THE IRISH VOICE FOR INTELLECTUAL DISABILITY

FRONTLINE

Volume 87 • Summer 2012

HEALTH AND WELL-BEING

SERVICES — RESPITE CARE — PRIMARY CARE— STANDARDS

FRONTLINE CONTENTS

FEATURE: HEALTH AND WELL-BEING

09 Health and wellness in day services for adults with an intellectual disability
Mary Reynolds, Niamh Gallagher and Jerome Moran, explain how the Daughters of Charity Services are introducing healthy eating and excercise routines for their clients.

10 Primary care for persons with intellectual disabilities: Issues for practice
Owen Doody, Maria Bailey and Rosemary Lyons review the issues in providing primary care services to people with intellectual disabilities.

13 How to improve health care for people with genetic causes of intellectual disability
Clinical syndromes associated with Down Syndrome and Tuberous Sclerosis.

14 The development of a higher diploma in behaviours that challenge (adults and children) intellectual disability service
Level 8 Qualification.

16 Physical activity and Autism Spectrum Disorder
Poor motor function, low motivation and poor social interaction make it even more difficult for people with ASD to be physically active, but with support, encouragement, and motivation anyone can improve their level of physical activity. Michael McKeon explores the benefits of physical activity for those with a disability.

MAIN ARTICLES

07 *Respite:* Enough is enough
Avril Webster asks why accessing respite services for parents caring for children with disabilities should be so difficult.

08 *Advocacy:* The Step and City Gate Advocacy Group

20 *Support:* One person at a time
Across the globe, organisations are questioning the quality of the supports and services they have been providing to people with disabilities. Hope Leet Dittmeier of Realizations LLC assesses the situation.

22 *Staff Appraisal:* So, How am I doing? Employee appraisal systems as a tool for enhanced performance
Ciaran Leonard proposes the use of 'Performance Appraisal Interviews' as a tool to enhance employee performance, improve employee-manager relationships and promote a continuously improving culture of relationships within the workplace.

25 *Services:* Talking straight about services
Mary de Paor listened to Christy Lynch at a recent staff conference of an Irish intellectual disability service organisation.

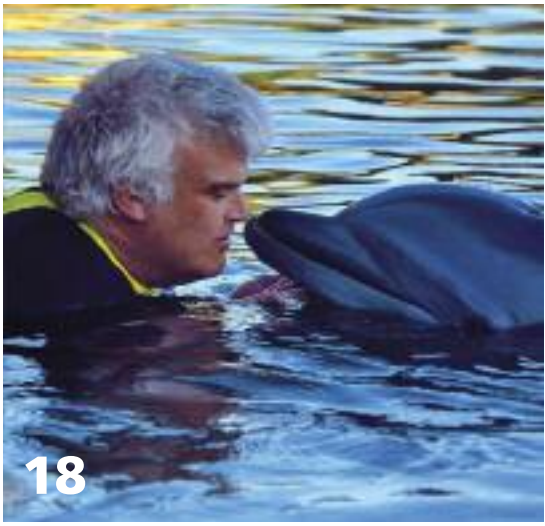
26 *Interview:* Edward Dunne, CEO of Nua Healthcare

30 *Mental Health:* Disability Psychotherapy: The analytical treatment approach
Angelina Veiga explains exactly what disability psychotherapy is and how it can support people with disabilities.

REGULARS

03 Editorial

04 News Update
—Oireachtas Justice Committee launch report on Capacity.
—JobBridge Scheme open to people on Disability Allowance.
—Disability Psychotherapy Ireland.
—Access to Justice for People with Disabilities.
—Disability Issues raised at Oireachtas Health Committee.
—New website for TILDA.
—Labour Party Conference passes Motion on Protecting Disability Supports.
—Useful websites.
—Dáil Debate on Domiciliary Care Allowance.
—Your Voice Your Choice.
—BILD outlines concerns about service provision in England—sounds familiar!



18 GALLERY: 20 years of arts and crafts!

28 STANDARDS: Preparing for registration and inspection of residential services for people with disabilities
Joe Wolfe and Trevor Nesirky introduce Part 3—Conducting Self-Assessments and Audit.

31 REVIEWS:
Forensic issues in adolescents with developmental disabilities. Group Music Activities for adults with intellectual and developmental disabilities.

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FROM THE EDITOR

CUTS!

This issue of *Frontline* comes at a time of reported over-spends by hospitals in excess of €100 million for the first quarter of 2012. Managing this over-spend is an imperative of the HSE—but at what cost?

As this issue goes to print, there is uncertainty about respite provision. Respite is seen by many families as important for the retention of their psychological wellbeing and general health. A concern for many is whether the HSE's imperative to control the hospitals' over-spend will lead to a blunt approach, spreading indiscriminate cost curtailment to community care and other provisions (for example, respite care). It is questionable whether people who make such decisions have a real understanding of the lived experience of caring for someone with a disability, particularly for those who have reduced incomes. It is reasonable, however, to question whether the current model of respite provision is the best fit for parents and the person with ID. If a more innovative non-centre-based provision were in place, could more families benefit? Would that long standing conundrum, *those in greatest need very often get the least supports,* be finally put to bed? The challenge is not to cut the respite budget, but rather to ask providers to do more through innovation, instead of placing undue reliance on a jaded model of provision

As more and more people with an intellectual disability move into living in the community, it is reasonable to question whether their needs are quantifiably factored into community care budgets. Their need to access GP services, to avail of physiotherapy, chiropody, occupational therapy, mental health services, individual counselling and supports (and other services) will have an impact on many cost centres. If their needs are not seriously factored into primary health care and access to their networks, people with intellectual disability will continue to be prisoners of indifference, even within the models of the rhetoric of inclusion.

This issue has a number of interesting articles, including one from the US by Hope Leet Dittmeier which highlights how people's lives can be improved through community living, provided proper and appropriate supports are in place.

Healthy living and psychological wellbeing are sides of the same coin and something all of us hope to enjoy. It is about having friends, enjoying activities, making decisions, to share and to receive. It is also about celebrating in the here and now.

There is, of course, the on-going challenge to help people with intellectual disability to live meaningful lives, providing the time to listen carefully to their needs—whether they are recreational, social, work, training, health and psychological well-being. It is about people who provide support in the community knowing how to listen, and with reciprocal respect.

Stephen Kealy

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Oireachtas Justice Committee launch report on Capacity

The Oireachtas Justice Committee recommended that new capacity legislation should be based on human-rights principles and must ensure that decision-making supports are 'voluntary, proportional and tailored to the person's circumstance and free of conflict of interests and apply for the shortest time possible so that the will and preferences of people with disabilities are respected.' The recommendations were contained in the Justice Committee's Report on Capacity which was launched on 1 May 2012. The Report arises from the submissions and public hearings into the Scheme of Capacity Bill. The current Irish law governing capacity is the 1871 Lunacy (Regulations) Act. In 2008 the Fianna Fáil and Green Party coalition published the Scheme of a Capacity Bill (This means the 'heads' of a Bill were published and not a full Bill.) The current government committed to introducing modern capacity law in the 2011 Programme for Government. A 'Mental Capacity' Bill is currently on the 'A' list in the schedule of legislation from the Department of Justice. This means a Bill should be brought before the Houses of the Oireachtas in the current Dáil term. In August 2011 the Justice Committee requested submissions on proposed new Capacity Law. Over seventy submissions were received from individuals and organisations, and Inclusion Ireland was one of eleven organisations that presented to the Committee in February 2012. Inclusion Ireland said:

> "This is not an outdated law that has no affect on people in modern Ireland. Every week Inclusion Ireland receives calls from people who have been severely adversely affected by this law. People with an intellectual disability, serious mental health problems, dementia and acquired brain injury are all affected by this law, which takes away a person's right to make decisions about their life. The Lunacy Act allows for the Ward of Court system, which means that for someone who has been made a 'Ward of Court', the Court makes all decisions about their lives, from medical and money decisions, to leaving the country and marrying".

The work of the Justice Committee in seeking submissions on this issue before publication of the Bill is a new initiative and it is hoped that the input given by individuals and organisations will speed up the passing of the Bill when it is going through the Oireachtas. The full report is available on the Oireachtas website www.oireachtas.ie.

JobBridge Scheme open to people on Disability Allowance

The JobBridge scheme is now open to those on Disability Allowance. The Minister for Social Protection, Joan Burton TD, made the announcement in early May. JobBridge is the National Internship Scheme that provides work experience placements for interns on a six- or nine-month basis. Interns receive an allowance of €50 per week on top of their social welfare payment. JobBridge aims to help jobseekers get practical work experience. The Scheme was launched in July 2011 and 6000 places are available on the Scheme. The eligibility criteria were extended to include those in receipt of One-Parent Family Payment and Disability Allowance from 28 May. See www.jobbridge.ie for more information.

Disability Psychotherapy Ireland

Disability Psychotherapy Ireland is an established group in Dublin, Ireland committed to the progression and advancement of Disability Psychotherapy within Ireland.

Members of DPI meet monthly in a therapy centre in Dublin city centre. Our activities include discussing clinical work, hosting Disability Psychotherapy events and networking. The group operates as a referral network amongst its members and is used as a peer supervision space. DPI also functions as a reading group. Selected reading is circulated in advance of each meeting which forms the basis of our discussion. The selection of the reading material is shared out among all members.

We find these meetings to be a valuable opportunity to think about theoretical approaches, discuss clinical work, share information and network. Membership of the group includes clinicians coming from a range of clinical backgrounds whose practices are informed by psychoanalytic psychotherapy. We warmly invite our fellow clinicians in Ireland to contact Angelina Veiga (angelinaveiga@gmail.com) or Theresa Merrigan (theresamerrigan@yahoo.co.uk) if they would like to find out more about Disability Psychotherapy Ireland.

ACCESS TO JUSTICE FOR PEOPLE WITH DISABILITIES

The National Disability Authority launched a Report in April, which found that attitudes of legal professionals and judges are crucial to people with disabilities accessing justice. Entitled 'Access to Justice for People with Disabilities as Victims of Crime in Ireland', the Report found:

- the criminal justice system can be intimidating to people with disabilities;
- Gardaí need to have information on delivering their services in a disability-friendly way;
- Garda stations and courthouses may not be accessible to a person with a disability;
- The attitudes of judges and barristers are crucial—the assumption may be that people with disabilities are not competent or credible witnesses;
- People with disabilities may be 'invisible' in the system because there is no systematic data collection on this aspect.

The full report is available on the NDA website, www.nda.ie.

Disability Issues raised at Oireachtas Health Committee

Young adults with an intellectual disability leaving school and the Value for Money Review of Disability Services were among the issues raised when Health Minister James Reilly and a number of senior HSE officials appeared before the Oireachtas Health Committee in May 2012. Laverne McGuinness of the HSE said while 'traditionally there has been funding to provide day services and day places for children finishing school...we did not get it this year as money is not available.' She said the HSE has met a large group of disability providers and asked them to look at other areas where they can generate efficiencies 'in terms of staffing ratios, back office functions and so on. We met them as a group and they must now come back with their plans.' Ms McGuinness added that the Department is working on the Value for Money Report and it will be available later in the summer or the autumn.

New website for TILDA

It is with great pleasure I announce the launch of a new website, www.idstilda.tcd.ie, for the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA). This website is as a result of an innovative multimedia approach to research dissemination. Our project entitled ***'Getting the Message to the People that Matter; Innovation in Research Dissemination'©*** encompasses several strategies to ensure people with intellectual disability are both active participants and comprehending recipients of research. The website offers a dissemination mode that enhances understanding of information and increases access, essential elements ofinclusion of persons with ID and a means to advance an emerging international framework for online accessibility. The findings are depicted through short filmed scenes all portrayed by amateur actors. The website also has a further information link with plans for future expansion. I hope you enjoy browsing our webpage.

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USEFUL WEBSITES

WebMD heart Health Center:
http://www.webmd.com/heart/default.htm
http://www.webmd.com/heart-disease/news/20120418/happy-people-healthier-hearts?src=RSS_PUBLIC

American heart Association Getting Healthy:
http://www.heart.org/HEARTORG/GettingHealthy/GettingHealthy_UCM_001078_SubHomePage.jsp

How to change your outlook:
http://www.coachandcounsel.net/Change_My_Life_outlook_changes.html

Psychological Bulletin, Boehm, J.K., Kubzansky, Laura D., online April 16, 2012: http://psycnet.apa.org/psycinfo/2012-10025-001/

Harvard School of Public Health: News release, April 17, 2012. http://www.hsph.harvard.edu/news/press-releases/2012-releases/positive-emotions-cardiovascular-health.html

www.yourmentalhealth.ie

www.psychologicalsociety.ie have a PDF brochure; Psychology Matters 40 Tips which provides very useful information for people, with or without a disability, on Healthy Living—well worth a read.

DÁIL DEBATE ON DOMICILIARY CARE ALLOWANCE

The Dáil Technical Group scheduled a Private Member's Motion in the Dáil on Domiciliary Care Allowance (DCA) in May. The Debate, which was held over two evenings, discussed the application and review process of the DCA. While the Independent TDs who brought forward the motion argued that there was a large increase in both the refusal rate and the number of families who were denied the DCA when it was reviewed, Social Protection Minister Joan Burton said there were no cuts in the scheme. In 2011, 13,552 applications were made and 46 per cent of applications were accepted. The allowance is €309.50 a month and is paid where a child requires substantially more care and supervision than another child of the same age. The Department of Social Protection recently increased the number of days within which parents must provide information for a review from 21 to 60 days.

LABOUR PARTY CONFERENCE PASSES MOTION ON PROTECTING DISABILITY SUPPORTS

A motion was passed at the Labour Party Conference in April that called for the immediate publication of the Value for Money and Policy Review of Disability Services and for the National Standards for Residential Services for People with Disabilities to be put on a statutory footing and subject to inspection by HIQA. Minister of State with responsibility for Disability, Kathleen Lynch TD, spoke in favour of the motion, which was passed unanimously. The motion read as follows:
'Conference notes that in the current economic climate, there is a need to maintain a strong focus to protect disability supports services in order to enhance the participation and inclusion of people with disabilities in our society and calls for:

— the immediate publication of the Value for Money and Policy Review of Disability Services;
— the National Standards for Residential Services for People with Disabilities to be put on a statutory footing and subject to inspection by HIQA;
— and supports the move towards individualised funding that will give people with a disability and their families greater control and choice over the services they receive.'

YOUR VOICE YOUR CHOICE

Kathleen Lynch T.D. Minister for Disability, Older People, Equality & Mental Health launched **Your Voice Your Choice** in the Royal Hospital Kilmainham, Dublin, on 19th June 2012.

"It is very important that we clearly hear the voice of people with disabilities in developing any policy or services that impact on their lives", the Minister said. "This event is about genuinely listening to the voices of people who often don't get an opportunity to have their voice heard and air their concerns and experiences". "This event today ensures that the perspective of service users can inform the development and implementation plan for the National Disability Strategy", she added.

Your Voice Your Choice is about facilitating people with disabilities to have their say about issues that matter most to them in living with a disability. This is the first time this event was held and included people from around the country, drawn from a range of ages and from across the disability and mental health spectrum.

"Today's event is unique in that it captures, at first hand, the lived experiences of individuals with disabilities. I have no doubt this will enrich our understanding of what needs to be continued and build on the progress to date," said Peter McKevitt, Chairperson, National Disability Authority. "We hope to make this an annual event", he added.

Disability Psychotherapy Ireland with the Institute of Psychotherapy and Disability and Respond announce

'Forensic Disabilities'

This seminar will consider some of the key issues in working with children, adolescents and adults with intellectual disabilities who have sexually harmful behaviours or sexually offend.

This seminar will focus on:

- Risk assessment
- Children and Families: Assessment, Treatment and Safeguarding
- Forensic Psychotherapy
- Paraphilias and Paraphilia Related Disorders

Speakers:

- Tamsin Cottis, Co-founder of Respond and Clinical Lead Sexually Harmful Behaviours Service, Respond, London, UK
- Richard Curen, Consultant Forensic Psychotherapist, Respond, London, UK

Saturday November 17th 10am - 1pm €45.00

The Teachers Club • Parnell St • Dublin 1• Ireland

Register your interest at: disabilitypsychotherapyireland@gmail.com

CPD points will be awarded

BRITISH INSTITUTE OF LEARNING DISABILITIES (BILD) OUTLINES CONCERNS ABOUT SERVICE PROVISION IN ENGLAND—SOUNDS FAMILIAR!

Half of services are failing people with learning disabilities – is the Department of Health's response up to the job?

BILD welcomes the reports from the Care Quality Commission (CQC) and Department of Health - anything that highlights issues important to people with learning disabilities and comes up with proposals to tackle poor services is valuable. But, while the CQC's new evidence is shocking, the response from the Department of Health may be a missed opportunity to be ambitious for people with learning disabilities and make sure this failed model of care is changed forever.

The CQC reviewed 150 learning disability services and found almost half were not meeting government standards. This was not a surprise to most of us, just proof that things are actually worse than we thought. Of the 145 services inspected, only 35, a quarter, met government standards and 110 services will have to be re-visited.

More than the numbers, this report proves yet again that many services completely fail people with learning disabilities and their families and the use of inappropriate physical restraint places people at real risk of harm. The failure to meet the basic human rights of people with learning disabilities would not be tolerated were this happening to any other minority group in society.

The Department of Health's interim report outlines 14 actions they say will improve the quality and safety of services for people with learning disabilities or autism who have behaviour which challenges. But they fall short of directing commissioners and providers of services to stop buying and providing this failed model of care and directly requiring them to implement the good practice set out by Jim Mansell. This huge gap between policy and practice has gone on for too long. It has to stop now.

It is clear that the present system doesn't work. We need to stop sending people away to large institutional services. People need instead to be living closer to home and their families, in smaller settings that follow the individualised support approaches set out in the Mansell reports. We know that the right policies already exist, but making them work in practice is about strong leadership and practical support to turn policy into action at a local level. This is where the system fails repeatedly.

"If the Department of Health can't recognise that these are systemic failures then they can't move in the right direction and at the right speed to fix them and, sadly, we will likely be here again at some point in the future," said Ann Chivers, BILD's Chief Executive. "The Department of Health's 14 actions lack the strong leadership, vision and drive to lead and set the pace. There are few examples that talk about fixing a system that is clearly broken, and fixing it fast. We would have expected a statement about ending this model of care and a clear new focus on performance and evidence based impact, showing how the 14 actions will make a difference to the lives of people with learning disabilities and their families."

We hope that the Department's full report in the autumn will provide a much clearer statement that will finally bridge the huge gap between policy and practice and, most of all, be ambitious for people with learning disabilities and their families, and for all those who support them.

Peter Salisbury | Communications Manager
British Institute of Learning Disabilities | www.bild.org.uk

ENOUGH IS ENOUGH!

Avril Webster asks why accessing respite services for parents caring for children with disabilities should be so difficult.

Why is there no joined up thinking in our government policy when it comes to disability services? There have been countless reports, most recently *Progressing children's disability services, New directions: Personal support services for adults with disabilities, Time to move on from congregated settings & Report of disability policy review* . All of these reports talk about the importance of building 'capacity' within families. We also know that the best place for most people to live is with their families and communities.

Yet, Carl O'Brien reported in *The Irish Times* on Monday 4 June that the Irish government are looking at withdrawing funding from service providers for the provision of respite for families. Apparently they are looking at families using an existing grant called the Respite Care Grant to go out and fund respite services themselves. I don't know how much the government pay the service providers for the existing respite service our family receives, but I would guess that it is at least 10 times the cost of the Respite Care Grant. So, yet again, the disability community is looking at cuts way above any other area of government spending.

Respite is a vital, I mean really vital, service for families. Without it many will not be able to cope and the end result will be the 'decapacitising' (the taking away of capacity) from families.

This is also very short sighted of the government because in the long run not providing sufficient respite will actually cost more than providing it in the first place. As well as the economic cost where an adult or child with a disability has to be put into emergency care because their family can no longer cope, what about the cost to that individual and their family in terms of the emotional well being and quality of life?

I am a parent to 3 children. Stephen is my eldest, he is a fun-loving happy 14 year old. He is a great singer and loves to walk and swim. Stephen also has autism, intellectual disability and physical and sensory issues. He needs a lot of support with personal care needs, feeding and toileting. He also does not sleep much. He has that lovely label of 'challenging behaviour'. We get two/three nights respite per month and it is essential for our family life and survival. We use this time to sleep, to spend time with our other children and to take a break so that we can cope with the various extra challenges. Yes, taking care of Stephen is hard and it requires more skills and patience than what you might call 'normal' parenting. However, the 'system', and the bewilderment of trying to navigate your way around it, is what makes life even more difficult.

I am all for reform, choice and looking to see can we get an improved service at a lower cost. But if the government's idea of 'individualisation' is to completely withdraw existing funding and services for respite, then they need to think again. Even if I was given sufficient funds for the respite our family needs, I wouldn't know where to start looking for a service, as there are no structures in place to support families in making this choice. We need to pilot individualised funding options and provide training for families and not just 'land them' in an unknown situation.

The last bit of my rant is this idea of 'kite flying' where the government leaks speculative information that causes families like us no end of worry. This is another cut to services coming on top of cuts in education, therapy services, no funding for school leavers this year etc. etc. It gets harder and harder to stomach when we read that the *Value for Money* report due to be published in the next few weeks will show the salaries for people working in the disability sector are almost twice the sums earned in other countries. The government has agreed that public-sector salaries are off limits, tied up in the Croke Park agreement, public sector salaries are frozen ...

Something has to give, government cannot keep chopping the services to people with disabilities and their families. This is a question of fairness, of social justice, of equality, of basic morality. Government are hell-bent on protecting the salaries of civil servants and service providers. But who is protecting the people with disabilities and their families? Is that not where government responsibility should be focused?

We all accept the economy is in a very poor state, but people with disabilities and their families have taken more than our fair share, it is time to say enough is enough. We all have to work together to safeguard and improve services where everyone shares in the reductions and it is not just taken out of frontline services. And as I said earlier, if the government removes respite services, in the long run it will cost more in every way. More worn out and exhausted families will be pushed into the situation where they cannot cope and will have to hand over their loved ones to the state to care for them full time. We simply cannot let this happen. **FL**

Please also see Emer Sherry's blog entry on www.disabilityinfo.ie for her excellent opinion piece on this subject.

Reprinted from: Avril Webster's www.offwego.ie/blog.html, 06 June 2012

Respite is not an additional service that can be seen as an 'add-on' or a luxury for people with a disability and their families –it an essential part of an overall service being provided. The needs of children and adults with disabilities vary greatly according to each individual, so the idea that a general figure of €1700 could possibly provide annual respite for everyone, regardless of their support needs, is simply not realistic. Residential respite care can be very expensive in cost terms, and €1700 simply wouldn't cover a meaningful service for many families. Alternative non-centre-based respite has been explored in many areas in recent years and is often very successful. While this needs to be further built on, many families still feel residential respite is vital. Reducing the amount of respite available will have a very negative effect on the person with a disability and their family. In some parts of the country, families are already paying towards the cost of their respite service. Current reports that the state may stop funding respite in disability services is also very frightening for people with disabilities and their families. There must be ongoing consultation and people cannot feel that decisions affecting them are being made over their head, without their voice being heard.

Siobhán Kane, Communications & Information Manager, Inclusion Ireland

THE STEP AND CITY GATE ADVOCACY GROUP

The STEP and City Gate Advocacy Group has 11 members. It meets every 2nd Monday at 4.30pm in the Corres Centre in Sandyford. If anyone has an issue they need help with in their work or community they can approach any member of the committee or the Advocacy Co-Ordinator, Anna Shinnors. An example of some of the issues we discuss and try to progress are: discrimination in shops, poor accessibility on local transport and difficulties using bank ATM machines.

Group members have benefitted from a sense of togetherness when tackling issues of concern, as opposed to tacking problems alone. The Advocacy Group has a stronger foothold now within STEP and City Gate, as well as in the local community. Recent Rights Assessments indicate an increase in knowledge about rights and an increased sense that change is needed. Families and staff have been informed of the results of Rights Assessments and reported rights restrictions are now all in due process.

We have also attended many conferences around the country and met with other advocacy groups. We have worked with some of these advocacy groups on certain issues. We partnered with Enable Ireland locally, as their service users had serious accessibility issues on local transport. We also worked with

- Foley Street Advocacy Group
- Southside Partnership
- NIID
- Galway Advocacy Services
- Inclusion Ireland
- Carmona Services
- Department of Health Sciences in Trinity College Dublin.

Significant developments have been:

- Representation to External Bodies/Organisations to address external issues/barriers impacting the men and women –e.g. County Councils/Supermarkets/Banks
- Development of Disability Awareness Training Pack for Secondary Schools
- Development of Advocacy Newsletter circulated three times a year
- Facilitation of anti-bullying course for the men and women in association with Foley St Advocacy Group (Inclusion Ireland)
- Raising awareness of complaints' process – Introduction of Complaints' Phone/Form
- Training facilitated for Advocacy Board Members
- Introduction of Mentoring Programme to support Advocacy Board Members
- Assisting the Health Promotion men and women at STEP and City Gate.

We have achieved many things—creating a mentoring programme, ongoing work on health promotion in STEP and City Gate, the creation of a Disability Awareness Training Pack that will be carried out in schools and other organisations in the future. We also meet management on a monthly basis to discuss issues that affect the men and women in STEP and City Gate. We have met with the County Council in relation to local access issues and this work is ongoing. We have created a newsletter which goes to all staff and the men and women in STEP and City Gate. This comes out three times a year. These are just some of our achievements and an insight into other projects that we are currently involved in. **FL**

Health and wellness in day services for adults with an intellectual disability

Health and wellness are an integral part of enjoying a good quality of life. The World Health Organization defines health as 'not only the absence of infirmity and disease, but also a state of physical, mental and social well being'. For people with an intellectual disability this is an important consideration, as many may have additional health care needs which must be appropriately managed. However, a balance must be struck between providing for health care needs while also ensuring that each person has access to a good quality of life.

Since 2007 the Daughters of Charity Services for individuals with an intellectual disability have utilised the services of a community liaison nurse, Jane O'Connell, for individuals attending adult day services. Jane carries out a health-needs assessments and develops a health action plan with each person based on their identified health risk and needs. The health assessment tool used is 'Integrate' (Hutchinson *et al.* 2006). Where possible, the person will answer questions themselves or with the assistance of their family or key worker. Based on areas of need or concern, an individual health action plan is developed with the person and his/her family. The emphasis is on empowering the person or their family to access health screening or services within their local community, in keeping with the philosophy of inclusion and accessing generic services. The health action plan is also incorporated into each individual's person-centred plan. The health screening ensures that any problems can be identified at an early stage and appropriate interventions made.

Since 2009 the Daughters of Charity have also been actively supporting Special Olympics Ireland in developing an evidence-based health promotion toolkit. The toolkit contains fifteen workshops and resources ranging from healthy diet and recipes, to advice on maintaining good bone health. The resource packs also include a food, dental and exercise diary, easy-read health leaflets and games. These workshops are run on a regular basis for individuals, their families and support staff.

Another component of ensuring health and wellness is health promotion. Changes in the delivery of day services with a move away from a campus-based programme have contributed to a more healthy lifestyle, with individuals participating in more active leisure and recreational activities. To date, the organisation has developed six small community-based day services which provide person-centred day programmes to individuals in Finglas, Mulhuddart, Mountview and Cabra. The meeting points are located in mainstream community facilities and service users who access them live within that local area. Each individual has a person-centred plan developed around their own needs and preferences, which includes the promotion of a healthy lifestyle. Individuals access a range of activities within their local community such as swimming, walking groups, tag rugby, a soccer club, Tai Chi classes, dancing and community gardening. These groups help promote a sense of well being, increase physical activity and give opportunities to develop and learn new skills. Many of these classes have been supported by local community grants.

One participant, Jerome Moran, who collaborated on the writing of this article, interviewed some of his peers and their families to hear what their experience of the programmes were and how it had helped their health and well being.

The responses were overwhelmingly positive, with an acknowledgement that the quality of life of individuals had increased along with a sense of health and wellness.

Left: Brian working out in the gym

Above: Learning all about healthy eating

Some of the comments from individuals:
'We learn what is good for you, fruit is good – coke is bad. Water helps you; you have to drink water every day, eight cups I learnt.'
'We go shopping and make our lunches every day. My lunch is Weight Watchers based.'
'We do a lot of different activities here. Every day we do something based around health and fitness.'

Some of the comments from families:
'My daughter is a lot fitter now and has a lot more stamina for walking long distances.'
'My son has lost 8lbs and is much more conscious of what he eats.'
'I attended the Healthy Food Made Easy workshops and got lots of ideas and tips.'
'He takes more interest in his personal hygiene – showering, for example, after the gym.'

The Daughters of Charity promote the concept of individualised supports within a community setting, as espoused in the *New Directions* report (2012). There are a number of benefits to this model of service delivery, one of which is an increased awareness of the importance of health and wellness—as already outlined above. The health screening programme, the use of the Special Olympics health promotion toolkit, and participation in community-based day programmes are directly resulting in a greater awareness of health promotion activities and increased health gains for people with an intellectual disability. **FL**

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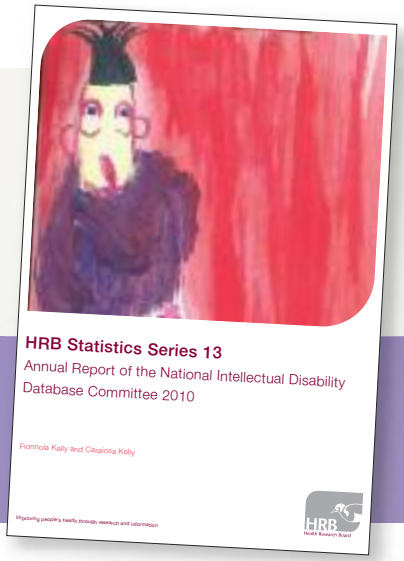
(References with the editor.)

Primary care for persons with intellectual disabilities: Issues for practice



Owen Doody, Maria Bailey and **Rosemary Lyons** review the issues in providing primary care services to people with intellectual disabilities

In tandem with a growing population, Ireland is further witness to a change in the demography of persons with intellectual disability. *The Annual Report of the National Intellectual Disability Database* highlights, in particular, that people with intellectual disability are surviving into old age and that they are requiring services appropriate to their age group (Kelly *et al*. 2008). The trend for institutional care has been outmoded (Sheerin and McConkey 2008; McConkey *et al*. 2005) with more persons with an intellectual disability living in the community. In 2008 a total of 26,023 people were registered on the National Intellectual Disability Database (Kelly *et al*. 2008). From the database it is evident that there were more males (56.6%) than females (43.4%), with the highest proportion of both males and females diagnosed as having a moderate level of intellectual disability. Of these individuals, 25,433 were in receipt of services, 16,708 (64.2%) were living at home with family/carer and only 8290 (31.9%) were living in fulltime residential services. These residential services mainly included community group homes and residential centres, while 950 individuals (3.7%) lived independently or semi-independently (Kelly *et al*. 2008).

This move to the community is based on the principle of normalisation (Wolfensberger 1972). Wolfensberger later reconceptualised normalisation and proposed to replace the term with 'social role valorisation', reflecting his concern that certain groups in society (such as persons with intellectual disability) were perceived as having devalued social roles (Wolfensberger 1983). He argued that devalued groups tend to be cast into negative roles and called for a move away from segregation, special treatment and institutionalisation. Social role valorisation embodies the ideal that persons with an intellectual disability should be integrated into society, and should be offered the opportunity to access generic services which serve the general public. In tandem with the increased life expectancy and prevalence of persons living in the community, it follows that all healthcare workers of the future will be required at some level to engage and support persons with an intellectual disability and their family/carer(s).

As the first point of contact, primary care is considered the appropriate setting to meet 90-95% of all health needs (Department of Health and Children 2001). This concept is founded upon the core principles of equity, person-centred care, quality and accountability. However, Ziviani *et al*. (2004) and more recently Michael (2008) identified that adults and children with intellectual disability experience significantly greater difficulties than others in accessing assessment and treatment for general health problems that are not related to their disability. International researchers Cummins and Lua (2004), Lennox *et al*. (2001), Powrie (2001), Whittaker and McIntosh (2000) have all indicated that there are significant shortcomings in the health of adults with an intellectual disability and that their healthcare needs are being overlooked in the community. For example, persons with intellectual disability are known to have greater health needs and yet they are less likely to visit general practitioners or avail of preventative services (National Health Service Executive 1998). As a result of communication difficulties, persons with intellectual disability may not describe symptoms to their general practitioners until disease has advanced

and, moreover, these individuals cannot always be expected to arrange their own preventative care (Iacono *et al*. 2003; Turner and Moss 1996). Disease progression caused by delayed presentation for healthcare screening will mean that many persons with intellectual disability will require earlier nursing intervention and support (Powrie 2003). In Ireland, the Department of Health and Children (2001) has argued that if primary care services and resources are available to all, this would reduce the potential for disparities in health, thereby increasing the population's opportunities to live healthy productive lives (Schoen *et al*. 2004).

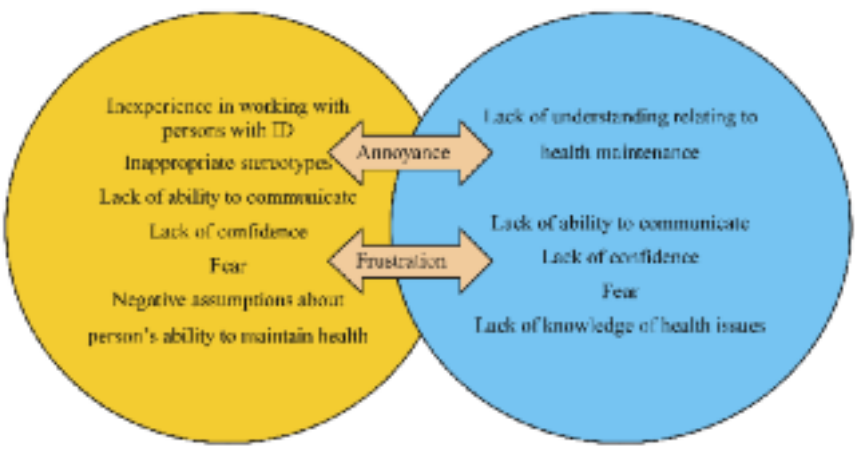
Issues in supporting the healthcare needs of persons with intellectual disability living in the community appear to be dual-focused around the client themselves and/or the process of accessing healthcare. Primary care teams rely strongly on an individual's ability to recognise and report symptoms of ill health (Turner and Moss 1996), and this poses problems for persons with intellectual disability and their family/carers. Ziviani *et al*. (2004) notes that clients may not have sufficient skill or knowledge to aid in the consultation process. When persons have difficulty articulating their own individual health needs, appropriate medical assessment is challenging (Ziviani *et al*. 2004). In the community, general practitioners within primary care teams have expressed concerns with communication difficulties which influence their ability to adequately diagnose, manage and inform clients/relative/carers (Melville *et al*. 2005; Ziviani *et al*. 2004). For the family/carer(s) of persons with intellectual disability, interaction with the primary care team frequently commences following the birth/diagnosis of a child with an intellectual disability. The primary desire of parents is to care for their child with intellectual disability at home (Llewellyn *et al*. 2005). This places increased pressure on families in their caring role (McConkey 2005). The older or more physically dependent the child, the more parents struggle to care for their child (Llewellyn *et al*. 2005; McConkey 2005) with the parent's capacity to continue in a caring role diminishing over time (National Intellectual Disability Database 2006).

The impact of caring is multifaceted and encompasses financial, social and practical aspects of the lives of families (Hartrey and Wells 2003; Redmond and Richardson 2003). Caring for a person with high support needs leaves parents exhausted emotionally and physically (Lecavalier *et al*.2006; Mase *et al*. 2003), experiencing cycles of anxiety, frustration, loneliness, stress and burnout (Jeon *et al*. 2005). Caring for a person with intellectual disability has a cascading effect on the health of the family and the needs of both the family and the person with intellectual disability should be met in order to deliver a quality service. Although needs vary, all families will require individual and practical support (Forde *et al*. 2004; MacDonald and Callery 2004) and the availability of such support provides an invaluable service to parents (Jeon *et al*. 2005; Miller 2002). Hartrey and Wells (2003) argue that families require services that are comprehensive, accessible and available in an emergency.

Melville *et al*. (2005), Voelker (2002) and Beange and Lennox (1998) note that an inadequate knowledge of services and resources, coupled with little time for examination and consultation were issues identified as barriers to the provision of adequate care for persons with intellectual disability. Similarly ascertaining whether the person with intellectual disability is able to give consent for medical procedures or screening (such as cervical smears, breast examination or testicular examinations) may also present problems due to a lack of understanding (Powrie 2003). It is interesting to note that similar difficulties may also be experienced by other healthcare workers. As illustrated in Figure 1, the imbalance suggests that the cause and therefore the 'cure' lie largely within the domain of the healthcare worker. The figure further suggests that many of these barriers are shared by both the healthcare worker and the client with an intellectual disability. This is of concern, given that one group has a professional role in caring and supporting the other. It is hardly surprising, therefore, that persons with intellectual disability report frustration and annoyance when they cannot adequately communicate, for example, to general practitioners or when they are overlooked in the communication exchange (Melville *et al*. 2005; Ziviani *et al*. 2004). This need for better understanding may be expressed by what is perceived as inappropriate behaviour and this can negatively affect the consultation process (Doyle 2006; Ouellette-Kuntz 2005).

Healthcare workers have a key role in addressing the health needs of persons with intellectual disability, ensuring equal access to all aspects of health promotion services, including health education and health surveillance with appropriate additional support as required to meet individual needs (Melville *et al*. 2005; Barr *et al*.1999). However, contrary to best intentions, health promotion can unconsciously create health inequalities (Leeder and Dominello 2005; Department of Health 1999), with the

Figure 1: Healthcare worker and client-focused barriers to primary care



... the inclusion of RNIDs (Registered Nurse Intellectual Disability) in primary care teams would aid communication skills between all parties and reduce the health disparities of persons with an intellectual disability.

result that those in greatest need of health promotion are those who most miss out. This is an extensive challenge to the primary care system, as health promotion presently is delivered for the general public as a whole, and has the potential to create problems in relation to comprehension and understanding of persons with intellectual disability. This can only further widen the gap of an inequitable, rather than an equitable, service. As health promotion focuses on the total population and its environment, careful attention is essential in order not to overlook minority/vulnerable groups (Leeder and Dominello 2005). In essence, health promotion within primary care may present numerous obstacles which relate to the nature of available information, the availability of time, the availability of adequate equipment and the knowledge, skills and attitudes of staff (Rimmer and Braddock 2002; Barr *et al*. 1999; Band 1998).

Although healthcare workers have identified that they feel they ought to strive to meet the health and social needs of persons with intellectual disability, they have also indicated that they perceive themselves to be ill-equipped to provide for this diverse group (Ziviani *et al*. 2004). Furthermore, and not altogether surprisingly, these healthcare workers argued that persons with intellectual disability are best suited to be managed outside of primary care services (Powrie 2003; Bollard 2002). This raises the need for a professional experienced nurse from intellectual disability to liaise between the family and the primary care team. In Ireland it may be argued that the inclusion of RNIDs (Registered Nurse Intellectual Disability) in primary care teams would aid communication skills between all parties and reduce the health disparities of persons with an intellectual disability.

Now in its 50th year of regulated existence in Ireland, the role of the RNID is specialised and unique from other disciplines of nursing with their education and training based upon the philosophy that each person with an intellectual disability has '*a right and a need to live within the community like other persons and they have a right to receive those services necessary to meet their specialised and changing needs'* (An Bord Altranais 2010, p.17). The RNID is equipped with an in-depth knowledge and skill in the provision of nursing care and management for a diverse range of disabilities, together with experience of client behaviours and client/nurse relationships of persons with intellectual disability. The nurse provides a comprehensive healthcare service responding effectively to the needs of persons with intellectual disability not just in terms of treatment of healthcare problems but also by addressing overall wellbeing and understanding and respecting the individual and their family (Lindsey 2002). The inclusion of RNID expertise may also provide a strategy to enhance the consultation process and reinforce screening a view expressed in the United Kingdom by Powrie (2003). Powrie argued for the inclusion of the registered nurse in intellectual disability within the primary care team or network, based according to the population statistics. Such an initiative is worthy of further consideration in the Irish context.

Quality healthcare is a social right that every citizen should experience. All citizens should be assured that care is guaranteed and appropriate in their times of vulnerability. A socially inclusive society takes responsibility for and reduces the social consequences of having intellectual disability. However, this can only be achieved by all services taking responsibility for and supporting the individual to be as independent as possible in the community (Powrie 2003; McConkey 2002; Duvdevany 2000). It must be emphasised that unmet or misdiagnosed health needs for the person with intellectual disability often result in carers becoming socially isolated and potentially vulnerable when the pressure on the family of caring for the person with intellectual disability becomes overwhelming (Powrie 2003; Llewellyn and McConnell 2002). As primary care is founded on the core principles of equity, person-centred care, quality and accountability, the delivery of an equitable multidisciplinary model of care is dependent upon qualified competent and flexible staff meeting the changing demands of the health system (Department of Health and Children, 2004). While this is a laudable and a positive approach to a significant health challenge, it may be argued that current health strategy fails to address the needs of existing healthcare workers in developing individual knowledge, skills and attitudes relating to caring and supporting persons with intellectual disability. Responding to the healthcare needs of persons with intellectual disability will always remain a challenge as communication barriers and ethical dilemmas make it difficult to fully implement all health provisions (Ouellette-Kuntz 2005; Ziviani *et al*. 2004; Powrie 2003).

Consequently the inclusion of relevant staff, persons with intellectual disability and their families should be an integral component of the planning, development and delivery of healthcare services and education programmes. Such initiatives should be tailored to meet the needs of persons with intellectual disability with the aim of providing accessible information and improving the client/healthcare worker interaction (Cumella and Martin 2004; Iacono and Davis 2003; Turner and Moss 1996). If we truly support the philosophy of healthcare for all, we need to live this through our endeavours to create a tapestry of education and support for the client the family and healthcare worker. In order to inform our practice, further research in Ireland pertaining to the utilisation of general healthcare services for persons with an intellectual disability is required. **FL**

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HOW TO IMPROVE HEALTH CARE FOR PEOPLE WITH GENETIC CAUSES OF INTELLECTUAL DISABILITY

Knowledge of a particular phenotype, physical or behavioural, can help a clinician in the consultation. For example, it is known that people with Fragile X Syndrome become uncomfortable when engaged in direct eye contact, so a clinician may have a more productive consultation if they sit next to the individual, rather than in front of them. A recent successful example of responding to a known physical phenotype is the addition of thyroid function screening in people with Down Syndrome to the routine screening services offered by GPs in the UK the QOF LD. In that case GPs receive a payment for ensuring a high uptake of thyroid screening in people with Down Syndrome.

Developing a personal plan

The question arises as to how, in the absence of a structured response from heath services, such as with health checks, an individual or carer can ensure that a person has health care focussed to their specific needs. In most instances it is quite likely that parents or other carers may become experts in a rare condition and feel their knowledge is greater than that of their physicians. It is possible that the syndrome charity may have provided written information to help the GP about health needs. This is the case for Rett Syndrome, where Rett UK (http://www.rettuk.org/rettuk-public/rettuk.html) has developed a pack for primary care teams. For most individuals it may simply mean that an empowered family will work with the GP to inform them of their child's health needs. This is an important and probably relatively simple way to inform the GP and to set targets for ensuring the appropriate health promotion is performed

In summary our management of the health needs of people with an intellectual disability should be changing for the better, with new knowledge gained through scientific research. Sadly such change is usually slow. We suggest that empowerment of carers, families and individuals is the most likely way to promote rapid change.

Dr Rose Thompson, Dr Glyn Jones & Professor Mike Kerr

Clinical syndromes associated with Down Syndrome and Tuberous Sclerosis
(Adapted from the Syndrome Specific Checklist Dr RG Jones)

	Down's Syndrome	Tuberous Sclerosis (Epiloia
Inheritance	TRISOMY Chromosome 21 94% non-dysjunction 3–5% translocation 1–3% mosaicism	Usually sporadic Autosomal dominant (Chr 9, 11, 16)
Cognitive Phenotype	Most Moderate LD (IQ 20–75, mean IQ 50)	Variable IQ (dep. on site & severity of tubers in brain) approx. 50% have LD (most severe-profound)
Psychiatric Phenotype	Alzheimer's dementia (45% > 45 years) Depression OCD	Depression Anxiety Specific phobias Psychosis (Epilepsy related)
Behavioural Phenotype ie: Predisposition to certain patterns of behaviour	Sociable Good-natured Stubborn	Autism Hyperactivity Self-injury Sleep problems Aggression
Weblink	www.downs-syndrome.org.uk	http://www.nlm.nih.gov.medlineplus/tuberousclerolsis.html www.ninds.nih.gov
((Somatic Phenotype)	Down's Syndrome	Tuberous Sclerosis (Epiloia)
CNS	Epilepsy (mostly linked with Alzheimer's)	Epilepsy (70%) Cerebral astrocytomas
Cardio-vascular	Congenital heart disease (46–60%) AV canal defect Tetralogy of Fallot	Cardiac Rhabdomyomas
Endocrine	Thyroid disorder in 25% (esp. hypothyroid) Advise annual TFT	
Audiovisual	Visual impairment Hearing impairment (both mulifactorial; advise annual checks)	Retinal tumours
Muscular/Skeletal	Atlanto-occipital and atlanto-axial instability Hypotonia	

THE DEVELOPMENT OF A HIGHER DIPLOMA IN BEHAVIOURS THAT CHALLENGE (ADULTS AND CHILDREN) INTELLECTUAL DISABILITY SERVICE (Level 8 Qualification)

Abstract

The ongoing development and support of people with an intellectual disability who present with behaviours that challenge within the intellectual disability nursing services in Ireland is improving. Nursing is a practice discipline and, hence, the attainment of higher level competencies is integral to the achievement and delivery of good standards of care. These competencies may be achieved through participation in further education at Higher Diploma level. An Bord Altranais (2000, p.10) suggests that competence is 'developmental' and 'not static', thereby alluding to the notion of competency as a continuum, which allows the practitioner to develop specialist knowledge and skills throughout their career. The Higher Diploma in Behaviours that Challenge, delivered by the Department of Nursing and Health Sciences, Athlone Institute of Technology, is in its third year. Nurses who have completed the programme are now putting into practice the skills and competencies that they have acquired. The continuation and development of the programme will provide the evidence to underpin a model in behaviours that challenge for specific individuals. This will assist nurses in their role when supporting people with an intellectual disability who present with behaviours that challenge.

Introduction

Behaviours that challenge are described as 'behaviour of such intensity, frequency and duration that it threatens the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion' (Royal College of Psychiatrists 2007, p14). The influence of staff behaviour in the maintenance of behaviours that challenge and the need for staff training in behaviour support skills is widely recognised in the literature (Bamford Review 2006; Hastings and Remington 1994; Cullen 1992). The HIQA (2009) National Quality Standards for Residential Services for People with Disabilities recommends that all staff supporting people with disabilities should have awareness and a qualification in behaviours that challenge. Nurses working in the intellectual disability services in the HSE Midlands and HSE West led the drive for the development of a higher education programme that focused on supporting people with an intellectual disability who present with behaviours that challenge. Collaboration between Nurse and Midwifery Planning and Development in the HSE Midlands, HSE West and AIT led to the development of a level 8 An Bord Altranais Category II Higher Diploma in Behaviours that Challenge.

The aim of the programme is to provide frontline staff with the practical and applied skills to support individuals within their organisations who present with behaviours that challenge. This is achieved through the use of a comprehensive holistic approach to positive behaviour support, in line with contemporary research and best practice, reflective of the evidence. The assessment and evaluation process ensures that students' work is of the highest ethical and procedural quality.

This programme, now in its third year, took in its first cohort of 19 students in September 2009. Students on the current programme are working in services throughout Ireland and this

offers the participants an opportunity to develop links with colleagues nationally.

Background

In the UK *Shaping the future: A vision for learning disability nursing* (2006) recognised that there is a growing evidence of a very high incidence of unmet health needs in the population of people with learning disabilities and this has a negative effect upon many people's quality of life. Gates (2006) commented that it is vital that intellectual disability nurses are leaders in avoiding social exclusion and that they work to ensure that service users' overall needs are addressed sufficiently.

The influence of staff behaviour on the maintenance and frequency of behaviours that challenges has become an important emergent issue in the last decade (Hastings and Remington 1994). The most recent document, *Linking service and safety* has highlighted within their educational remit that 'education and training in the management of work-related aggression and violence be provided to all healthcare personnel' (2008 p13). The authors of this report have placed emphasis on the need for service-specific education that is fit for purpose.

The Higher Diploma in Behaviours that Challenge provides students with a clear pathway to achieve the posts of Clinical Nurse Specialist and Advanced Nurse Practitioners in behaviours that challenge, in line with national standards. The area of management of behaviour that challenges has been under-researched and often inadequately addressed (Braine 2005). This current programme, run over the academic year, offers students the opportunity to share experience, pool knowledge and examine professional and organisational boundaries. This facilitates the development of specialist knowledge and skills to meet the requirements for holistic support for people with intellectual disabilities.

Preliminary evaluations of the programme

Continuing education is a lifelong learning process. This programme consists of planned learning experiences which are designed to augment the knowledge, skills and attitudes of registered nurses, thereby enhancing nursing practice, education, administration and research (ABA 1989). It is essential that we continue to develop initiatives that enhance the support and understanding that people with an intellectual disability receive in the clinical environment within the domain of behaviours that challenge. Successful completion of the programme provides nurses with the requisite knowledge and competence to function more effectively within a holistic interdisciplinary environment.

An important consideration is that on completion of the programme the student has the necessary skills to effect real change within the workplace. In order to capture information on the views, opinions and considered appraisal of the programme from all of the relevant stakeholders, a questionnaire was sent to each of the clinical site managers and students. Students have commented that the mix of expertise in teaching makes the programme worthy, interesting, legitimate and contributes to the wider exploration of the value of a multidisciplinary approach in supporting people with an intellectual disability who present with behaviours that challenge.

Some of the students and their managers' responses are outlined as follows:

Question: How has the student added value from a professional perspective to the work of staff in your area of responsibility?

Manager's response: 'After attending the course the student was able to adopt positive strategies when behaviours that challenge presented and was able to direct other staff members on how to manage a crisis situation.'

> ... there is a growing evidence of a very high incidence of unmet health needs in the population of people with learning disabilities and this has a negative effect upon many people's quality of life

Question: Did the course meet with your expectations?

Students' response: 'This course has helped me view and deal with challenging behaviour from a different perspective and I am using more positive evidenced-based approaches to overcome these challenges.' 'The course lived up to my expectations and beyond.' 'I gained a wealth of knowledge and insight.'

Conclusion

The considerable growth in specialisation within nursing is reflected nationally in the range of programmes that are available to nurses. Successful completion of this programme in AIT provides nurses with the requisite knowledge and competence to function more effectively when supporting individuals with an intellectual disability who present with behaviours that challenge. The programme reflects the national agenda ensuring that all staff should have awareness and a qualification in behaviours that challenge (HIQA 2009; *Linking Services to Safety* 2008). The programme content engages constantly with professional and organisational boundaries. By doing so, it facilitates the development of the specialised requisite knowledge and skills that are required to ensure that the current and future needs of this vulnerable group of people are adequately met. **FL**

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(References with the editor.)

PHYSICAL ACTIVITY AND AUTISM SPECTRUM DISORDER

Poor motor function, low motivation and poor social interaction make it even more difficult for people with ASD to be physically active, but with support, encouragement, and motivation anyone can improve their level of physical activity. **Michael McKeon** explores the benefits of physical activity for those with a disability.

Physical activity generally refers to exercise and physical fitness as important elements of a healthy lifestyle. Approximately 30 minutes of moderate physical activity is necessary each day for an adult to acquire vital health benefits. Recommendations for children are 60 minutes of moderate physical activity each day (*The National Guidelines on Physical Activity for Ireland 2009*).

Physical activity can be instrumental in improving sensory integration, coordination, muscle tone, and social skills development for a person with autism (ASD). Disability should not be used as an excuse to opt out of physical activity, when it can only improve ability. This is especially true for individuals with autism who have been found to have little opportunity to be physically active (Pan and Frey 2005). Additional benefits of physical activity for an individual with ASD include reducing stereotypical behaviour, increasing appropriate responses and providing potential social interaction. With increasing numbers of people with ASD, physical activity initiatives are required, not just for children but also for adults, over the lifespan (Todd and Reid 2006).

Participation in physical activity is generally challenging in the modern world, where a sedentary working life provides few opportunities for physical activity. A sedentary level of activity maintains life, but provides no health benefits. Poor motor function, low motivation and poor social interaction make it even more difficult for people with ASD to be physically active, but with support, encouragement, and motivation anyone can improve their level of physical activity and meet the recommended level of physical activity for a healthy life (Department of Health and Children 2009).

A sedentary lifestyle and low fitness levels are commonly reported in studies of people with ASD. However there are only a small number of studies done on physical activity for adults with ASD. Obesity has become a major health concern for people around the world and, in particular, for people with ASD (Curtin *et al*. 2010). Sustained engagement in physical activity is needed for weight loss and for a healthy lifestyle. Outside help with a qualified coach may provide the start needed for physical activity. Later the coach can be replaced by personal self-motivation or determination to sustain an independent level of physical activity (Todd and Reid 2006). Individuals with ASD may have hypoactive or hyperactive responses to any of the senses, including sounds, touch, taste, and smell. Every individual with ASD is different, yet daily physical activities, including those that are sensory in nature, are important. Exercise plans should be tailored to the needs and wishes of the individual. For example, one individual may need heavier and active routines in the morning and more calming, soothing activities in the afternoon; another may need calming activities throughout the day. Being aware of sensory difficulties that an individual with ASD may have and incorporating individualised sensory activities into daily activities can benefit the individual (National Center of Physical Activity and Disability 2012).

A study by Muller *et al*. (2008) of individuals with Asperger Syndome and ASD (but not intellectual disability), outlined the benefits gained from physical activities which were used as a strategy to manage social isolation, anxiety and stress experienced by the individuals. Physical activity was found to counter the stereotypical view of ASD as lacking social skill and being aloof. The people with ASD found respite in outdoor physical activities from the social isolation and stress where 'the outdoors felt like home'. Exercise routines helped reduce social stress and deal with social frustration. People noted that engaging in physical activity with others allowed them to connect socially without the need for too much conversation.

A walking programme is an easy way to start. A study by Todd and Reid (2006) explained how three teenagers with autism and severe disabilities found that walking/jogging promoted their participation in physical activity. A further study by Todd *et al.* (2010) found that the self-determinant behaviour of cycling was effective in promoting sustained physical activity for adolescents with severe autism.

Physical activity may not appeal to and may sound like a hard task for some individuals with ASD. A small study by Hellier (2011) found that physical activity and relaxation decreased levels of stress and anxiety among individuals with ASD. A 30-year old man with autism and severe challenging behaviour found the use of deep touch pressure was more beneficial than rigorous physical activity (Blairs *et al.* 2007). The challenging behaviour provided the cardiovascular exercise, while the deep touch pressure provided the flexibility and relaxation elements of physical activity.

Obrusikova and Cavlier (2010) found many barriers to physical activity for children, but they also found ways to overcome the barriers. Individuals may use perceived barriers as an excuse not to engage in physical activities. Within disability, Miller (1995) identified three main barriers: physical, attitudinal, and

resource barriers. Chien-Yo Pan (2008) argued that strategies are necessary to plan physical activity for children with ASD in order to meet physical activity guidelines. A strategy, plan and a qualified leader can mean the difference between an effective, enjoyable and safe programme, and a mediocre and possibly even dangerous one. A study of athletes with intellectual disabilities found that they suffered fewer and less severe levels of injuries than the general population of athletes. However, in the study, athletes with autism had the highest rate of sports injury among their peers. This should not discourage such activities, but it does caution on the need for careful monitoring, planning, and support for individuals with autism who partake in athletics activities (Ramirez 2009).

Individuals go through both physical and psychological changes during the course of their lifespan, but early physical activity habits will influence health benefits, regardless of disability and age. Early intervention of physical activity has been shown to be effective in improving the development of children with ASD and the prevention of secondary health conditions (Filipek *et al.*1999).

Outdoor recreation can provide an opportunity for the entire family to become physically active. Parents and carers may need to take the initiative to establish summer camps to create enjoyable physical activity opportunities for individuals with ASD, or to include them in existing clubs/camps.

A gym or exercise program can be taken up at any time during the year. A regular exercise program needs to address the four components of fitness: cardiovascular, strength, flexibility, and balance. Programs should be simple to start with and progress to more complexity, as desired. Above all, activities should be enjoyable, using the individual's interests and strengths, always including the four components of fitness (National Center of Physical Activity and Disability 2012).

Cardiovascular exercise (for example, cycling, running or swimming) benefits a person's heart, lungs and circulatory system. Cardiovascular exercise is important for individuals with ASD, not only for physical fitness, but because studies have indicated that vigorous cardiovascular exercise has beneficial effects on behaviours. Yilmaz *et al.*(2004) found that cardiovascular, flexibility, balance, and strength exercise levels increased, and that stereotypical behaviours decreased after swimming.

Strength training (e.g. weight training) improves muscular strength and endurance. Core muscles have an effect on other activities, such as balance and coordination. Since individuals with ASD respond best to structured learning, it is important to develop a sequential and consistent strength-training program, incorporating repetition of movements in the same order, with visual cues and exercise diagrams to prepare an individual for changes and to foster their ability to exercise independently.

Flexibility exercise encourages the movement of joints through a full range of motion, for example Yoga and Pilates. Flexibility is an important area for individuals with ASD who often have low muscle tone. (For example, individuals may walk on their toes, resulting in high tone in their calf muscles.) Flexibility exercises may be helpful in stretching the legs and feet.

Balance activities (for example, Tai Chi and Chinese martial arts) develop the ability to stabilise the body. Balance and coordination activities are important for individuals with ASD because they develop the balancing system of the body. Individuals with ASD may have a poor sense of direction and may need visual cues, such as standing on a carpet square or at a mark on the floor. Balance activities, such as using a therapy ball or walking along a line on the floor, can improve balance and coordination.

An exercise program is important for everyone; it can start slowly, but even a little physical activity each day can offer the reward of a more healthy lifestyle... **FL**

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20 YEARS OF ARTS AND CRAFTS!

Fiona O'Farrell, arts and craft instructor in Sunbeam House Services, celebrated 20 years of offering arts and crafts tuition with Sunbeam House Service users on the 6th of June. A special celebratory Arts Day was held in Fiona's art room and a group of volunteer artists joined in with her and SHS service users to spend a day creating and exploring artistic mediums. Much fun was had by all and activities ranged from using 3D textures to model making to learning how best to use watercolours.

Top: Sean Sheeky doing some video work for Sunbeam House.

Above: A joint effort by Angela, Aaron, Janet, Stephen and Rebecca.

Left: James Woodgate does some 3D effects with volunteer artist Eithne Griffin.

Top: Rebecca McAuley creates a model of a fried egg!

Right: Volunteer artist Paraic McFarlane demonstrates how to work with watercolour.

Below: Stephen Browne meeting a dolphin in Florida.

ONE PERSON AT A TIME

Across the globe, organisations are questioning the quality of the supports and services they have been providing to people with disabilities. It has become painfully clear that few, if any, of the people involved in the delivery of support would choose to live the way that those receiving our services do. **Hope Leet Dittmeier** of Realizations LLC assesses the situation.

We recognise that new ways of supporting people with disabilities to live enviable lives are desperately needed. Many initiatives have been developed with the earnest intent to find better ways of supporting people to live good lives. Some of these initiatives are being referred to as 'individualised', while others use 'person-centred' verbiage. Some focus on 'self-determination', while others emphasise 'choice'. Reliance on these simple descriptors is problematic in a number of ways:

— We lack an operational definition that is universally understood when using most of these terms. What criterion is used to determine whether a service qualifies as 'person-centred'?

— Some of these terms have been used interchangeably as if they mean precisely the same thing. For instance, some people believe 'individualised' and 'person-centred' are virtually the same, while others believe they have unique meanings. What is actually implied when we use the description 'individualised'?

— Most of these terms emphasise only one narrow concept of what qualifies as good support, rather than a more comprehensive understanding of all the features required for a service to be of good quality. A service might, in fact, be individualised and still not provide good, relevant support.

— Many services describe their programme using the preferred terminology of the day (or funding source) when, in fact, the service remains the same as it was prior to the formulation of the new ideal intended by the term. This contributes to the confusion surrounding our current descriptors.

This author believes that current terminology fails to offer an adequate guide for describing good work and offers a description of some of the most seminal features of innovative and quality practice.

Doing the work *'One person at a time'*

'One person at a time' is often the definition given for 'person-centred' work. When this rather simplistic criterion is utilised, meetings held or forms completed that refer to just one specific person could be said to be person-centred. Based on this definition, numerous organisations could rightly say they have been providing person-centred supports for many years. As my colleague Michael Kendrick has often reminded us: 'We can do *harm* to one person at a time!' The converse is also true: it would be difficult to do our best work in any way other than one person at a time. Thus, the concept of person-centredness is crucial, but not sufficient, to ensure good work and good lives for people relying on our work.

Getting to know people in a different way

Typically, service providers have focused on assessing, quantifying and documenting people's deficiencies with great thoroughness and precision. What people *can't* do is given much greater scrutiny than what they *can* do. The problem with this approach isn't just that it is a negative exercise. The problem is that it doesn't yield the kind of information that leads to revising service practices in meaningful ways or that results in good lives for people. In order to assist people in living enviable lives, we will need to shift our focus to a *capacity* approach. We need to find ways of discovering people's interests, skills and potential contributions. A greater investment of time will be required to get to know people in this way, before designing supports. Perhaps some of the best work in getting to know people differently, referred to as the 'discovery process', has been formulated by Michael Callahan (see www.marcgold.com).

Magnifying the voice of the people being supported and their families

Magnifying the voice of the person being supported requires the professionals involved to relinquish previously held power and control (something many of us find quite difficult to do) in favor of listening to the voice of the person whose future is at stake. Empowering people to be the primary decision-makers in their lives is an absolutely critical component of quality work! The concept of self-determination must be solidly grounded in a broader framework than that of simply giving people what they say they want. There are many complex issues related to self-determination that need clear and coherent responses: life experiences void of opportunity to know the typical ways of the world, the balance of wants and needs, informed choice, risk-taking and proper safeguards, and the interplay of rights and responsibility.

Adding new planning tools and methods to our repertoire

A number of organisations have adopted new planning tools and methods, including ones that involve large sheets of paper and colored markers (as opposed to fill-in-the-blank forms), that take place in libraries or living rooms (instead of conference rooms), and where hospitality is offered in the form of delicious food. These planning gatherings are often viewed as a huge success, perhaps because they spared the

Above: **Marietta has her own home!**

Left: **Glen is a member of the remote control airplane club!**

Right: **Mallory is a teacher! She teaches two days a week at a day care. This is paid employment and no small accomplishment for her given the only use of her body that she has is turning her head 90 degrees to the right. She is so amazing and inspiring.**

participants from the drudgery of our more standardised ways of planning. However, plans can quite easily be drafted in this fashion and still not be good plans. The converse is also true: plans drafted in conference rooms with no markers or food could be far superior to those embracing this new culture. Ultimately, the plan is a good one when it addresses other issues of quality discussed in this article, and when the plan is effectively implemented.

Describing desirable lifestyles

Traditionally, many of our planning efforts have focused on answering the question, 'What does this person need?' The resulting answer often involves ascertaining which service from a predefined list of options would best match the support needs of that person. The list usually specifies various levels or models of service: low support hostel, day service, etc. For instance, it might be agreed that what a person needs is a 'high support hostel'. Better outcomes are more likely to result if, instead, we begin with a different question: 'What would be a desirable lifestyle for this particular person?' Consideration of the features of an ideal 'home' for a person yields a description that might include: living in the community they grew up in, with a large garden, affordable, within walking distance to shops, with a second bedroom for a live-in supporter, etc. Rather than determining which residential service is best, we describe what home would ideally look like. Service then becomes a means to an end (a good life), not an end in and of itself.

Creating new options

Currently, most providers have invested available resources in existing service options. If we intend to do the work one person at a time in a way that honours the voice and desired lifestyle of each person, we will need to figure out ways to un-bundle funds so that resources are used to create unique support configurations. In some circles, this is referred to as 'the money follows the person'. The process of un-bundling funds requires very complex and political strategies. It also requires the courage and commitment of leadership. Once fiscal resources are freed up to fund the desired lifestyles of individual people, service providers will need a new set of skills and mechanisms to go about the work of creating new options.

Focusing on contribution to build community

The idea that innovative service delivery is embedded in community is not at all new. For a number of years now, efforts have been made to locate services in community and to help people access the community. Now best practice encourages us to think more deeply about the true meaning of community and to assist people in becoming integral members of their community. People we support have too often been presented as liabilities in community—always the recipient of the generosity of others. Instead, we need to help people identify the unique contributions they can make locally, the ways that they can matter to others. Our communities can be made stronger by the contributions of all.

Facilitating meaningful relationships

It is commonly understood that the vast majority of people who rely on formal services for support are terribly lonely. Often, people have very few freely-given (unpaid) relationships, have a disproportionate number of friends with disabilities, and sometimes have absent or strained family relationships. If we are to improve the quality of our services, we must address this most fundamental need in more effective ways. Portraying people to other citizens in positive ways, finding opportunities for people to be routinely present in a valued community setting, helping people be good neighbors, identifying ways for people to personally connect with others who share common interests or life experiences, and helping people contribute are just some of the new support strategies we will need to embrace.

Supporting people to embrace typical, valued roles

The purpose of much of the services provided to date has been to protect vulnerable people, to keep people busy, to entertain, to train people in new skills, to provide housing, and/or to give relief to families and primary caregivers. A shift in how we see the purpose of formal support is required if we are to envision lives that are more fulfilling. As a foundational framework, Social Role Valorization (SRV) posits that the good things are most likely to be accorded to a person who holds roles that are valued by her/his community. Thus, one proposed way to think about our purpose is that of helping people fulfill new, socially valued roles in community. As providers, we will need to become more proficient in our understanding of SRV theory and practice, in order to successfully support people to obtain new, socially valued roles.

Revising our support roles and relationships

Many services have embraced the role of carer, with a primary focus on assuming responsibility for keeping people safe and adequately housed, fed and dressed. This role has necessarily forced us into an authoritarian relationship with people being supported. If we are to accomplish

The intention of this article is to offer serious food for thought for those interested in finding new ways to better support people to live good lives. Significant changes in the principles and practice embraced by providers of formal support are required. While this article initially suggests some of the most relevant issues to address, it in no way should be construed to be comprehensive. There are numerous other factors worthy of serious consideration.

While the information contained in this article is derived from Social Role Valorization (SRV) theory, the richness and complexity of the SRV framework is beyond the scope here. Interested readers are encouraged to learn more by visiting www.socialrolevalorization.com. **FL**

SO, HOW AM I DOING?

Employee appraisal systems as a tool for enhanced performance

The health and well-being of employees is intricately linked to the health and well-being of the organisation they work for. In this article **Ciaran Leonard** proposes the use of 'Performance Appraisal Interviews', as a tool to enhance employee performance, improve employee-manager relationships and promote a continuously improving culture of relationships within the workplace environment through greater communication and sharing.

Human resource management has evolved over the last thirty years and best practice now envisages how to support the employee in order to bring out the best capabilities and performance to the advantage of both the organisation and the employee. Good appraisal systems have at their heart the ability to motivate and incentivise employees, while simultaneously seeking to avoid any escalation of difficulties associated in whatever way with the particular enterprise. The benefits from a good appraisal system should accrue on three levels in any organisation: organisational, managerial and to the individual employee. It involves bringing the best out of employees, overcoming any obstacles to the development of the service and is a solid application of the common-sense principle – to deal with any problems or issues at the first instance. To the three levels mentioned above I would add a fourth, given the nature of our business, the benefit to the service user.

Gunnigle et al. describe systems of appraisal as 'a systematic approach to evaluating employees' performance, characteristics or potential with a view to assisting with decisions in a wide range of areas such as pay, promotion, employee development and motivation' (Reidy 2011).

In this article I propose to look at how a suitable system might be introduced (if not already present), the changes necessary for the successful implementation of this management strategy, and the obstacles which could reasonably be envisaged in developing such a system. I will present some strategies which may be helpful in anticipating and overcoming such resistance as there may be, before presenting some initiatives to manage an appraisal system on an ongoing basis. Finally, I will conclude with some general remarks on the benefits of good appraisal as a necessary management tool, particularly within the intellectual disability care setting.

Requirements for implementation

HR Driven

To consider the successful implementation of a formal appraisal system several criteria need be met. The initiative needs to be a coherent one, driven by the Human Resources Department and not left to individual line managers to develop in a piecemeal, fractious manner. So a solid HR project needs to be developed in accordance with best practice in the industry. The onset of HIQA inspections envisages that such a system is in place, functional and operational, with all the necessary documentation available. This alone should be sufficient motivation, but an innate desire to improve performance, deal constructively with issues in the workplace and increase the level of quality care afforded to service users would ensure a more positive incentive for the development of a suitable system. A constructive, positive approach by management would provide far more opportunity for a successful roll-out, rather than a haphazard system designed only to meet HIQA standards and regulations. Many organisations (such as Vodafone) have introductions to their employee appraisal system as part of their pre-induction training. I feel this would be an important and positive element of induction training for any organisation.

Culture change

Many organisations affording around-the-clock care have experienced a culture change in the model of care offered over the past decade or so. This transition would be greatly supported by a positive appraisal system where difficulties and doubts would have a proper, constructive airing, leading to changes in practices which are to everyone's benefit. On top of this, we have to acknowledge that management styles have and continue to adapt and develop in response to new models of care. Formal appraisal systems are about changing practices after all.

Clear objectives

Any appraisal system needs to have clear objectives and structure from the outset. This will help to clarify what it is about and how it is to function, for both appraiser and employee. This heralds back to the point above concerning HR taking the lead and formalising a suitable system for the organisation. This also ensures that organisational support and any necessary resources are in place from the beginning.

Choosing an appropriate model

Reidy (2011) outlines seven possible methods of appraisal and, while this article does not analyse each one individually, I would like to mention the 'management by objectives (MBO)' approach to appraisal (Reidy 2011:76). I would consider this the most suitable and potentially the most beneficial approach given the particular circumstances of our business.

Working alone or in pairs, away from management supervision means that a set of objectives to be attained by the carer can be agreed for a set period. The social care worker will usually have recourse to the 'person centred plan' and 'behaviour support plan' for the clients in their care. Objectives have to be met to ensure these plans are successfully implemented to the benefit of the service user and it appears to me most appropriate that this would be the driver for evaluating the employee's performance. It ensures also that the employee has greater control over and direction for their work. To this end I would suggest that a form of 360 degree appraisal be used in order to have as much feedback as possible from individuals better placed to observe the social care worker. This is important, given the difficulty for managers to be constantly present in a variety of disparate locations, making hands-on management or direction extremely difficult. This would allow input from one's colleagues, families and advocates of service users and, where possible, from service users themselves. Undoubtedly, this would require an enhanced level of skill from the manager to gather the information, weight it appropriately and overcome possible communication difficulties with service users.

Management skills

Given what we have said above about the culture change involved in both the organisation's modus operandi with the model of care and the challenges this presents to managers, it is imperative that they receive any training necessary to successfully implement an appraisal system. This would focus on the role of the appraisal system within the strategic development of the organisation and aim to provide the communication and analytical tools necessary for the successful rollout of the system. Not every manager may be a suitable candidate for implementing the process and this needs careful consideration at a more senior managerial level.

Possible Obstacles

Positive v negative perceptions

Success ultimately depends on how the project is presented and envisaged by all concerned. It would not be uncommon for employees to view such a program with suspicion initially. It may be perceived as a tool to 'check up on them' or to 'keep tabs on them'. At worse it may come to be viewed as a mechanism to formally criticise their performance in the workplace—an extension of the disciplinary system.

On the other hand, a positive presentation of the scheme, pointing out the benefits to all concerned, can go a long way to change the gloss on the project. Staff have an innate suspicion of management motivations, especially during periods of change or turbulence. In the present context, where there are economic challenges, the culture change in care models and employees' lack of knowledge around the concept may well challenge the system initially.

Discipline v reward

Suspicion is a powerful feature of industrial relations. It would not be difficult to envisage the challenge being presented in such terms: 'Is this about getting me to do more?', 'Are they scrutinising my work, and if so why?' 'What will I get if I do as they say?' 'Why should I try to improve my performance – after all, if it's not broke, don't fix it.' Again, clear objectives and information will go a long way to changing attitudes.

Bad relationships

It would be naïve to believe that every manager–employee relationship ran smoothly or was approached with objectivity. The possibility of a pre-existing negative relationship needs to be considered, as this would have a detrimental impact on the appraisal system from the outset. Likewise, while it is to be understood that employees might not initially be fully conversant with the methods, objectives or purposes of appraisal systems, there is no excuse for the manager who is involved in implementing the system. The human factor in any relationship has to be considered and appropriate action taken to redress any negative aspects to it. If we were to adopt a 360 degree approach, factors such as relationships with other colleagues, the service users themselves and their families would have to be considered and evaluated appropriately.

Strategies to overcome resistance

HR strategy for rollout of appraisal system

Once a suitable method for appraisal has been chosen and HR have put together their strategy to incorporate it into the general management of the organisation, a positive rollout strategy needs to be implemented. This might involve a presentation for employees, literature being made available, testamentary evidence from other employees/managers where a similar system is in operation. Workshops where the obstacles and potential points of resistance can be named and addressed will also be likely to defuse negativity at an early stage. Active listening and effective feedback should be visible at this stage. A relatively senior manager with good communication skills will help demonstrate the seriousness of the organisation to pursue its objective while ensuring a positive gloss.

Involving the service users (despite the difficulties which would invariably present themselves) would require creativity, but it would also be a very

strong statement from the organisation about the 'person centredness' it purports to encourage through its mission statement.

Clarity

Employees should be given clear information about how the system will work, the roles and responsibilities of each partner, and the practical details involved. Again, positive examples need to be given and demonstrated. Employees should be encouraged to look forward not back—at how things can improve for them also.

Achieving commitment

Ultimately this is what we want to achieve. Creativity plays a major role, especially where there may be strong opposition. Management need to communicate effectively with staff to demonstrate that this is a process of equals, that managers too will engage in the process with their respective senior managers. The positives need to be stressed and the benefits to all. Recourse can be made to the organisation's mission statement and ethos. Ultimately, staff need to know that it is happening. It may be helpful to build in a review period, especially when the scheme is new to the organisation.

Acceptance by doing

Over a relatively short period of time staff can be seen to buy into the process, especially if it is well conducted. Praise and recognition are strong motivators and can play a major role in bedding-in the system. As part of a wider strategy, it may be beneficial to focus on the employee's positive aspects and what they are seen to bring to their job, until such time as a positive attitude and relationship have been developed.

Some resistance is not necessarily a negative, as it helps to keep management focused on the scheme's development, which might need tweaking at the early stages. This is a marathon not a sprint; issues arise and once they are handled and addressed well, this in turn buys commitment from all concerned.

Initiatives to manage system

KRAs and KPIs

A structured appraisal system should identify key result areas (KRAs), both for the organisation, for the department concerned and for the individual employee. Once the staff member see's how attaining their objectives fits into the wider scheme of things, a more positive dynamic should ensue. Clarity over how to measure change around a particular issue can utilise agreed key performance indicators (KPIs), so that fairness and objectivity are part of the process from the outset. One of the interesting possibilities in such a project is the possibility it affords managers to assess the suitability of an employee to work with particular service users. Strengths and weaknesses, likes and dislikes, can be considered which benefit the staff member, the service user and the manager alike.

Review

It is always beneficial to build in periodic reviews of any new initiative or strategy, to ensure changes can be made effectively and notice taken of any genuine problems or issues that may arise in the early stages. At this stage it might also be evident that not every manager has the skill-set to do this task and a group of managers more able in this area may be an advantage. Similarly, reviewing the appraisal interview system with the employee can help identify concerns and build positive changes.

Benefits and rewards

In a properly functioning appraisal scheme, if promotion opportunities and pay or bonus payments are part of what emerges from the process, a more ready engagement will probably result. Meeting the employee's personal needs will also reduce difficulties for all concerned, especially if there are specific family issues or some other exceptional difficulty interfering with employee performance. It assists the employer to make the best decisions when promotion is the issue and can throw up positive surprises in discovering areas of competence or skills, previously unknown to management, which can be utilised to the benefit of the organisation. In the current Irish care environment, however, pay-scales are set by the HSE and no room for maneuver exists. Likewise, working hours are fairly set by the needs of the service users. Recourse could be made to Employee Assistance Programmes and possibly the development of 'Stress Buster' policies. Creativity is the key.

Conclusion

As an avid football fan, I find that an appropriate analogy might be seen in the comparison between the apparent abilities of team managers to bring out the best in their players through skillful man-management. When Roberto di Matteo assumed command of the Chelsea team, he inheirited basically the same squad of players as his predecessor, Andre Villas-Boas. The turn- around in the team's performance (with the same resources) as evidenced by their reaching two major cup finals, is witness to how employees can be skillfully assisted to utilise previously hidden skills.

In the particular circumstances of an organisation which provides care for people with intellectual disability, the inclusion of those skills, where possible, would be a clear indicator as to how the employee is addressing the objectives for the enhancement of the quality of life of the service users, as outlined in their person-centred plan. This, ultimately, is the nature of the business and improved quality care can be the only true measure of the employee's performance.

Employers must comply with a raft of employment legislation. Should disciplinary procedures need to be used, the appraisal system can be of benefit in establishing how difficulties were addressed or tackled previously. Ideally, if the system is functioning well, it may stave off disciplinary procedures, but it provides the employee with another opportunity for putting things right—should there be a necessity to do so—and this in turn can have massive cost implications.

Finally, there is an old adage that a happy employee is a good one and positivity in the workplace has real benefits. Employees can experience working life as something akin to being in a box where routine dictates performance. Watching an employee grow, develop and contribute to the objectives of the organisation is something to be pursued and encouraged. When the quality of life of the citizens in our care is improved measurably, then the appraisal process can be heralded a success. **FL**

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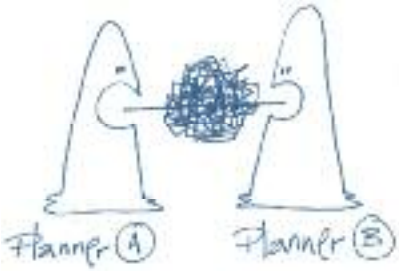
TALKING STRAIGHT ABOUT SERVICES



Mary de Paor listened to Christy Lynch at a recent staff conference of an Irish intellectual disability service organisation.

Recently I had the opportunity to listen in on the staff conference of an Irish intellectual disability service organisation. Christy Lynch had been invited to set the 'National Context' for the day's discussion. No better man! He continues to visit other countries, and other continents, as supported employment guru; he has recently been elevated to the status of 'De-institutionalisation Designated Expert' because of his exhaustive work as Project Leader of the recent Congregated Settings Report. He is currently Chair of the National Federation of Voluntary Bodies, so he flits between meetings with government ministers and service providers. Christy is, of course, CEO of Kare –although it's hard to imagine that the Lillywhites actually see very much of him.

With that CV, Christy Lynch knows a fair bit about the 'national context' of intellectual disability services in Ireland. In his presentation to the staff, he referred to the myriad of current national strategy reports, the *Disability Policy Review*, *New Directions*, as well as his own *Time to Move on from Congregated Settings*, and the lurking-although-still-not-published *Value-for-Money Report*. With such props setting the scene, Christy posed the stark question: Are existing services fit for purpose? Is the current provision of intellectual disability service sustainable? His conclusion: NO, not in the current economic climate, and with changing demographics and changing expectations.

Services talk (and talk) about person-centred services. Because they have admittedly developed to a considerable extent over the past decades, they do now hear what people want—but they are still not doing what they say! Services need to talk with people with intellectual disabilities and their families about the supports they want—not services, but supports—to enable them to participate in their communities, as citizens, as fully as possible.

Services have too much power. They have traded the 'medical model' for a 'clinical expert model', in which multidisciplinary professionals assess what is best for service users. But the very near future will involve individualised budgets or individualised funding in some form. Organisations will have to adapt very quickly, to be efficient and responsive and innovative—all those buzzwords combined—to survive in this new world.

Irish disability services cost too much. That's what our government ministers keep saying. Admittedly, the outcomes from services' expenditure levels do not compare favourably with those in many other countries. And some of our 'best' services—at this time of enforced cost-cutting and new frugality, perhaps they are a luxury that Ireland cannot afford? This presents massive challenges. How can services (whose budgets have been trimmed by up to 15-20% over the past four years) continue to provide supports for their clients—let alone for new entrants—with the additional cut of 1.7-3.7% imposed this year? (In a desperate attempt to avoid staff redundancies and resultant service reduction, this actually amounts to a massive cut of about 8-9% in a budget's non-salary elements.)

The only response to this challenge for services to get 'a better bang for the buck' in the expenditure of disability funding is to reconfigure how supports are given. This will necessarily involve far more flexible working practices in order to give individualised social supports for people how and when they want them, as well as making better use of family and community supports.

The core business of intellectual disability services NOW is to provide individualised social supports for people with disabilities. Their residential needs should be met by social housing services—that is the logic of the de-congregation report, as people move out of institutions and group homes into their own communities. The expertise of ID-trained professionals will be essential in the provision of additional supports for people with significant health needs, in conjunction with the services provided by the much-promised mainstream primary care teams. Social supports will be aimed at supporting vocational training and work opportunities, personal expression and creativity and the development of wider social roles—and in influencing service policy and practice.

Christy Lynch concluded with a vision for the future for service providers, providing:

— Person-centred focus and planning processes for community inclusion and the provision of supports not constrained by 9.00–5.00 service delivery boundaries.
— Ways for service users and families to influence policy/provision and evaluation
— Complying with HIQA guidelines, as reflected in *New Directions*
— Collaboration and shared learning locally, to make best use of resources in the sector (e.g. staff training and HR management).

For those who remained unconvinced, Christy quoted several relevant quotes:

'Change is the law of life and those who look only to the past or present are certain to miss the future.' (John F Kennedy)

'It is not the strongest of the species that survive, nor the most intelligent, but the one most responsive to change' (Charles Darwin)

'Everybody has accepted by now that change in unavoidable. But that still implies that change is like death and taxes—it should be postponed as long as possible and no change would be vastly preferable. But in a period of upheaval, such as the one we are living in, change is the norm.' (Peter Drucker) **FL**

Edward Dunne, CEO of Nua Healthcare

When we think of service providers, we usually think of the HSE or the Voluntary Sector. How is Nua Healthcare different?

Well, essentially Nua Healthcare is a private limited company or 'for profit' entity. This model is quite common in the UK and Northern Ireland, but seems somewhat alien in the Republic, given the historical make up of services in this country.

When we first started the company, we thought a lot about whether we should be a private entity or a charity/voluntary body. I believed strongly at that time (and still do) that individuals with intellectual disability had never really been seen as consumers in Ireland. Why should any individual or sector of society be viewed constantly as the subject of charity, as opposed to consumers of a social/health service? After all, it is much harder to complain when you know someone else is providing you with a service for free or out of charity—even if that service falls far short of your expectations!

I believed that the only way to break this cycle was to get to a point where service users could effectively 'shop around' for a product that best suited them. Quality initiatives can only go so far if individuals don't have the ultimate choice, to move on—if they so wish!

A consumerist model would bring about change. Organisations would have to compete for resources and customers. Poor quality organisations would cease to exist. Good quality providers would prosper and grow. We established as a private 'for profit' company for that very reason. We wanted people to 'choose' Nua as their provider.

When and why was Nua Healthcare established?

Nua Healthcare was established in the summer of 2004 as a respite service for people with Asperger Syndrome. At that time, there was a significant deficit in services for individuals with High Functioning Autism, Asperger Syndrome and mild intellectual disability. Individuals were very often left without services or catered for in very inappropriate settings. Unfortunately this is still the situation for many people today.

I had been working in the community with some of these

individuals, providing home support services and supported employment links. Our services at that time were very effective in alleviating challenging behaviours, but they fell short in meeting the overall need as we were not offering appropriate supports in people's home settings.

When the home situation could no longer cope, therefore, individuals were nearly always referred to institutional settings for residential care. Saddened by this, a colleague and I established the first Nua residential service on the grounds of a farm in County Kildare. The service has since expanded to over 14 residential facilities and 5 day services across the greater Leinster region.

What is different (if anything) about how Nua Healthcare supports people?

Nua is very lucky in that it is a relatively new entity. We didn't have the legacy issues that other organisations have to face in terms of trying to break up institutional models or practices. We were in a position to provide person-centred services from day one of the organisation's inception. We were also very lucky in that we were small and so could change and adapt extremely quickly.

We subscribe to the service model of 'services without walls' and 'not putting square pegs into round holes'. We believe that services should be moulded around each person, as opposed to requiring people to 'fit in' to existing structures. This is really evident in how our services have evolved over time. Our first referral was an individual who had an interest in horticulture, so we developed a market garden and community market link. The second individual hated the notion of gardening and so an entirely different service was developed for him. This is what we aspire to do for every individual referred in all areas of need, be it day services, clinical interventions or specific training/social supports.

For parents, one of the primary concerns is about standards. What sort of standards (if any) does Nua Healthcare benchmark against? Are Nua Healthcare services inspected by HIQA?

Nua Healthcare gained accreditation in January of last year through the National Autistic Society (UK). This award gives us the status of being the only autism-accredited service provider in Ireland. Our service was rigorously vetted against 32 general and autism-specific service standards. Accreditation lasts for a period of three years and is subject to ongoing review.

We are not currently inspected by HIQA. As a private entity, however, we are constantly striving to keep standards to a very high level and we welcome the prospect of independent inspection.

Why would someone be referred to Nua Healthcare, instead of other providers?

For a number of reasons -

— Nua Healthcare has built up a level of expertise over the past number of years in the area of supporting people with high functioning autism. We are a quality service with individual specialist facilities and supports as required.

— Nua has a significant track record in providing high support/challenging behaviour services in ordinary community settings.

— Sometimes it's as basic as the fact that there is simply no alternative provider in the country prepared to accept the particular individual.

Who funds those attending Nua Healthcare?

At the moment, the HSE funds the majority of placements in Nua Healthcare. Funding has (at other times) also come from other state departments (e.g. Justice), private bodies and overseas agencies.

Can people fund their own services with Nua Healthcare?

Theoretically they could, but costs can be prohibitive for individuals and/or families, given the nature and level of supports required. Residential support services are often very staff-intensive and therefore costly. We have had some individuals fund respite services in the past, but for limited periods of time only.

What sort of services does Nua provide?

Nua Healthcare provides a range of services including residential supports, day services, community outreach/home support and assessment services.

People who avail of services with Nua Healthcare present with a broad range of challenges, which include intellectual disability (ID), acquired brain injury (ABI), mental health (MH) issues, challenging behaviour and Asperger's Syndrome, amongst others. People are supported based on the levels and types of services they require, rather than on a particular diagnostic label.

If one were interested in accessing Nua services, what is the process?

Nua Healthcare will conduct an initial assessment so as we can determine the needs of each individual. This initial assessment can be triggered by a referral from the HSE, a clinician, a family member or a self-referral. Once the initial assessment is complete, Nua Healthcare puts together a proposed support package based on the identified needs and submits it to the appropriate body for consideration.

How do you prevent Nua from becoming just like one of the other services—particularly as you get bigger with greater demands?

This is a very valid question and one that I have always been cognisant of since the organisation's inception. I have been working for roughly 16 years now in the disability sector and have been lucky enough to have worked in an array of organisations, both big and small. I always believed that the smaller an organisation was, the better the quality of care it could deliver, irrespective of what 'quality system' it had implemented.

As organisations grow, so too does the distance between the manager at the top and the person receiving the service. From my experience, people become 'numbers' in big organisations and the focus shifts from individual prosperity to the organisation's prosperity. I strongly believe that service users need to have access to an approachable senior manager who has the skills to relate to and understand their needs.

Of course, as Nua Healthcare grows, I have no doubt we will experience the same challenges as do the large service providers. It will not be possible for me to have a meaningful relationship with everyone we support, as the organisation gets bigger. I believe if we are to retain a focus on the individual, we will have to split the organisation up into smaller 'pocket-sized' services, each with its own senior manager who is highly experienced and is totally committed to the ethos on which Nua Healthcare was founded, as well as being capable of developing and nurturing relationships directly with service users. **FL**

Joe Wolfe and **Trevor Nesirky** introduce the third in a series designed to support service providers in preparing for registration and inspection of their services by the Health Information and Quality Authority. This article focuses on conducting self-assessments and audit. It draws on Joe Wolfe & Associates' extensive experience in conducting audits and reviews of over 150 services nationally. It also draws from the lessons learned from published reports of HIQA inspections of Older Persons Services, and from experience in working with service providers in that area who have undergone the registration and inspection process. The purpose is to provide practical advice, rather than academic comment.

PREPARING FOR REGISTRATION AND INSPECTION OF RESIDENTIAL SERVICES FOR PEOPLE WITH DISABILITIES Part 3: Conducting Self-Assessments and Audit

Introduction/background

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. HIQA is responsible for the registration and inspection of residential services for people with disabilities under the Health Act (2007). The Authority published ***National Quality Standards: Residential Services for People with Disabilities*** in 2009. There are regulations being developed at present which will give statutory strength to the standards, and which organisations will be measured against as part of the registration and inspection process. These regulations will also provide further detail to organisations on what is expected of them.

One of the requirements of the HIQA standards (Standard 17, criteria 17.12) is that organisations must have a process in place for auditing their service against the national standards. Furthermore (if the approach taken for disability services is similar to criteria 30.2 in the Older Persons' Standards), services will need to carry out specific audits in areas such as:

- residents who have had moderate to severe pain within the previous week
- residents who have pressure sores
- residents who have been physically restrained within the previous week
- residents who have received psychotropic drugs (including sleeping tablets) within the last week
- residents who spent most of their time in bed or in a chair within the last week
- residents who have fallen within the last month
- residents who experienced significant weight loss over the last three months
- complaints
- unexplained absences of residents
- significant events.

In our experience, services have approached quality in a range of ways:

- Some services have an internal quality process in place, where they self-assess against the standards.
- Some services buy into an external quality process or system.
- Some services carry out a range of audits over the course of the year (often sporadic).
- Some services do not have any structured approach to audit and quality improvement.

The introduction of the standards requires organisations to have a structured approach to auditing the standards themselves in core areas such as those referred to above. In essence, all organisations will need to have

- An annual structured schedule of audit that measures the service against the national standards, and
- A further range of audits of key issues within the organisation.

The organisational approach to quality and audit

In our experience, the most effective organisations are those that have a structured approach to quality and audit. Put simply, the current national standards provide a framework to audit all elements of an organisation. The standards are written in a manner that addresses all elements of a quality service—considering the broad themes of governance and management, the environment, staffing, development and health, rights, protection and quality of life.

From the above perspective, our view is that if the organisation puts a structure in place that enables a substantial and significant focus on quality and audit, then this can replace many of the traditional elements of organisational structure. A representative group (one which includes senior management of the service) should oversee and drive the approach to quality and audit within the organisation. This group should have very clear terms of reference, should have an annual quality and audit plan and should have very strong linkage with the strategic and service planning forums of the service. In our experience, the organisations that spend time properly establishing and bedding down this structure have a far better likelihood of being successful.

Audit cycle and process

Once the above structure has been established, it is crucial that the organisation establishes its audit function and begins the audit cycle and processes. There are a number of pitfalls that organisations can often encounter, such as:

- A lack of sufficiently skilled auditors
- A perception that if people have an audit tool, that they can automatically carry out audit effectively
- A dependence on internal audit and self-assessment, which can result in a biased effect
- A lack of understanding of the standards and, in some instances, applying a tick-the-box approach to testing against the standards, using personal judgement only. (This results in very subjective and inaccurate measurement of compliance against the standards.)
- Audits being completed and no root-cause analysis being conducted into reasons for non- or poor compliance.
- A lack of senior management buy-in, resulting in reports sitting on shelves, gathering dust.
- A lack of clarity on corrective action plans, negatively impacting on their implementation.
- The non-closure of the quality loop, where corrective actions have been identified, but not implemented or followed up.

Organisations need to be conscious of the above pitfalls and try to minimise these in implementing the audit function. Services need to:

- Ensure that the staff carrying out audits have, and continue to build, the necessary skills in conducting audits
- Ensure that it has a structured approach to quality and audit, with one representative group driving this across the organisation
- Have an audit schedule in place on an annual basis
- Balance the audit function with internal and external audits
- Use robust, well developed audit tools (Joe Wolfe & Associates have developed a suite of specific audit tools to this regard.)
- Ensure that the quality circle is completed, with an emphasis on monitoring the implementation of corrective action plans.

Joe Wolfe and Trevor Nesirky,
Joe Wolfe & Associates,
The Tannery, Thomastown, Kilkenny.
Contact email: joe@jwolfeassociates.com

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 have 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.

FRONTLINE

The Theme of Issue 88 of *Frontline* is **EDUCATION IN IRELAND FOR PEOPLE WITH AN INTELLECTUAL DISABILITY**. Issue 88 is for circulation in September/October. Articles on Life Long Education and Learning can be sent to the editor at: editor@frontline-ireland.net

The copy date is August 20th.

The Editor and Board of Frontline *invite articles relevant to the theme of the above issue, as well as articles on personal experience, events, conference reports, etc. Frontline provides an opportunity to showcase the achievements of people with intellectual disabilities and examples of innovation and good practice within services.*

DISABILITY PSYCHOTHERAPY: The analytical treatment approach

Angelina Veiga explains exactly what disability psychotherapy is and how it can support people with disabilities

Disability psychotherapy is an evidence-based treatment approach concerned with providing psychotherapeutic supports for people with disabilities. While psychotherapy has not traditionally been considered a treatment option for people with intellectual disabilities, this approach advocates that individuals have a rich and mature emotional life despite any cognitive impairment (Sinason 1992). The analytic approach seeks to explore the individual's inner world in order to make meaning of past and present experiences and, so, it promotes insight, integration and the management of unbearable thought and emotional states.

Treatment occurs through the use of regularly scheduled psychotherapy sessions., which usually occur at least once weekly. Regular sessions offer the conditions needed for a secure base (Bowlby 1988) to be developed which supports the creation of the therapeutic alliance. It is within this alliance that the therapist and patient can begin to think and experience together the workings of the patient's inner world. This is done by recognising and interpreting the individual's thoughts, feelings, dreams, nightmares, fantasies, fears, behaviours and any non-verbal communications. It is not a prerequisite of the therapy for the person to have verbal communication, because the therapist is skilled at using many different interventions through which to communicate and understand the individual.

Generally people enter into psychotherapy treatment when they are in a state of crisis. This is no different for people with intellectual disabilities. Treatment is often initiated to help manage self-injurous behaviour, grief, loss and mourning, experiences of abuse or sexual violence, or the risk of or engagment in sexualized or seriously harmful behaviours. The use of psychotherapy recogniaes that behaviours are a symptom of psychological distress. A reduction in symptoms is ideal, but it is not the focus of the therapy. The focus of therapy is to support unmanagable thoughts and feelings to become tolerable, thus facilitating personal growth and self-understanding. When this happens, there can often be a reduction or ceasation of risky or harmful behaviours.

Disability psychotherapy acknowledges the pain and impact of having a disability. Disability carries the knowledge that one is profoundly different from others. Sinason (1992) introduces many insightful concepts which help deepen our understanding of the psychological impact of disability. The 'handicapped smile' suggests that one has to smile and be compliant, but underneath the façade is tremendous pain, loss and grief. We see this with our patients who disclose the most horrendous experiences with a smile. While this phenomenon is not limited to people with disabilities and regularly occurs in mainstream psychotherapy practice, it highlights the pain of disability in a profound way with this patient group. A highly evolved defense mechanism is developed which protects the person from unwanted thoughts, feelings and experiences. The 'secondary handicap' allows us to recognise that a disability can be exaggerated and used as a defence, and for respite against the pain of the disability. This can be seen, for example, where the individual behaves in a way showing the organic disability to be much greater than it may actually be.

Disability challenges us to enter into a world that can be filled with despair. Hollins (2000) has noted that disability, mortality and sexuality all feature for people with disabilities. The disability itself brings lifelong struggle within society and, in some cases, the family. Having to depend on another for intimate care needs can be difficult, stripping one of autonomy and independence. Sex and procreation may be viewed as damaging for the person and the family system. The thoughts of sexuality and engaging in sexual relationships may be taboo. It often appears that people with intellectual disabilities are seen as asexual beings without sexual needs, drives and desires. Sex may be viewed as bad or wrong; that there was something wrong with the act or that one/both of the parents may have contributed to the disability. Shame and guilt may be entrenched in the family's psyche. The longed-for able-bodied child may need to be mourned within the family system.

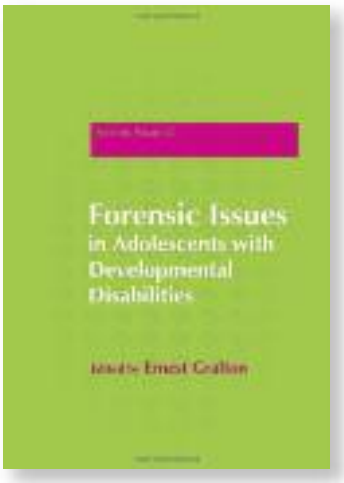
There are some families and service providers who struggle to support the adult with an intellectual disability to be autonomous, as the cognitive impairment can anchor the person to discreet developmental stages. This vulnerability to the world outside the home or service provider can be threatening. Alternatively, the person may find it difficult to step into being an adult, which requires facing greater challenges and being responsible for one's own thoughts and actions. There can be underlying thoughts of destruction and death wishes or fantasies towards the person with the disability, which is mirrored in our society where disability is shunned.

Psychotherapeutic treatment provides a space for these feelings and experiences to be examined. Sinason notes that 'whenever a handicapped patient says "I don't know", it means that they do know but don't know if we can bear it' (Sinason 1994: 15). This insight is incredibly helpful in supporting the therapist to think about what they may find too difficult to let in. The therapist's own supervision and personal psychotherapy can provide the spaces to think about what can seem most unthinkable.

While Irish clinicans have been working psychotherapeutically with people with disabilities for many years, this work has frequently occupied an isolated space within the profession. The creation of the Institute of Psychotherapy and Disability, UK, in 2001 serves to support its Irish members. It was set up to develop, accredit and regulate psychotherapists who work in this field. The field of disability psychotherapy advocates for equal access for all citizens to psychotherapeutic treatment. It recognises that emotional intelligence cannot be labelled as disabled. **FL**

Angelina Veiga, MICP, MEAIP, MIPD is a Disability Psychotherapist and founder member of Disability Psychotherapy Ireland

(References with the editor)



FORENSIC ISSUES IN ADOLESCENTS WITH DEVELOPMENTAL DISABILITIES
edited by Ernest Gralton.
Jessica Kingsley Publishers, London.
ISBN 9781849051446

From time to time a book is published that is important to practitioners working in specialist disabilities services—this is one of them. People with disabilities come to the attention of the police and the courts, but very often the needs of this small, but growing, group of people are not brought to the attention of the courts in a way that takes account of their lack of understanding, poor social-emotional development, and what are often additional presenting problems of co-morbidity (for example, mental health needs). Systems purporting to support people with intellectual disabilities and family members may also not have the knowledge, skills and understanding to make meaningful interventions.

There are people with intellectual disabilities who require detention in secure settings, not only to protect the public, but also the person themselves.

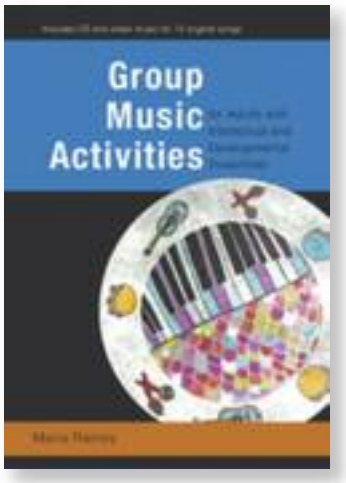
Ernest Gralton is a lead consultant Forensic Psychiatrist in Developmental Disabilities and Senior Research Fellow at the Institute of Psychiatry, Kings Hospital, London. Practitioner contributors to the book come from a broad range of work settings and assist daily with the practical outcomes for the offender with an intellectual disability and staff involved in their care.

Co-morbidity is a significant issue which repeatedly presents for practitioners and is dealt with by each contributor in writing about their specialist area. An underlying theme from all the contributors is the understanding that any model of care for people with an intellectual disability, and particularly those who come to the attention of the police and come before the courts, has to be grounded in developmental principles.

What is also clear from all the contributors is the importance of training, ensuring staff are fit for purpose and that all involved in the care of this small but complex group of people have an understanding of the importance of micro-environmental interactions.

This book will be a welcome addition on the bookshelves of any practitioner.

Stephen Kealy



GROUP MUSIC ACTIVITIES FOR ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES
by Maria Ramey
Jessica Kingsley Publishers, London, 2011.
ISBN 978849058575

It's Monday evening and I am just finished a drama class with a group of people with intellectual disability. We know each other well and meet every Monday for two hours to create, talk, discover and uncover our stories through drama. Today the theme was bullying; as I make my way home, I am left humming the tune of Tom Petty and the Heartbreakers 'I won't back down'. It is playing its way through my head as I flick through the book *Group music activities* by Maria Ramey. Boom! Suddenly I see it staring back at me in print, on page 91.

Maria Ramey's book is packed with 100 musical exercises that I, as a drama facilitator for people with intellectual disability, find instantly engaging. Maria has produced a very clear and well laid out book that is accessible and easy to follow. It incorporates movement, art, conversation and thinking into each musical exercise and it provides an excellent tool for any creative arts practitioner's toolbox. The book itself is user friendly and not aimed solely at therapists; as I read I imagine teachers filling their classrooms with the sound of the Twist or the beat of an African drum. What better way to learn than through all of the above.

The blurb on the back of the book suggests that it has been written to provide more age-appropriate material, moving away from the childish material that exists in some music therapy resources today. As a parent of two young boys, I am constantly fascinated by their ability to play, and equally fascinated in the way their play develops and changes as they get older. I would go so far as to say that the older we get the less in touch we are with our ability to play. When I think of music I immediately think of play—musical instruments are played, musicians play in an orchestra, children play together. So, while Maria's book has made these exercises more palatable for an older population, it is important to note that they will remain exercises on a page unless they are *played* with.

One of the many beautiful things about play is the space it provides for the moment. The moment is bursting with potential and waiting to be filled, so while I welcome this book with its myriad of exercises and well thought-out clinical applications, I would encourage any music therapist, teacher, parent or care-giver to play with it and allow room for spontaneity and improvisation. The moment and our ability to inhabit it is where the potential for growth, creativity and change truly lies.

Let the group find their rhythm and they will play the tune and sing the song that they need to be played and sung.

Nicola Kealy

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