right to live as others in the general community. This vision placed an onus on the government to respond positively by planning to provide community-based services with an emphasis on positive quality outcomes for the people concerned.

Alvernia House and the transfer programme

Alvernia House in Portlaoise was de-designated under the Mental Treatment Act (1945) and the centre became a facility for people with intellectual disability, and part of the community care programme in 1989. An area of St Fintan's psychiatric hospital in Portlaoise was separated from the psychiatric services and devoted to the care of 39 adults with intellectual disability. The residential service was provided over three floors of a building that was built in the middle of the 19th century and which was adjacent to the psychiatric hospital. The accommodation consisted mainly of large dormitories, large day rooms and dining rooms.

In the intervening years, international best practice called for the development of community-based services. In keeping with this philosophy, the Midland Health Board (MHB), as part of its 1998 service plan, established a project team to review the future direction of service provision for the 39 people with intellectual disability who continued to live in Alvernia House. As a result of the recommendations of the project team, a no-admissions policy to Alvernia House was implemented and the transfer programme was subsequently

established in 2001. The Midland Health Board's transfer programme secured ring-fenced funding to re-house a total of 206 people with intellectual disability from congregate care in HSE facilities in the Midlands; 39 of whom resided in Alvernia House, Portlaoise, Co Laois.

A consultation process commenced with the people residing in Alvernia House, nursing and care staff, staff representatives, families and the wider community. In 2006, six people with intellectual disability moved to a community group home in Vicarstown, Co. Laois. The success of community living for those individuals further endorsed the HSE's commitment to progress the transfer programme for other people with intellectual disability living in HSE congregate care settings across the Midlands.

The transfer programme was also in keeping with the Irish government's health strategy (*Quality and fairness: A health system for you*" (2001)) which further endorsed policies previously outlined in *Planning for the future* (1984)). *Quality and fairness* (2001) is a blueprint to guide health policy makers and service providers towards the vision of a health system in the field of intellectual disability comparable to the best examples in other countries. One of its principles is that all new service developments will be coordinated through person centred planning (PCP), with the principles of community integration at its core. In 2011, the HSE published a long-awaited document entitled *Time to move on from congregated settings*, a strategy calling for the continued transfer of people with intellectual disability still residing in congregated care settings in Ireland. It is important to remember that there are still over 4000 people with intellectual disability languishing in large congregated settings in Ireland today! This strategy describes it as essential for current programmes to include PCP, advocacy, support for community inclusion, in-home supports, community-based primary care and specialist supports and a right to work and lifelong education.

Making it happen

In 2011, a joint application was submitted to Genio for 'once-off' funding by the HSE Regional Disability Services and the Muiriosa Foundation (formally the Sisters of Charity of Jesus and Mary Services), to support the progression of the remaining 27 people with intellectual disability living in Alvernia House to more optimal individual services in the community. As a

result of this successful application, staff training in a new model of care, individually assessed needs and research in the use of assistive technology were implemented to act as a catalyst for the move from Alvernia House.

Regional Disability Services (RDS) of the Health Service Executive (HSE) Midlands area is pleased to announce that Alvernia House, Portlaoise closed its doors on Monday 4 September 2012, with the transfer of 27 people with intellectual disability to alternative living arrangements in community settings in the area.

All people who formally resided in the congregated-care facility in Alvernia House are now living their lives as part of the wider community. People are supported based on their individual needs in their own apartments, rented accommodation with signed tenancy agreements and in community houses supported by staff from the HSE and the Muiriosa Foundation (MF). The ultimate aim in this new model of service is to empower people with intellectual disability to lead lives of their own determination, where they will continue to be supported by the HSE and MF.

Conclusion

Disability service provision in Ireland has gone through a process of evolving change through the years, with religious organisations being the predominant service providers for the last fifty years. Specialised services for people with intellectual disability were developed in earnest throughout the 1960s, and it was from this process of specialisation that the notion of normalisation was introduced into Ireland. *Planning for the Future* (1984) was an attempt to separate people with intellectual disability from people who had a psychiatric illness, and it made recommendations to move people with intellectual disability from large psychiatric hospitals to community services. *Quality and Fairness* (2001) reiterated those recommendations, and community intellectual disability services continued to develop. In the MHB region the transfer programme (2001) started a process of de-institutionalisation for 206 people with intellectual disability from three large institutional settings, 39 of whom resided in Alvernia House. As part of the de-institutionalisation process in the Midlands, person-centred planning has been utilised with the stated aim of making the services about the person rather than about the services. The

challenge today in implementing the congregated settings report is not only to effect closure of the large institutions, but also to continue to meet the support needs of the individuals in a person-centred way as they move to community living. Achieving community presence is the first step in community participation. It is important to remember that this is only the start of a process of including people with intellectual disability in their individual communities. The challenge begins now. **FL**

**Donal Fitzsimons,
Manager of Disability Services,
HSE Midland Area**

References

- Department of Health 1965 Commission of Inquiry on Mental Handicap. Dublin. Stationery Office.
- Department of Health 1984 *Planning for the future*. Dublin. Stationery Office.
- Department of Health 1990 *Report of the Review Group on Mental Handicap Services: Needs and abilities: A policy for the intellectually disabled*. Dublin. Stationery Office.
- Department of Health and Children 2001 *Quality and fairness: A health service for you*. Dublin. Stationery Office.
- Health Service Executive 2007 National review group on congregate care. HSE, Dublin.
- Health Service Executive 2011 *Time to move on from congregated settings: A strategy for community inclusion*. A Report of the Working Group on Congregated Settings. Dublin.
- Kirkpatrick, T.P.C. 1931 *A note on the history of the care on the insane in Ireland*. Dublin University Press.
- McCormack, B. 2004 Trends in the development of Irish disability services, in Walsh, P.N. and Gash, H. Lives and times: Practice policy and people with disabilities. Dublin. Rathdown.
- Midland Health Board 1998 *Report of the working on the future direction of residential services for people with intellectual disability in the midlands*. Tullamore, Central Office.
- Mulcahy, M. and Reynolds, A. 1984 Census of the mentally handicapped in the Republic of Ireland, 1981. Dublin. Medico-Social Research Board.
- Robins, J. 1986 *Fools and mad: The history of the insane in Ireland*. Dublin. Institute of Public Administration.
- Robins, J. 1992 *From rejection to integration: A century of service by the Daughters of Charity to persons with a mental handicap*. Dublin. Gill and Macmillan.

EARLY REFLECTIONS ON A 'DE-INSTITUTIONALISATION' INITIATIVE

The *Alvernia* unit, housed in a wing of the St Fintan's mental health facility at Portlaoise, offered a 24/7 support to a group of individuals with intellectual disability since the early-to-mid 1980s. At that time a decision was made to 'de-designate' the unit (i.e. to remove it from the regulatory framework of mental health legislation) and to manage it as if it were a community-based facility. Persons with intellectual disability who had been distributed across various wards in the psychiatric hospital were brought together in *Alvernia*. Notwithstanding the best efforts of staff to individualise and personalise support arrangements, the context was inescapably group-based and institutional in character.

In July 2010, the Congregated Settings Report was published, recommending the closure of all congregate settings (defined as those in which ten or more people live together). At this time there were 28 people living in *Alvernia*. A collaborative initiative between HSE Midlands and Sisters of Charity of Jesus & Mary/Muiríosa Foundation, supported by *Genio* funding, was developed with a view to relaunching people's lives in more personalised community settings. Animating this initiative was the positive vision of the alternative life that people could be supported to build, rather than a negative, tick-the-box motivation of 'closing the institution'. There was a deep recognition that the institutional context presented insurmountable obstacles to developing a way of supporting people that would give them a realistic shot at a life worth living.

The main disadvantages flowing from the institutional context were:

1. Living in a context where the organisational and institutional needs dominate the agenda and shape the focus and rhythms of the day to a degree that overwhelms person-centred initiatives. While there were instances of good individualised work, these were generally promoted off-radar, or against the grain of how the institute typically operated, which made it very difficult to sustain commitment to person-centred initiatives and practices.
2. People are managed in groups throughout the day. This inevitably leads to individuals' lives being geared to a lowest common denominator factor. The default position becomes one of what works best for the institution to function, rather than how do we optimise arrangements to best address the very particular and diverse needs of each individual. One particularly adverse consequence of the group-managed situation is that individuals regularly have the emotional tone of their lives determined by the most distressed and distressing person with whom they are grouped.
3. Individuals experience a major loss of control over both the direction of their lives and their day-to-day experience.
4. People quickly adapt to living in this very different kind of world. Some become distressed and protest. The majority display a form of resignation. Some retreat into themselves to a degree bordering on a kind of shut down. Many seek to manage by becoming highly compliant and approval seeking, acutely sensitised to staff cues and expectations.
5. Routine and predictability are cardinal features of congregate environments. The narrowness and predictability of the ensuing lifestyle finds its complement in a narrowness and predictability of response by the service user caught up in the system. In the segregated, closed-circuit world of the institution, people typically only manifest a limited and impoverished expression of who they really are, or potentially can become. Deprived of the oxygen of possibility and spontaneous opportunity, all but the most resourceful become a shadow version of their deeper-lying possibilities.

Ongoing exposure to this hollowed out, narrow version of the person can lead staff to conclude that they know the person very well. Typically this activates a self-confirming chain of assumptions:

evidence of the service user's accommodation to the untypical and impoverished life within the institution becomes a basis for concluding that they would have little interest in or capacity for exploring alternative horizons and possibilities. Too often this can translate into a 'what's the point?' fatalism.

The vision underpinning this initiative is a *going somewhere* life embedded in neighbourhood and community. The gap between where people are currently lodged and the ultimate destination to which we aspire is immense. Even though we had a good conceptual knowledge of the cumulative impact of institutional life, we had under-estimated the full effects of this experience on the individuals' capacity to identify interests, exercise even simple decision-making, aspire to horizons beyond their immediate experience of the world. Even in their physical presentation, most service users appeared as if they were in their 70s, rather than their 50s. Physical health—activity levels, mobility issues, obesity—was very compromised. Diet, nutrition and medication levels also needed to be addressed. We had naively assumed that after an initial period of two-three months we could fast-track to address more ambitious lifestyle and inclusion issues. Our actual experience has been that enabling people to establish a home has taken longer than we thought. New experiences have to be introduced in a carefully phased manner. Moving quickly and spontaneously from this new base has not been as straightforward or automatic as we had assumed.

One assumption has been strongly confirmed, however: the domestic-scale house in the community is a much better context in which to get to know somebody. It also offers a more productive platform for launching a meaningful and fulfilling lifestyle. Challenges remain in breaking out of the closed-circuit, self-restricting patterns which many seek to reintroduce in these new arrangements. Three months after the move we recognise that we have now to commit to a very intentional investment in a *discovery-based approach* to getting to know people more fully and

more deeply. This involves introducing people to new experiences and places, and paying close and mindful attention to how they react. Trying things on for size, and other forms of trial-and-error learning, will feature prominently. It will involve both staff and service users moving beyond our comfort zone.

Some of the people who have been quickest to adapt and flourish in the more personalised settings are those who were seen as being most in need of the scaffolding and security provided by the institution. Among this group were some about whom staff members had harboured anxieties that the move might trigger a sharp deterioration in physical and mental health.

The assessments conducted on people in the institutional context have been a poor, often misleading, guide to a) how people would react in these new arrangements, and b) what level of supports they would require. This has posed a particular challenge in making resource-allocation decisions. Some require less support than the detailed assessments had identified. Others require significantly more.

Of the 14 people who have transferred to the Muirlosa Foundation,

- 5 are currently living in a house with three other residents;
- 3 reside in houses with two other residents;
- 5 reside in houses with one other resident; and
- 1 resides in a single-person arrangement.

Our preference would have been to install an individualised arrangement for each person. Funding and other capacity constraints have impeded our ability to realise this aspiration. In forming the groupings that currently apply, we sought to honour the following criteria (although they do not always align conveniently with one another):

1. Preserving established friendships. (The evidence of how people have reacted to one another following the transfer does not always confirm the friendship patterns that were described in the institutional context);
2. Grouping together those with intensive support needs in order to optimise the cost-effectiveness and efficiency of resource allocation;
3. Moving people back to, or at least closer to, their area of origin;
4. Avoiding evident or likely incompatibility between people living in the same house.

What does this tell us about how we might implement the Congregated Settings recommendations?

We do not need to wait until the national implementation group has worked out all the details of its planning and secured whatever level of additional resources it believes necessary before taking local action. However, such local action is not without risk. Three months in, we are certainly spending more money on bedding down the transfer. It is currently costing us about 30% more than the average funding available (€85,000 per person to cover 24/7 supports). We did anticipate that it would cost more during the initial year, particularly during the first six months, than it would cost during the second year and beyond. This represented a calculated risk on our part, a risk which hopefully will not become an ongoing liability. (If the challenges of adequately supporting people in the current configuration of small, personal arrangements are of the magnitude we are currently experiencing, what does this say about the possibility of even beginning to address their needs in a congregate setting?)

Independent review of our current situation may validly diagnose inadequate planning. Alternatively, it may reflect a faith in a level of planning precision and foreseeability which is more in the realm of illusion than reality. A very significant level of information-gathering and profiling of need (involving the perspectives of families, frontline staff and multidisciplinary professionals) extended over many months before the transfer. The more fundamental issue may perhaps be the unreliability of planning for supporting people in these advantageous settings on the basis of how people manifested in the institutional setting. We were conscious of this from the outset and always operated on the assumption that the initial transfer settings to which we would move people were unlikely to be the ultimate settings in which they would be supported. They primarily constitute a new ground within which to discern *what next needs to happen* for the individuals. Some might construe this level of provisionality and open-endedness as deficient planning. We view uncertainty, provisionality and a *what's needed right now?* orientation as the cardinal features of a *going somewhere* life.

The complement of the *what's needed right now?* mindset is the orientation to

provide a *just-enough* level of support. In practice, this means that the resources allocated will dynamically track the unfolding circumstances—additional resources may need to be invested, at other times resources may be scaled back. This introduces a strong focus on cost-effectiveness, frugality, and a recognition that over-committing resources to a situation introduces unjustifiable opportunity costs for those drawing on the same resource base. This contrasts sharply with the approach to resource allocation which has been more typical in the disability sector, namely allocating resources on a *to be sure, to be sure* basis (which can often relate as much to addressing staff needs for reassurance and comfort as the actual support requirements of the service user).

Mistakes will occur in this process. We have already made mistakes in the formation of particular groups and locations. These became evident very quickly and advertised the imperative to address them. Perhaps such errors and incompatibilities pressed less insistently for resolution in the context of the previous congregate setting?

Has it been worth it?

We are at a very early stage in implementing many aspects of our ambitions for this initiative. This applies particularly to connecting people to social networks of ordinary folk, building inclusive lifestyles, and helping them find meaningful roles in their local communities. To date we have been largely preoccupied with helping people adjust to the transition and building a sense of *home*. However, even within three months for many individuals, huge benefits are already evident. It is now apparent that many people spent much of their time in the institutional context living in a state of hyper-vigilance and alarm. The behavioural manifestations of this mode of hyper-arousal have reduced very significantly. In some cases this has allowed medication levels to be reduced. Some who, on the basis of previous reports, were inclined to self-isolate are displaying emerging capacities for interaction and relationship. Many are already revelling in having their own space, their own possessions, their own foothold in the ordinary world. **FL**

**Brendan Broderick, CEO,
Muirlosa Foundation,
Moore Abbey, Monasterevin**

HOME IS WHERE THE HEART IS

Marie is a 57-year-old woman. She came from Athlone to live in Moore Abbey Institution in Monasterevin in 1980 and she lived in what was known as 'Main House,' in a large unit style setting for group living. During the 1980s, Marie moved into a community residential house with 4 other people and she attended a day service with 16 other people. Marie's typical day consisted of attending the day service Monday to Friday 9am-5pm, where she took part in activities such as Special Olympics, recreation, arts and crafts. She returned to her community residential home each evening. Marie was very quiet—she would have got lost in the crowd, lacked confidence and found it difficult to make her own decisions.

Early in 2010 Marie began to be supported by the Person Centre Wing of the Muiriosa Foundation which was set up in October 2009 with my support as Coordinator. I began to work with Marie, using the social role valorisation framework. I had also known Marie previously, when I worked in Marie's day service. I began the process of 'discovery'—really getting to know who Marie was as an individual. Even though I thought I knew Marie before as her key worker in the day service, I really only knew her basic likes and dislikes, her interests—the the usual tick-the-box information we traditionally had to know. Looking back on the discovery process now, three years later, I realise I really did not know who Marie was.

As a coordinator we look at valued social roles (SRV) for the people we support—as a tenant, a friend, a neighbour, an employee or employer. For Marie, the fundamental need was to look at where 'home' was. When I was first getting to know her, people said that Marie could not make decisions—that she would be unable to decide where home was for her. Both her family and other support people said that Marie's life was in Kildare, as she had lived there for the past 30 years. So Marie and I began to look and discuss what a home was and where she would like to live. We viewed houses in the areas Marie had lived. It was obvious early on that if I, or other people

involved, led her to what we thought was best for her, she would just follow our lead. So to support Marie to make choices, I had to give her options—starting with three choices of something like—where would you like to go today? I would also put a 'red herring' (an option I knew Marie would not like) and whether, if I put a positive emphasis on that option, Marie might agree, just because I said so. I found Marie would often do that, because living in group homes had taught her to accept a preset option—what everyone else was doing. I also gave Marie opportunities to make small decisions in everything that we did to support her, in order for her to gain the skills and confidence to make larger decisions. Slowly I saw that Marie was building confidence and making decisions for herself. Other people also saw changes in Marie—she was beginning to have a voice. One day, when I suggested three places where Marie might want to live, she came up with an option of her own, not one of the three I had given her. Marie said 'Athlone'. She wanted to move back closer to her family. We decided to visit Athlone twice a week to really see if this was what Marie wanted.

By visiting Athlone every week for about 4 months it was obvious that Marie did want to live back there. Each visit was a trip down memory lane for her—with memories of different places from her time growing up and people she and her family had known. So we decided to test the waters carefully—we all know sometimes we have desires and dreams, but the reality may be somewhat different. We looked at a 'try before you buy' option for Marie to experience life in Athlone. We met different estate agents and found a suitable house in Monksland Athlone. The day we helped Marie move in, I realised that her entire belongings fit into two small cars, and it was obvious that even though she had lived for 30 years in Kildare, she had really never made a *life* for herself there.

We looked at how Marie could make connections in her new community; the best place to start was in the role of 'neighbour'. Marie always liked baking, so she made scones and delivered them, on china plates, to all the surrounding

neighbours and introduced herself. This was done with 'purpose' and 'intention'; the neighbours would return the plates, giving Marie another opportunity to make connections, invite the neighbour in for tea and ask them what was happening in Athlone socially. This was all new for Marie—she had never known what being a neighbour was. Her support staff had to teach her the social skills to be a neighbour. Marie easily made friends with one neighbour in particular, because of their common interests. Marie now attends a social group weekly and she has made great connections and is continuing to have new opportunities and experiences.

Through our work we acknowledge the importance of the role of the support worker. Marie interviewed and recruited three support workers based on common interests, their connections within the community of Athlone and what value they could add to Marie's life. They have helped her to become not just a presence, but an actual participant in her community. Marie really does have a life now, not a service. Marie is now a volunteer in both her church and with Meals on Wheels, enabling her to fulfil the 'volunteer' role and give back to her community. This is important, as the people we support are often seen as 'charity', on the receiving end of services, rather than as someone contributing their skills and gifts within their community. Marie also is involved weekly in her local women's social group and her active age group and she attends a local prayer group once a week.

Marie also wanted to have a job. She has now begun to sell homemade jams, marmalades and chutneys in local markets, shops and hotels—currently she has five sales outlets. Marie also restores and stresses second-hand furniture to resell for customers and this has led her to be self-sufficient and to hold a valued role of 'entrepreneur' and 'business woman'.

Marie had 24-hour residential care when she lived in Moore Abbey and in the group homes. Marie now has support workers for 50 hours per week; they have supported Marie to make decisions and helped her to become independent within her home and her community. Marie also has assistive



technology which provides 24-hour monitoring when she is alone in her home. Marie can talk to a support worker via a pager, and one of five people assigned will respond to her call, if the need arises. This system also includes sensors which are activated if water or a cooking appliance is left unattended. If someone calls to Marie's door, she can press a button and the monitoring company can listen in. This system has given her independence, but it also ensures that she is safe.

For all of us, family is a most important part of our lives. Moving back to Athlone has helped Marie to recapture that part of her life too. We forget that the people we support should and can play the role of 'son' or 'daughter', or valued relative. For Marie this is the role of 'cousin'. She has reconnected with her family and has been able to attend family weddings and celebrations, and to spend Christmas with her family. She also continues to rebuild connections with old family friends.

The real lesson I have learned throughout this journey with Marie is that if we support her to grow and develop as a person—keeping our expectations high—she can do everything she wants. The person who really made this happen is Marie herself—not me, her support workers, or family. We have just given her the opportunity to have options, to experience new opportunities and to make decisions. For Marie to lead her life according to her own vision, and not what others see as their vision for Marie. This is still only the beginning of that journey for Marie, but 'home really and truly is where her heart is.' **FL**

Sean Bohan

Sean Bohan is a coordinator for the Person Centred Wing for the past 3 years. Sean studied as a social care worker for his degree in the Open Training College Marino for 3 years. Sean currently provides support services to individuals with intellectual disabilities in partnership with their families for the South Kildare Region. The Person Centred Wing also works in Laois/Offaly and Longford/Westmeath.

A HOME AT LAST

Stephen Lawless tells us Philip's story.

Alvernia House, in Portlaoise, closed its doors on 4 September 2012, with 27 people with intellectual disability moving into alternate living arrangements in community settings in the Midland area. The following is an account of one of these people, Philip Brady, and his progress so far in his new home.

Philip (42) moved from Alvernia into Russellstown in mid-July. He is a native of Mullingar and his new home in Russellstown is on the outskirts of the town, only a 10-minute drive from his parent's house. Philip lives in the house with one other service user, Donal. On one of the very first visits to the house in Russellstown, Philip's father Phil remarked that 'it was a dream come true' to see Philip in his own house. This sentiment, I think, encapsulates what it means to make the transition from institutionalised care to a community setting. Perhaps the most significant change in Philip's life in terms of the two settings can be summed up in one simple word, choice. Philip is no longer expected to conform to the needs of the majority, as was the case in Alvernia. A recent study (Fitzsimons 2012) found that a common feature of institutionalisation was that the person with intellectual disability relinquishes control and responsibility of their own life. What we are seeking to do is empower people with the willingness to take back that control and responsibility and to live their lives on their own terms.

This has started with Philip on a small scale. Slowly the rigid routine of institutionalised life is being broken down. Philip now decides what time he would like to get up; he decides what clothes he is going to wear and what food he is going to eat. However, it is not simply a process of being presented with choices and responding. He increasingly has more input in these choices. For example, within the last month he has started to make his own lunch with staff support. This is something which may seem trivial, but it is a far cry from the set unit meals of Alvernia and it is another important step on the road to self-determination. That was a big day in the house.

Philip has recently had his first person-centred planning (PCP) meeting in Russellstown. The meeting was attended by Philip's father, sister and brother, along with staff and Philip himself. Before the meeting we were keen to establish a plan that was specific to Philip, instead of a 'fill in the blanks' exercise not necessarily tailored to the person's personal goals and aims. The meeting focused on improving Philip's quality of life in specific domains, such as recreational activities (The Brady family and Philip have always had a lively interest in a broad range of music.), Philip's identity as a Mullingar man and creating social roles for him. Philip sees himself as a son of Philip and Kathleen and a brother to his six siblings. He is fond of his nieces and nephews and is endeavouring to be a good housemate to Donal. However, Philip will require supports to develop his role as a neighbour and to become a more active citizen. This is something all of us working with Philip are keenly pursuing with him.

Philip's transition from Alvernia has not all been plain sailing. There are challenges every day, not least is the often difficult task of trying to motivate him to try new things and engage in new activities. This reluctance is most likely the result of his institutionalised way of life for so many years. All we can do as staff, working closely with his family, is to try to expose Philip to as many new experiences as possible which may lead to a more fulfilling life. This is perhaps the most evident change between Philip's former institutionalised life and his current way of life. The decision to engage in these new experiences, or not to do so, ultimately lies with one person—Philip. **FL**

Stephen Lawless



Stephen Lawless graduated from the NUI Galway, with a BA (Hons) in Psychology and Sociology in 2010, and with a post-graduate diploma (Hons) in Psychology from the University of Nottingham in 2011. He volunteered with St Hilda's Services in Athlone for 6 months and now supports two people with intellectual disability in Russellstown, Mullingar. He is Philip Brady's key worker.

A NEW START

Stephen Keating tells the story of Jim Kinsella, a former resident of Alvernia House.

Little was known about Jim when the initial project team first met him in May 2012. There was very brief information as to his level of ability—but nothing about him as a person.

The person introduced to the support team on that first meeting at Alvernia House was a physically imposing man. The Muiriosa team were feeling apprehensive, as indeed was Jim. He presented as a large, nervous and socially unskilled person—uncertain as to what was expected of him. He did have a reputation for being demanding and aggressive. However, we quickly realised that there was no intentional harm in that. Some people were reported as being uncomfortable in his presence. The team quickly formed the impression that he had a big heart, wanted to enjoy life and could do so with a little help and support. It was clear to the team that Jim had the POTENTIAL to have a much better life.

Jim met our team many times over the next two months and every time he would take me aside and ask about the 'house' that he would be moving to. He appeared genuinely excited by the prospect. It had been decided that for the first part of his transition Jim would live on his own with his support team. This was to allow his anxiety levels to fall to a more acceptable state as he moved from institutional life.

In August 2012, Jim arrived—with a new suitcase, clothing and bright new shoes, so reminiscent of institutional life in Ireland in the mid 20th century.

Three months later where are we?

A vision for a better socially integrated life is a wonderful dream, but that's all it can ever be until Jim is better known and understood. Jim's team need to explore his needs, strengths and abilities. What does he want? What would he like to do with his life? What valued role does he have? What meaningful roles can he fulfill? This period of discovery is now being embarked on in earnest with Jim.

Settling into his new environment was the easy bit. He wanted his own space, peace and quiet, and to have some control of his own home. That's the first step; this is Jim's home.

One of earliest tasks identified was Jim's physical health. After many years of living in an institution, his weight had significantly increased, coupled with type II diabetes. Minimal exercise made him breathless and led to excessive perspiration. Blood sugar levels were in the mid-

20s. An immediate action was to assist Jim to move away from his preferred diet of chips, sausages and coca cola. His diet is now more balanced, varied and lower in fat. Coca cola, despite the best efforts of his team, continues to be a problem although it has reduced to only one drink per day. Jim continues to be preoccupied about his coca cola and asks people for money to purchase his favourite drink. The good news is that his blood sugar readings have reduced to the low teens, but further reductions are needed.

Jim's initial presentations also included a pronounced tremor of the arms, and self-inflicted abrasions on his body and limbs. Needless to say, his support team worried about those issues, and they decided that some alleviation could be achieved by addressing his lifestyle and medication regime. Reducing his medications has been difficult for him and also for his support team, particularly assisting him with the ensuing confusion and anxiety. His support team has been superb in assisting him through this transition. A significant and positive outcome has been a reduction in self-inflicted cuts.

Going out for a drive in a car is really important for Jim, but unfortunately this need is not confined to daylight hours. He very

much enjoys these day or night journeys and assisting him to enjoy them at more appropriate times is a real challenge for his support team.

Jim has three brothers and a sister (Tom, John, Liam and Bridie) and he regularly meets them. His support team is now working with him on sibling relationships. The team is assisted by the psychology services and even at this early stage great improvements have been observed. He has enjoyed visits to the family home and stayed overnight. He is looking forward to an overnight stay at Christmas.

Jim is a warm hearted, sociable, engaging 52-year-old with many skills, a wonderful sense of humour, although his communication difficulties can often lead to misunderstandings.

It is likely that institutional living has caused Jim considerable frustration and lost opportunities. The focus of his support team is to unlock his potential and assist him to develop a mutually beneficial valued role within his community. His move from a large congregated setting now allows for many life-enhancing opportunities to be explored on his behalf. **FL**

Stephen Keating

Jim is a warm hearted, sociable, engaging 52-year-old with many skills, a wonderful sense of humour, although his communication difficulties can often lead to misunderstandings . . . His move from a large congregated setting now allows for many life-enhancing opportunities to be explored on his behalf.

VALUE FOR MONEY AND POLICY REVIEW OF DISABILITY SERVICES

(National Federation of Voluntary Bodies' Summary)

The National Federation of Voluntary Bodies welcomed publication by government of the *Value for money and policy review of disability services* in July 2012. The National Federation engaged with the review in a spirit of constructive cooperation since its start date and is now looking forward to further engagement with the Department of Health and the HSE in the development of a comprehensive implementation framework. The Policy Review offers exciting opportunities and very real challenges to organisations to achieve a new vision for people with intellectual disability in Ireland and, in spite of the huge financial difficulties facing the sector, we are up for meeting the challenges required to achieve this vision.

What follows is a brief summary of what the author considers to be the key points arising in the Review Report. The National Federation of Voluntary Bodies carried out a comprehensive survey to ascertain where their membership stood in respect of the recommendations, the results of which were very positive.

The *Value for money and disability policy review of disability services* is an evaluation of the efficiency and effectiveness of disability services in Ireland wholly or partly funded by HSE, encompassing both the statutory and non-statutory sectors. It is an extensive report running to 285 pages and containing a total of 117 recommendations.

The review, which was overseen by a steering group chaired by Mr Laurence Crowley, was conducted under the government's Programme of Value for Money Reviews 2009-2011. Its primary purpose was to assess how well current services for people with disabilities meet their objectives and support the future planning and development of services and to make recommendations that will ensure that the very substantial funding provided to the sector is used to maximum benefit for persons with disability, having regard to overall resource constraints.

As part of the overall value-for-money review, a separate Expert Reference Group on Disability Policy was established to look specifically at existing disability policy and assess whether it needs to be changed to better meet the expectations and objectives of people with disabilities. The Reference Group oversaw a public consultation process on existing disability services, which concluded that people with disabilities and their families want more choice in the services they receive and more control over how they access them.

The over-riding focus of the recommendations is on a programme of governance, delivery-model change and a detailed upgrading of information in respect of precision, scope and format. It proposes a fundamental shift in approach, moving from provision which is predominantly centred on group-based service delivery, towards a model of person-centred and individually chosen supports. The achievement of measurable outcomes and quality for service users at the most economically viable cost underpins the recommendations. Re-articulated vision and goals are proposed with a recommendation that a set of realistic, meaningful and quantifiable objectives be developed to support their realisation. With regard to implementation, the Review asserts that implementation of the recommendations should be driven at national level by a strong, standard and consistent approach.

Administration and governance:

The national disability function within the HSE must be strengthened and given a central directional role in funding, shaping and driving the Disabilities Service Programme. A Director of Disability Services would have responsibility for implementation of the Review recommendations.

Person-centred services and supports:

The HSE should drive migration towards a person-centred model of services and supports through the Service Level

Agreement process. Agencies will be required to initiate demonstration projects to run in parallel with current services and evaluate their suitability for subsequent wider application. (Note work already being done in this regard: Genio Projects; Next Steps Project.)

Commissioning and procurement:

A new Commissioning and Procurement framework is needed to drive a directional re-shaping of certain services and models.

Resource allocation:

A national resource allocation model should be developed based on a standardised and appropriate assessment of need process, a methodology for associating standard costs with assessed needs, and transparent protocols for determining the basis for allocating finite resources.

Information infrastructure:

The strategic information requirements needed for the effective management of the Disability Services Programme should be established, having regard to existing information sources and datasets, and an implementation plan put in place.

IMMEDIATE ACTIONS:

1. The Service Level Agreement process needs to be adjusted to make immediate improvements to information gathering and performance monitoring.
2. Standardise Financial Reporting – Development of a common coding system to enable expenditure to be tracked, analysed, and compared at national, regional and local levels.
3. A unique identifier should be put in place to facilitate:
 - Individual needs assessment;
 - Person-centred planning;
 - Individualised budgeting.
4. Examination of Value for Money Findings – Each agency should undertake an immediate examination of the findings and key recommendations of the Value for

Money Review, and draw up an implementation plan to give effect to the recommendations with a particular focus on the following:

Audit of rosters: Rosters should be critically examined with a view to making the necessary adjustments to rationalise staff deployment across service units in accordance with client need and cost effectiveness.

Skill mix: National guidelines should be developed to advise on the appropriate mix of professional and non-professional staff needed to deliver supports through an in-depth examination of skills, functions and grades.

Unit costs: The HSE should work jointly with service providers to critically examine existing cost bases in the light of the findings and recommendations contained in Chapter 5 of the Value for Money Review, with a particular focus on establishing reasons for costs that remain higher than the average costs detailed in the review.

Average costs: Pending the development of a resource allocation model, the Service Level Agreement process should be used to reduce current direct pay costs.

Policy appraisal: The new policy direction enunciated in Chapter 7 of the Review should be appraised in accordance with government guidelines on policy appraisal.

Implementation plan: A robust Implementation Framework should be developed which takes account of the policy appraisal. It should be comprehensive in nature, paying particular attention to the following issues:

Disability Programme Objective—The review confirmed that people with disabilities want more choice in the supports they receive and more control over how they access them. They want flexible services that meet their individual needs and systems which vest more control with the service users, and, where appropriate, their families.

Economy and efficiency—The results of the data analysis conducted as part of this Review reflect the complexities of disability service provision, which is not a single, homogenous and easily-

measured programme, but rather a multiplicity of service types and agency types servicing a very varied client population with widely differing needs.

The data showed that in general some agencies are more efficient at one particular type of service and less efficient at another. Some models are extremely cost efficient, but score poorly on quality of life. Other types of service are cost efficient and support the move to social inclusion and mainstreaming.

There is a requirement to develop a framework to assess need, identify outputs and outcomes and plan and monitor resource usage. The Review found that there is no national standard methodology for assessing client need or for linking those needs with target outcomes. Similarly, there is no nationally agreed means of predicting the amount of resources which an individual is likely to require, and no common method of calculating the amount of resources which an individual actually consumes and the cost of those resources.

Effectiveness—There is a requirement to develop national indicators to objectively measure the effectiveness of the Disability Services Programme in promoting personal progression, community inclusion and participation, and the application of choice, control and independence. The public consultation conducted during the course of the Review found that once people had accessed services, the supports received were considered by respondents to have a beneficial effect. However, almost all respondents indicated that the objectives of the Disability Services Programme had not been fully met and that services did not support choice, control and independence.

Governance and accountability—While the National Disability Unit of the HSE has lead responsibility for the management and delivery of the Disability Service Programme nationally, it has no authority over resource allocation on operational service delivery. This responsibility lies with the Regional Directors and Integrated Service Area Managers who discharge this responsibility by entering into Service Level Agreements with individual service providers. Partnership structures which are representative of the major stakeholders operate within a collaborative framework at a regional and local level.

Information framework—The Review found that the information systems operated by the HSE were wholly inadequate. Information on output delivery was not available in a comprehensive and easily comparable form. There is an immediate and urgent need to address this serious deficit.

Funding framework—The block grant approach to funding had a pragmatic historical basis, but is no longer sufficient to address the degree of accountability and transparency expected of the modern Disability Services Programme. The implementation of the Service Level Agreement process is a welcome development in this regard, but requires review, evaluation and refinement so that it will make a more positive contribution to monitoring performance, controlling expenditure and shaping service development.

Future policy direction—The Review found that current objectives are still valid, but the policy approach used to deliver these objectives has not been effective. The continued sustainability of the current policy approach is questioned, particularly given the demographic pressures and changing societal and family expectations which will place increasing demands on services. It was recognised that the delivery of services and supports has been evolving towards a more person-centred approach, but that the pace of change has been slow and uneven.

The Review concluded that instead of a slow and tentative drift towards individualised services, the policy approach should be re-calibrated to focus more closely on the proposed vision and goals, and that all future developments would be planned and evaluated in terms of their progress towards those vision and goals.

This progress should be advanced in parallel with the recommendations around reframing existing services, so that the development of new resource allocation models and units of cost can provide a basis upon which the transition from traditional programme type to more individual costing approaches can take place. **FL**

Brian O'Donnell,
Chief Executive,
National Federation of Voluntary
Bodies

VALUE FOR MONEY AND POLICY REVIEW OF DISABILITY SERVICES—HOPE FOR THE FUTURE, OR A DAMP SQUIB?

Last July, shortly after government ministers, TDs and senators went on their summer holidays, the *Value for Money and Policy Review of Disability Services* (VFM) report was published to little or no fanfare, discussion in the media or, conveniently, debate in the Dáil. This long-awaited review, commenced in 2009, is not an easy read, but for those willing to go through its over-300 pages, there are many illuminating nuggets of information. The Review puts to bed the myth that services for people with intellectual disability are provided by poorly-paid service providers struggling valiantly with insufficient resources to provide quality services to meet increasing demand.

This myth was first debunked in 2005 when the Comptroller and Auditor General (C&AG) highlighted the scandalous lack of transparency and accountability when it came to funding not-for-profit organisations. Money was allocated by the HSE to services without any proper audit of money spent or services provided and no tendering or measurement of outcomes achieved. A system of block funding existed, in which annual funding for a specific service was based on what had been received the previous year, with a bit more added on. In the early 2000s, I recall being told by a provider that each time a person came off the waiting list, the funding for that new place was linked to that person. I now find out that this was patently untrue, as the VFM report shows that once allocated, the funding did not remain associated with the individual, but was absorbed into the agency's base funding (Finding 3.11 of the VFM Report). Despite the evidence of the C&AG Report, money continued to flow into this discredited system.

The VFM report shows that total gross expenditure on disability services increased by 34% from €1.34bn in 2005 to €1,789bn in 2009. Expenditure for 2011 is estimated at €1.708 bn. Pay costs account for up to 85% of this spending. While in the last two years there have been pay reductions and a moratorium on recruitment, the amount of these reductions (approx 5%) is significantly less than the 34% increase over the 6-year period.

Some changes were introduced on foot of the C&AG Report, most notably the establishment of Service Level Agreements (SLAs) with the HSE. However, the VFM Review notes that the information from the SLAs is not collated at a national level and does not contribute to any national monitoring of performance. It also says that there has been no objective evaluation of the operation of this new process, which took over five years to be established, against considerable opposition from some large providers.

The imperative to reform was simply not there. As long as money was flowing freely, nobody cared. It is now clear that little of the extra cash was being allocated on the basis of rigorous analysis, evaluation or consideration of value for money. Much of the spending was targeted at pleasing vested interest or buying them off, the main vested interest being voluntary service providers, trade unions, professional groups, and quangos, who all have done extremely well out of the disability sector in the last ten years and continue to do so with the protection offered under the Croke Park Agreement. The failure of the HSE and the Department of Health to monitor this use of tax payers' money can only be termed gross negligence. However, it is not surprising, given that we live in a country where the political system, as recently (Oct 2012) described by Stephen Collins, political correspondent of the *Irish Times*, has the propensity 'to be captured by narrow interests rather than act for the common good'.

It is unlikely that issues of excess in spending, waste or accountability would have raised their ugly heads if the government had not run out of money. The VFM Review provides us with a great deal of information which we did not have before. The Review had great difficulty in obtaining basic information from both the HSE and voluntary disability providers which would enable conclusive findings to be made in many areas. Consequently, the Review had to undertake original data collection itself, which added considerably to the time it took to be completed.

Not surprisingly, two of the Review's key implementation priorities relate to the urgent need for better data collection in two key areas:

- The financial reporting system where allocations and expenditure can be tracked, analysed and compared at national, regional and local levels, and
- SLAs which are streamlined for immediate improvements to basic information gathering and performance monitoring.

The failure to have such basic systems in place for a 'billion-euro industry' is a clear indictment of successive Ministers for Health and senior officials in the Department of Health and the HSE.

Much is made in the Review about the need to facilitate individualised service provision, and it is encouraging to read that the Review recommends that the HSE should drive this through the SLA process. Disappointingly, it does not say how this should be done. The only way to ensure individualisation is to link it to the service providers' annual funding allocation each year: providers would agree with the HSE a percentage of their allocation to be spent on individualised planning and budgeting. Failure to meet the agreed target would then cause a proportion of the allocation to be withheld or withdrawn.

I disagree with the implementation priority of seeking more demonstration or pilot projects to look at person-centred models of support. The country is awash with such projects, whose end results benefit a few, but which will have no real impact on the 4000 still living in congregated settings. An independent VFM review of all the pilot projects is essential.

To change policy requires action by government to real reform at a national level. This will require strong leadership from the top and a Minister for Disability who has the full support of the government to stand up to the vested interests. I posed the question in the title of this article, whether the Review offers hope for the future, or whether it is just another damp squib—something that fails to live up to expectation. Unless people with disabilities mobilise into a cohesive group, making alliances along the way with others, as they so ably did outside Government Buildings last summer, I fear this Review, worthy and all as it is, will end up on the shelf gathering dust—just like all the other reports of the last twenty years. FL

Deirdre Carroll

Joe Wolfe and Trevor Nesirky introduce the fourth and final article in the series about standards. It focuses on their view of the potential benefits of the standards and the inspection process for people with an intellectual disability.



PREPARING FOR INSPECTION OF RESIDENTIAL SERVICES FOR PEOPLE WITH DISABILITIES

Part 4: The benefits of national standards and inspections of services

The Health Information and Quality Authority (HIQA) is the statutory authority with responsibility for setting standards for health and social care services and for ensuring that such standards are met. This responsibility extends to residential services / centres for people with disabilities. There have been repeated calls for the introduction of national standards in services for people with intellectual disabilities for many years and these standards are clearly long overdue. They are overdue and necessary for three fundamental reasons:

- The person with an intellectual disability has a right to a minimum standard of service, regardless of where that service is or who provides it.
- Good services need to be acknowledged and they need to be recognised and promoted.
- Services that fall far short of the standards need to be identified and unacceptable practice and standards need to stop. Services that continue to fall far short of the standards, despite being given a reasonable time frame and opportunity to improve, should not remain open.

What should people expect?

The benefits of national standards, if implemented properly and if monitored fairly and effectively, are potentially considerable. Effective regulation has shown to improve standards in services nationally and internationally. It does improve quality. It does improve the degree of person centredness of the service. It does result in safer services for the people who use them. It does result in improved governance and management. It does improve the protection and promotion of people's rights and it does improve people's health and development.

Once standards are formally introduced, people with intellectual disabilities should expect the following:

With regard to rights

- To be given a formal written service agreement / contract by the service provider, which clearly sets out what they will receive from the service and the conditions of their residency.
- That services and staff will promote and respect their rights, including their basic human rights.
- To be treated in a dignified and respectful manner by the service and by all staff working in the service.
- To be given choices and control in relation to their life, in accordance with their preferences and abilities.
- To be informed and involved in decision making, in line with their preferences and abilities.
- To have access to an advocate and advocacy services.
- To be consulted with regularly by the service and by staff.
- To be supported to develop relationships and friendships and links with the community, in accordance with their preferences.
- To have an assessment of their capacity to manage finances and to consent to medical treatment.

With regard to safety

- To be protected from abuse and neglect.
- To have their safety and welfare promoted.
- To have ongoing assessment in relation to any major risks to them and to have a plan in place to reduce and minimise those risks.
- To be provided with information and support to help them reduce the risks to themselves.
- To live in houses and environments that are accessible, safe, comfortable and homely.
- Not to have restrictions or restrictive practices applied unless they are absolutely necessary from a safety point of view and unless they are carried out in strict accordance with best practice and legislation.

With regard to personal planning and person centredness

- To be treated as an individual and be supported to live a fulfilling life.
- To be treated fairly and equally by the service and by staff.
- To be valued, respected and treated with dignity by the service and by staff.
- To be consulted in developing a comprehensive personal plan, which is based on their abilities and needs and which supports them to achieve a good quality of life

With regard to complaints

- To have the staff in their service actively listen to them with regard to any concerns or complaints they have.
- To have any raised concerns or complaints responded to properly and, where necessary, investigated properly and fairly.
- To be informed of the outcome of the complaint and have any action necessary taken to redress the situation.
- To have their complaints taken seriously and to be informed of the outcome of their complaint. Services will have to provide evidence that they do this properly and effectively.
- That the service will keep proper records of all complaints and their management for scrutiny by the regulator.
- That if the service makes mistakes, it corrects them and does all in its power to prevent them from happening again.

With regard to staff

- For staff supporting them to have been properly screened and recruited.
- For staff supporting them to be properly trained and developed in line with the person's needs and abilities.
- For staff supporting them to have regular supervision.
- For staff supporting them to have their performance reviewed on an ongoing basis.
- For staff supporting them, who breach acceptable standards of practice, to be subjected to appropriate disciplinary processes, and to be managed effectively.

With regard to information

- To receive information in a manner they can understand and which is appropriate for their level of communication ability.
- An increase in the use of accessible notices and signs.
- An increase in the availability of accessible policies and other information, with services using new technology to make it easier for people to understand important information.
- That information about them is maintained in a confidential manner.
- That the service uses information to plan and deliver safe and effective services.

With regard to health and development

- To have timely, comprehensive assessments of their health.
- To receive appropriate support to meet any health needs.

- To have their health and development supported and improved.
- To have opportunities in relation to education, training and employment appropriate to their needs and preferences.

With regard to the management of the service

- That the service will be well governed and managed.
- That the managers are competent to carry out their roles and responsibilities.
- That the service has safeguards in place in relation to safety, risk and well-being.
- That the service complies with legislation, regulations and national policies and standards.
- That the service has documents setting out clearly its purpose and function and that it implements this effectively.
- That the service plans and manages its resources effectively.
- That the service regularly reviews and audits its quality and continually improves the quality of the service provided to the person using it.
- That management consults regularly with the person around the quality and development of the service.
- That effective management systems are in place to enable a person-centred and safe service to be provided.

While the final standards and regulations for residential services / centres for people with disabilities are not quite finalised; they are almost complete and the current plan is to commence inspection and registration from the summer of 2013. It is extremely positive that this is finally close to fruition and we should see immediate improvements in some areas as a result of the introduction of standards and registration. There will, no doubt be a 'teething-period', as there is with the introduction of regulation and standards in any sector of life. However, if standards and regulation are implemented fairly and effectively, we will see an improvement in the lives of people with intellectual disabilities living in residential services. **FL**

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Having spent their careers working in, managing and developing human services, Joe, Trevor and their team have been supporting organisations across the health and social care arenas to prepare for registration and inspection over the last number of years. They support organisations through:

- Establishing quality structures and systems in preparing for registration and inspection
- Conducting GAP analysis / reviews of organisations against national standards
- Providing training on preparing for the fit person's process and on auditing and self-assessment skills.

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