

# the frontline

OF LEARNING DISABILITY



Health Matters  
*Are You Being Served?*  
Quality of Life

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## So, Farewell then...



THIS ISSUE OF *FRONTLINE* IS MY LAST; it takes as its main theme the health of people with intellectual disability. Various articles present different facets of how one might care for one's health through utilising the services of twenty-first century Ireland. However, most articles seem to suggest that our health is in our own hands and that as carers we are in a position to greatly influence the healthy life that the person we care for may obtain. Quality of life is a topic that Richard Redmond deals with at some length and it is also an aspect of Michael Kendrick's and David Kieran's articles. As I reflect on the past four years as editor it seems to me that Kieran's comment is correct—that 'there is a growing appreciation that what is currently on offer [the services provided by the state] is not necessarily in the best interests of those citizens we claim to serve.' It seems to me that service provision has certainly improved in coverage over the last four years; I am not sure how much better the quality of services has become. Some services have become beacons of good practice; others, however, seem to remain eternally rooted in practice that is based in the 1970s. I hope that the establishment of the Health Information and Quality Authority will finally convince those recalcitrant

services that they need to do what everybody in the sector wishes them to do, which is to put the service user at the centre of their planning, their thinking and their actions. This is not rocket science. There are plenty of services which are delivering quality care here in Ireland, and those that need improvement know where they can learn how it is done.

*'... there is a place for frontline staff to report on what they do in their practice and also for service users and relatives to write about their lives and concerns'*

The Gallery section of *Frontline* was an innovation four years ago and is now firmly established at the [literal] centre of the magazine. For this edition I have asked my friend Tor Torp who lives in Oslo to take pictures in the Vigelandpark. This town-centre park has 192 sculptures that reflect the human condition. They were constructed by Gustav Vigeland in the 1920s and 1930s. It seemed to me when I first saw them two years ago that they had something to say about people, about how they interact and about how they manifest challenging behaviour. These pictures

show life in the raw but in so doing they illustrate feelings that we all share at different times in our lives.

Finally I wish to reflect on the changes that have taken place in *Frontline* during my watch. As the reader survey which was reported in the last edition [68] stated, the magazine has changed, it has perhaps become heavier in that some articles have reported on research in fairly academic terms. I have tried to balance these by emphasising that there is a place for frontline staff to report on what they do in their practice and also for service users and relatives to write about their lives and concerns. *Frontline* serves a broad community and as such it will generally contain some articles of interest to everyone, although they will not be the same for different communities. Secondly, I have tried to publish articles that stimulate thought and that tell of innovations in education and care practices that we, as people with disabilities and their friends and carers, should demand from services and government. In other words, *Frontline* has informed the debate on disability in Ireland. The magazine itself has had some production difficulties over the past year from which it is slowly recovering and we hope to get back to schedule soon. As there are now four board members with experience of editing the magazine, the editorship will be rotated among them for the next couple of issues before a new editor is chosen. I will remain on the board and perhaps get more of a chance to write now I have relinquished the editorship. Finally, I would like to wish you all well in our continuing quest for the best for people with intellectual disabilities in Ireland.

**Colin Griffiths**

## First annual conference of the division of behaviour analysis, Psychological Society of Ireland

A ground-breaking day for behaviour analysis in Ireland was on 22 March 2007, with the first annual conference of the PSI division of Behaviour Analysis, held in Trinity College Dublin. This topical conference attracted quite a large attendance, many of whom were parents waiting anxiously for the outcome of the Seán Ó Cuanacháin case the following day (23 March 2007). Academics, practitioners, students, parents and other interested parties came to appreciate a full programme of quality research displayed on the day. Abstracts were submitted from students at University of Ulster (Coleraine), NUI Galway and Trinity College Dublin, with tutors from ABACAS ABA school in Kilbarrack, Co. Dublin also presenting examples of successful interventions employed by them in their workplace.

Entertaining talks comparing Positive Behaviour Support and Applied Behaviour Analysis were given by Ken Kerr and Brian McClean. Kerr's paper entitled 'Will the real behaviour analyst please stand up?' aimed to identify the role of behaviour support workers in Ireland today. He also addressed issues and identified factors influencing successful adaptation of PBS and ABA. Finally, the implications of the titles that practitioners use, its effects upon consumers, and possible effects on the training and clinical decision-making of future behaviour analysts in Ireland was discussed.

Brian McClean discussed outcomes of 45 multi-element behaviour support plans, developed as part of three consecutive longitudinal training programmes. Strong focus was placed upon the social validity of the Outcome Rating Scale, with its results compared to monthly data on behavioural frequency, episodic severity and management difficulty of multi-element behaviour support.

Coordinators of the MA in Applied Behaviour Analysis at NUIG, Dr Olive Healy and Dr Geraldine Leader, gave



l-r: Bob Remington and Ken Kerr at the conference

broad and informative talks on the status of ABA in Ireland in the past, present and future.

Finally, Dr Bob Remington, Professor of Psychology at the University of Southampton, who was invited to address the event, presented the findings of a two-year field effectiveness evaluation of early intensive behavioural intervention. The Southampton Childhood Autism Programme (SCamp) was compared to education provided by local education authorities over two years. After two years, differences favouring intensive behavioural intervention were observed on measures of intelligence, language, daily living skills, and positive social behaviour.

This inaugural event provided interested parties from the field of behaviourism with a fantastic opportunity to share, explore and appreciate the very high quality of material presented. The future for ABA in Ireland seems bright, with this conference providing further recognition of the maturation of behaviour analysis into a recognised division within PSI.

**Padraig Walshe**

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## Inclusion Ireland AGM

The Rebel Capital was sparkling in the sunshine when Inclusion Ireland members assembled for their AGM and Conference on Friday-Saturday, 20-21 April 2007. Cork had been chosen as the venue for this year, partly to coincide with the celebrations for Cope Foundation's Fiftieth Anniversary. The centrally located Clarion Hotel provided gracious and efficient service for the conference delegates.

Following the short conference-opening speech of Michael O'Connell, Deputy Mayor of Cork, Chairperson Finula Garrahy gave an energetic and articulate address; she summarised the year's work and voiced the membership's thanks to the organisation's executive staff and the two directors who were retiring—Siobhán McConnell and Stephen Kealy. While acknowledging the strides that have been made nationally in service provision in recent years, Finula lamented the evident difficulty in accessing appropriate special needs educational assistance, as well as the continuing dire shortage of speech therapy services and of planned respite care.

Because of the imminent General Election, local Cork political representatives had been invited to take questions on their policies on intellectual disability issues. Alan Crosbie of Thomas Crosbie Holdings ably chaired the panel and even succeeded in keeping them, with very few lapses, 'concise and to the point'. Those on the panel were Micheál Martin (FF), David Staunton (FG), Dan Boyle (Green Party), Kathleen Lynch (Lab) and Frank O'Neill (SF), with additional contributions from some aspiring candidates including John McCarthy (ind).

Questions put to the politicians by Inclusion members concerned a request for the abolition of the present Disability Act, difficulties with the assessment of needs, and access to needed services within the EPSEN Act, dissatisfaction with the proposed Charities Bill, and the need to raise standards in existing intellectual disability services.

Saturday's agenda began with CEO Deirdre Carroll's report of the year, and the AGM general business. There were six resolutions before the members, and discussion resulted in near-unanimous agreement on the first few resolutions. However, there was a lengthy debate about how best to represent the members' concern/objection to the reinstatement (and most particularly the backdating of repayments) of long-stay residential charges. It was decided that a working group within Inclusion Ireland should attempt to assess the level and fairness of charges, given differing individual needs and circumstances.

Deirdre Carroll launched the ambitious Strategic Plan 2007-2012 for Inclusion Ireland. The plan states the organisation's mission 'to be the independent champion of people with an intellectual disability and their families whose standing and expertise in intellectual disability is acknowledged and to ensure that people with an intellectual disability have their voices heard, are not isolated or segregated, and can lead more independent and healthier lives.' The Strategic Plan can be found in full on the updated Inclusion Ireland website ([www.inclusionireland.ie](http://www.inclusionireland.ie)). Clíona Ní Chualáin and Paul Alford gave a brief presentation on the website, which has been re-designed to be more accessible for people with disabilities.



Margaret Trundle, recipient of the John Ryan Award 2007

The conference keynote address was given by Ombudsman Emily O'Reilly, who carefully explained her role and invited people with intellectual disabilities and their advocates to avail of the services of her office, when necessary, 'to protect the individuals who avail of the public services from unfair, unsound or unjust actions on the part of those who are entrusted to deliver those same services'. Ms O'Reilly's address, (the text of which can be found on the Inclusion Ireland website) provided a clear explanation of the nature and scope of the office of Ombudsman in Ireland.

The afternoon session of the conference began with four presentations on the theme of 'Including All—Inclusion in Practice'. Principal Clare Ryan of St Leo's College, Carlow, explained her experience of inclusion in the Irish secondary school system—and the



Inclusion Ireland directors with political party panel members and Alan Crosbie

complexities involved in it. Frieda Finlay explained the background and development of the National Institute of Intellectual Disability at Trinity College Dublin, Sally and Eugene O'Brien joined their daughter Ita in explaining her successful introduction to supported employment, and Margaret Trundle described the growth of a summer-long 'camp' (and more recently established Saturday youth club) in Midleton, Co. Cork, which brings together children and adults with intellectual disabilities with youths from the local school community. (At the Saturday evening dinner and dance, Margaret was presented with the John Ryan Award 2007 for her valuable pioneering work.)

Audrey Carroll of the St John of God Carmona Services (Dún Laoghaire) and Garda Sergeant Angelene Conefry explained the initiation of the 'Streetwise' programme for people with intellectual disability, that helps to increase their awareness of public safety, crime prevention and garda procedures.



Cope Foundation 'African Rappers' with Eoin Nash

Conference delegates were entertained by an impressive performance from 'African Rappers', a talented group of percussionists and singers from Cope

Foundation, led by Eoin Nash.

At the close of the AGM, the annual Advocacy and Media Awards were announced. The 'Kilkee Project', coordinated by Antonio Cebas of the Brothers of Charity Services (Clare), was presented with the Advocacy Award. The project, in partnership with local community groups, provides individual supports for people with intellectual disabilities to enable them to access and take part in community life and in mainstream projects, such as local radio.

The Media Award 2007 was collected by *Irish Examiner* Editor Tim Vaughan for that newspaper's fair and consistent coverage of issues relating to people with an intellectual disability.

Mary de Paor

## *Best Buddies: a pilot project linking Our Lady of Good Counsel School and Ballincollig Community School*

Best Buddies is an international programme providing opportunities for one-to-one friendships between people with intellectual disabilities and their non-disabled peers. It was founded by Anthony Kennedy Shriver in the United States in 1989 and is now available worldwide. Participants are matched with people who are close in age and share common interests and hobbies. Best Buddies asks participants to meet twice a month and to contact each other once a week.

Students from Our Lady of Good Counsel (OLGC) Special School in Ballincollig joined with Ballincollig Community School (BCS) transition-year pupils to pilot the ever-growing Best Buddies programme. With the guidance of Ken Kavanagh, Director of Best Buddies Ireland, seven students from Our Lady of Good Counsel School were matched with transition-year students from Ballincollig Community School in autumn 2005. Twenty-four other transition-year students formed a committee to fundraise and support the programme. They held 13 committee meetings to plan events.

### **Activities enjoyed:**

Matched buddies enjoyed a number of activities together, including shopping, going to the cinema, having a meal, bowling and hockey. The fundraisers raised sufficient funds for the year's group activities by holding two events: a red-and-white day at school and an 8 km walk.

### **Organised group activities:**

Sharing a picnic after fundraising walk  
2 Bowling nights  
Christmas dinner  
Football, rounders and barbeque at BCS  
Joint music class and refreshments at OLGC school

### **What the participants said:**

Our Lady of Good Counsel students and their parents completed evaluation sheets. Ballincollig Community School students and contact teachers from both schools also completed evaluation sheets.

### **Students from OLGC School**



#### **Deirdre**

*My Best Buddies are Elaine and Maeve. We went to the movies. We saw Narnia. We had a pizza afterwards. I went to Maeve's house. We played some games. I went shopping with them. I got a text message from Elaine and Maeve. We went out to dinner. We went to Currans (restaurant). All the Best Buddies came. I would like my Buddies to text me more, I love texting.*



#### **Ian**

Ian met with his Best Buddies when 'bowling/phone calls'. He reported that they ring at night. Ian reported this was 'nice' and that he would like to take part again next year.



**Lisa**

*My Best Buddy is Laura Bracken. She goes to Ballincollig Community School. It is near my school. We go lots of places together. We go to the cinema and we visit our homes. We also text and phone one another. At other times the Best Buddies all go out together. We go bowling and we also go out for meals. I love having Laura as my Best Buddy.*

**Debbie**

Debbie reported she particularly enjoyed 'football, hockey, bowling and dinner'. 'I had chips and a burger'. Debbie would like to take part next year. She would like to go bowling and to the cinema.



**Diarmuid**

*I met my Best Buddies Paul and James at the cinema. My school helped me. We go to the cinema and bowling. We play games. We all went bowling together and we had dinner too. We had chicken and chips. We had great fun. Paul and James are cool and fun to be with. I would really like to go out with them more times. I would really love to do 'Best Buddies' again next year.*



**Aoife**

*My Best Buddies are Lorraine and Lisa. They like the same things as me. We all like shopping and hanging out. I went to town with Lorraine twice. I bought a pink top and a red top. Lorraine bought pants with gold glitter. A pink belt came with it. I'm getting the same pants as Lorraine for Rome. I went to the movies with Lisa in Ballincollig. We saw Narnia. I love our bowling nights out because I get to talk with my Best Buddies. We all wear our best clothes. I like going out to dinner with the gang. Last time I had a triple cheese burger with chips. All the Best Buddies came to our class and had a party. We had a sing-song with them. I love my Best Buddies. I'd like them to ring me again.*



**Alex**

Alex enjoyed the group dinner and bowling.



### **Parents of Buddies from OLG School**

All parents wished their son or daughter would continue the programme next year. Comments included:

*... really enjoys separate independent friends and feels grown up around them.*

*... looks forward to going out with non-family members for a change.*

*It was most beneficial for ..., the chance to be a teenager/meeting in town, shopping, going to the cinema without her mum or another family member in tow. She really enjoys that.*

*Interaction with her best buddy has built her confidence.*

*... loves being involved; he loves going out with his buddy—he looks forward to each meeting with great anticipation.*

Parents suggested the programme could be improved by:

- ❖ more texting from transition-year pupils
- ❖ enabling OLG students to meet with their new buddies with a family member so that initial meetings are less awkward
- ❖ more frequent contact from the transition-year Buddies.

### **BCS transition-year students**

Twenty-three of the 24 student participants responded to the questionnaires. Over half of the students found the group activities the most enjoyable in the programme. Most of the matched buddies favoured the group activities. They reported more excitement and feeling more at ease in the group. One comment illustrated the general feeling of the group:

*I preferred the group activities because there was more fun and excitement and we were more at ease with our friends around.*

All respondents said they would like the programme to continue next year.

Two of the matched buddies found both activities equally enjoyable.

One preferred the one-to-one contact:

*I like the one-to-one contact because you get to know your buddy more.*

One-third liked the group meal out best.

One enjoyed most a Chinese meal she had with her buddy.

Challenges reported included difficulties in communicating:

*My buddy sometimes just drops the phone and walks away but I know he still likes to get calls.*

They were also challenged by trying and failing to make contact with their buddy. They reported

*overall the programme was a great success—we always have a laugh.*

Transition-year students' suggestions:

Over half of them wanted more organised group activities in the year. Interesting suggestions included:

- ❖ encourage both sets of parents to meet at the beginning of the programme
- ❖ meet with other committees and Buddy pairs in the city for group activities
- ❖ more school visits. Meet for a class such as art or cookery at school
- ❖ encourage OLG Buddies to text and phone more frequently
- ❖ frequent reminders to maintain regular contact.

### **Contact teachers**

#### **Our Lady of Good Counsel School**

*It added a new dimension to our children's lives—contact with the ultra stylish and fun children from the local community school*

#### **Ballincollig Community School**

*It was a very positive experience for Fourth Years—they have learned many skills, e.g. bonding, running a committee, making decisions and choices, fun and interacting between both groups.*

Overall the Best Buddies programme was met with interest and enthusiasm in its first year at these two schools. Participants helped to identify positive aspects and highlighted areas needing development. The challenge of ongoing motivation to maintain contact and the issue of ease and communication both need to be addressed in the future in order to build on this worthwhile programme in the coming years.

**Deirdre Lovett, Ian Kelleher, Debbie Manning,  
Diarmuid O'Leary, Aoife O'Sullivan, Alex Roe  
Clare O'Keefe,  
PRO, Best Buddies,  
Ballincollig Community School.  
Yvonne McCarthy,  
Brothers of Charity Services, Cork**

# Are you being served?

Nowadays people describe every service as 'person-centred'. But what does person-centred actually mean? What kind of service do you have? Specialised, individualised or person-centred? Do this quiz to find out if your support system is *cruisin'* or *snoozin'*.



## It's pay time!

1. My Disability Allowance goes into a central fund, and is spent on holidays and other outings.
2. I get €10 pocket money. I would not know how to manage the rest.
3. I am learning money management and coin recognition. I go to the local shop to buy what I like!
4. My keyworker helps me to budget my money across the week. Some goes on food and clothes; some I keep towards the holiday!
5. My biggest problem each week is to limit what I spend on cds so I have enough to survive! I need a job with more pay!

## I have been aggressive. What does my service do?

1. Up my medication for a while.
2. Verbal reprimand.
3. Reward contract.
4. Try to figure out what is the function of my behaviour. Teach me to communicate in a more effective and appropriate way.
5. Try to figure out what sources of satisfaction are missing in my life, and how I can be better connected with people. Why am I on the outside of what is in?

## It's my birthday!

1. Careful not to overdo it on the birthday cake. The dietician would not be pleased with me!
2. They bought a cake for me at the training centre and I got to give everyone a slice!
3. I am learning about sharing, so at my party there will be lots of opportunities for turn-taking games.
4. My IPP says I get to go out for a Chinese tonight. Yippee!
5. I have organised a reggae theme party. I have invited the neighbours around and Jago is the DJ.

## I am getting a job

1. The service says I need a job to occupy my time and improve my manual dexterity.
2. Down at the day centre I pack shampoo bottles onto crates.
3. The psychologist and OT have recommended a programme of training.
4. My keyworker found me a job cutting lawns.
5. I love acting. My mother says it will never pay, but the service has located an acting workshop in the Temple Bar and I'm going on the 20th!

## I am moving house

1. The house for people with challenging behaviour has a better staff-client ratio and I am lucky to have a placement there. The staff who look after me are wonderful.
2. We need some training programmes to learn to do cooking, cleaning and other household chores more independently.
3. The house is autism-specific, so there are other lads who need visual schedules and low arousal approaches as well as me.
4. In my new house I have a person-centred plan. With the support of my keyworker, my time is divided between working on a neighbour's farm, collecting old engines and learning to make the perfect pizza.
5. Tony and I have decided to rent a house together for a while. My parents have been in to train my support staff in what I need.

## Dinner time!

1. Dinner is cooked centrally. It is so much more economical that way, and the service can ensure that nutritional requirements are being met.
2. I am learning to set the table.
3. I helped cook the dinner.

4. My keyworker is teaching me to make the perfect pizza. I decided to squeeze some fresh lemon juice onto it this time.
5. Dad is coming over to dinner in my house tonight.

## It's the weekend

1. Outreach does not work on Saturdays.
2. The five of us went for a walk and fed the ducks. It was lovely.
3. We are going out for lunch.
4. In the morning I have my recycling job, then in the afternoon I am heading into town on the bus to buy some clothes. Tonight my keyworker and I are going to the cinema.
5. Pat wants me to go over to his house to help with painting. But Sarah and I were supposed to go out to lunch together today. So much to do, so little time!

## Answers:

**Mostly 1:** This is a very traditional model of service. Based on charity, its primary goal is to care and protect people. People with disabilities are seen as needing sympathetic treatment. Often the understanding of disability is medicalised. The person has something wrong with him or her. As a result others are in control of the life of the person.

**Mostly 2:** This is a developmental model of disability. Intellectual disability is not an illness. It is a developmental delay. With the right training people can be taught simple skills. The emphasis on what people can do independently, rather than with supports, limits the range of skills that are taught.

**Mostly 3:** This could be called special needs model. People with disabilities need specialist advice and training in order to integrate into ordinary living. The difficulties with this model are subtle. There is often an unwitting disparity between the service's mission statement and what happens in practice. The model professes that everyone is an individual, but often ends in group-based, segregated activities. Services become log-jammed because there are not enough specialists to go around. Parents and frontline staff are often inadvertently undermined because they are not seen to have the specialists' expertise.

**Mostly 4:** Community participation. Living in the community is not enough. Specific training and interventions are required to ensure that the environment fosters as many opportunities for learning and community participation as possible. Typically, a keyworker is empowered to take decisions with the person, and to ensure that the person's choices and preferences are taken on board. The model is person-centred, but only up to a point. People participate in the community often, but sometimes it feels like 'community tourism', rather than real belonging.

**Mostly 5:** This is a person-centred service. It is not just the schedules and opportunities that are adapted to meet the person's needs, but the entire service is designed to meet individual need. Here the effort is to follow the person's choices, whatever they may be, and to incorporate these into a real lifestyle in which the person is needed and belongs. Because inclusion is the goal, inevitably family, friends and neighbours are centrally involved. Both the advantage and the risk are that responsibility can easily fall back on families. It is important to ensure that reliance on natural support is not a rationalisation of failure to provide paid or specialist support.

Brian McClean

## In pursuit of excellence

Pursuing excellence is like searching for the Holy Grail. People frequently hold different views as to what excellence is and, accordingly, they can find themselves searching in different directions. In my view the pursuit of excellence is best thought of as a road to be travelled rather than a final destination. Just when you think you are getting close to attaining excellence, new challenges arise and new roads open up ahead. Over the years I have come to recognise that there are three broad avenues along which services for people with disabilities, enduring mental health problems and older adults travel in the pursuit excellence.

Firstly, there are those services that travel along the 'resource-driven' path. These service providers believe that excellence can only be achieved if they can obtain sufficient resources to meet the varied and multiple needs of people who use their services. Often the focus is on creating a perfect haven by constructing a purpose built 'centre of excellence' that provides shelter from the hazards of life found on the outside. Emphasis is typically placed on special facilities and amenities, staffing levels and on physical appearance in the belief that service users will have little reason to look outside the centre where they live in order to have their needs and wants met. The management structure in resource-driven services tends to be hierarchical and those in charge often direct their energies outside their service to campaign for more finances and resources. In practice, the search for resources is never-ending as the construction of the 'perfect world' away from the community where most people live will require limitless resources. Because of the tendency by senior management to concentrate on what is happening on the outside, service users, families and frontline staff can feel that they are less important than the acquisition of resources and, therefore, that their concerns are ignored or put on hold.

The next route towards the pursuit of excellence is along the 'treatment-driven' road. Treatment-driven services have a long history going back over two centuries in the area of disability and mental health. From the 1960s onwards there has been a tendency to equate treatment-driven services with the medical model, though in fairness educationalists were among the strongest early advocates of this approach. These services hold the belief that excellence can be attained only through quality therapeutic intervention. Typically, treatment-driven services tend to focus on achieving excellence in one area of service delivery, e.g., physical disability, learning disability, mental health, and very often focus on one treatment approach. Examples that come to mind are the PETO Institute for conductive education, psychopharmacology, intensive behavioural intervention and various types of psychotherapy. Emphasis in this model is usually placed on a careful assessment and diagnosis, followed by treatment, which aims to cure or ameliorate the deficits and enhance the service user's coping capacity. In treatment-driven services there is typically a professional hierarchical structure where those with the greatest expertise are placed in the most influential positions. Emphasis is on ensuring treatment integrity. Services are usually located in a specialist facility, though sometimes attempts are made to provide the service in an inclusive setting. This model is beneficial for those who respond to the treatment, but offers little solace to those who don't. Treatment-driven services are always keen to highlight and advertise their successes. Service users who fail to respond to the treatment are usually encouraged to persist with the approach, but this is often in vain. With time, expectations for a cure or improvement diminish and the service users who don't respond can get overlooked as more service users enter the service.

The final category I have encountered is what can be termed 'rights-driven' services. Here the emphasis is on providing service users with the necessary supports and environmental adaptations to enable them to participate as citizens in their community. These services focus on ensuring that people's rights are regarded as paramount. These rights include: freedom (which in practice is often referred to in its negative form, i.e., the right not to be detained against one's wishes), the right to make choices, to be treated with respect, the right to protection, to be treated as an equal member of society, and the right to receive education and medical care. The vision of the service is to enhance people's quality of life, citizenship, inclusion and self-determination. The process focuses on meeting the rights and needs of service users, rather than diagnosis and treatment. The management structure aspires to be flat and decision-making powers are devolved down to the service user or those working closely with the person. The typical concerns expressed about this model are that a person's deficits and limitations are ignored; that service users are denied access to expert help and specialist supports; and that vulnerable people are exposed to ridicule and possible rejection in their community. In addition, rights-driven services struggle to be fair to all who require services and attempt to ensure the equitable distribution of scarce resources. Many rights-driven services that are committed to supporting people with disabilities or mental health problems can quickly become overwhelmed by demands placed on them.

Ideally it would be wonderful if all services had sufficient resources to provide the best treatments, while at the same time ensuring that service users' rights were protected. In practice, of course, many services do try to embody all three models, by focusing on resources, treatments and rights simultaneously. When they do this they encounter various tensions and struggles. The resource-driven and rights-driven models focus on changing the environment, the first by creating a haven of excellence inside the service, the latter by establishing a supportive community of excellence outside. The treatment-driven model seeks to change the person. Typically within any service one model tends to dominate, which in turn defines the ethos of the service.

Over the years I have had the privilege of visiting many different services for people who are unable to manage without the support of others. These have included services for people with learning disabilities, autism, sensory and physical handicaps, mental health problems and services for older adults. Only a small number of these would, in my view, approach a level of excellence. Service excellence is more than simply treatment approaches, staffing expertise, sharing community facilities, interior design and décor. In my opinion, services that attain excellence are distinguished by the palpable sense of respect shown to service users and the concern expressed for each individual's welfare. It is usually possible to detect this high level of commitment towards service users within the first hour—if not minutes—of visiting a service. Excellent services behave in ways where you know that decisions are always made in the best interest of those who avail of the service and are truly person-centred. Those who provide services of excellence tend to be modest in their claims, eager to share and talk about their experiences and open to new ideas as they struggle to find better ways of delivering services. Excellent services are those who are way ahead of other service providers and as such are travelling along an uncharted and uncertain path.

**Mitchel Fleming**



# A Dream Comes True: A Trip to Oz

**O**n Saturday 21st January we set off to fulfil Deirdre's dream trip to Oz. She had wished for a long time to visit Australia—ever since she started following *Neighbours*, the Australian TV soap. Many parents will identify with how our children love the soaps; indeed most of the time TV is the only social entertainment they have. The characters in the programmes become their friends. Sometimes it can even start to take over their lives. I know that Deirdre sets her daily timetable around all the soaps—*Hollyoaks*, *Eastenders*, *Home & Away* and, of course, *Neighbours*. This can cause problems as the rest of the family's plans are disrupted.

Well anyway, Deirdre reached the age of 30 in November 2005 and unlike many of her friends she didn't want a big birthday party—she wanted to go to Australia! After a lot of saving and planning, the three Spain women (Deirdre, Tara and I) set off to Oz. We first landed in Singapore, where we visited our friend Gráinne. Deirdre loves swanky places so we had to visit Raffles Hotel and Morgan's Hotel, both very luxurious, with beautifully dressed people. There were individual fans to keep you cool, car doors were opened for you as you arrive, and the car was parked for you. Deirdre was disappointed when she came back home—she thought these services should be available at Dublin hotels too!

Our first port of call in Oz was Melbourne, where we arrived on Australia Day which is just like Paddy's Day here. Everybody was enjoying themselves at Independence Square. The first thing on Deirdre's list was a *Neighbours* Bus Tour. We visited Ramsay Street, Erinsborough High School and the TV studio where the series is filmed. Deirdre was thrilled to be standing at last on the street she sees every day. She pointed out where each of the characters in the series lives. She knew more than the tour guide! Later on the same day we nearly thought we were back in Ireland, when we got caught in a thunder storm in St. Kilda's, the beautiful beach area of Melbourne. It was very funny. Tara and I got soaked, but Deirdre, ever-prepared, had her raincoat!

The next day we went to a sheep ranch and also saw emus and kangaroos there. After all the times Deirdre had said she wanted to pet a kangaroo, she got frightened and wouldn't feed them. We next went to see the koalas in their natural habitat—that was more successful and Deirdre was in her element when one of the cuddly chaps, usually nocturnal, woke up to put on an act for us.

The next animals on our list were the penguins on Phillip Island. The famous little pygmy penguins come back from the sea to their beach-burrows every evening at dusk. Tourists wait sitting on concrete steps until the show starts. At first, two or three penguins can be seen coming in on a wave, and then run back waiting for others. Then, we could spot other little groups of penguins coming in along the beach. Deirdre thought they looked

like nervous stars of a stage show and after a while they start to show off. When the penguins were back in their burrows, they chattered like neighbours gossiping about how their day went. It was wonderful to see Deirdre's face as the penguins started to come out of the sea. She just could not believe what she was seeing—she actually cried, and that made Tara and me weepy as well! Even though Deirdre is 30, sometimes she is still a child at heart.

After Melbourne, we flew to Alice Springs, where the heat was unbearable. When we got to the resort and saw the swimming pool, Deirdre was in heaven. She thought this was 'a bit of alright!' The next morning our guide Tim picked us up at 6am to go camp near Ayres Rock. Deirdre doesn't usually like an early start, but Tim got round that problem—Deirdre still talks about him and wonders what he's doing now. It took 4 hours to reach the camp. We saw the sunset, camped under the stars, and then saw the sun rise over Ayres Rock. The only worrying thing for Deirdre was the flies. We had to invest in flynet hats, although we stopped short of getting those hats with the corks (but we now know why those hats were invented!). The flies covered us all like a blanket.

The next day, after the spectacular sunrise at Ayres Rock, we went on to Kings Canyon—for the camel rides! Deirdre wanted to have a go, so I went up to a handler to get Deirdre on one. He said that I would have to get up on the camel as well! Tara had disappeared, and I had no excuse. There is a great photo of us—with me looking frightened and Dee enjoying herself!

That night we were not looking forward to sleeping in a tent in the intense heat. We cooked a meal under the stars and everything went well until we had to go to the washing hut. While Dee was in the shower I had to clear the sink of insects. Of course, she didn't listen to me when I said 'go to the first sink'. You could hear her screaming for miles. She never knew insects could be so big. In the middle of the night I heard Tara calling me—she had seen a dingo at the bins and was afraid to go to the washroom, so I had to accompany her. I had just settled down and next it was Deirdre wanting to go the same place. So off I went with the torch, and got rid of the insects once again. As we were going back to the tent I saw a snake wheeling its way along the path, so I made a detour and we got a little lost on the way back. I didn't tell Deirdre about that until we were back in Dublin!

Next we set off for Cairns and the Great Barrier Reef. The plan was that Dee, who is a great swimmer, would swim among the coral and the beautiful fish. But she just wouldn't, so it was up to me and Tara to snorkel among the fish. It was a wonderful experience. Deirdre sat and watched and laughed at us in our blue protective suits (to protect us from dangerous stingers). She said we looked like the teletubbies.

In Sydney we were lucky as it was Chinese New Year and there was lots of fireworks. Deirdre wanted to get to Bondi Beach to see the hunks surfing, and yes, we did see lots of hunks—but most of them were Irish men who were working their way around Australia. We also managed some shopping with Deirdre, of course, getting an Oz track suit, bag, hat etc.

Deirdre talks a lot about the trip. She still loves anything Australian and wants to go again, maybe for her next big birthday. It was certainly a great experience for all of us, and worth every moment to see Dee's face light up with every new experience down under.

Jean Spain



# Organisational and systems investments that can stimulate beneficial innovations



Intentional innovation: Innovation need not be something that is dependent on serendipity

**W**hile it is most certainly true that many insights leading to innovation may arise unbidden and seemingly are 'unplanned', it is much more likely that positive innovations eventually emerge because they are actively being sought. Frequently, this will come about due to motives that have their roots in dissatisfactions with the status quo that precipitate intense scrutiny regarding how many matters of substance are currently managed. This disquiet can both consciously and unconsciously engage our minds and attention and begin a search process for better answers than the ones available at a given moment. This engagement may even carry over into sleep as the unconscious mind continues to work away at a problem, albeit below the level of our conscious awareness. Many of what be called 'intuitive flashes' may actually be the consequence of an initial engagement with the problem that seemed to need innovative answers.

## Innovation as a product of innovative people

One could get the impression from some sources that positive innovations directly arise from organisations and systems and their various machinations. However, bureaucratic abstractions cannot in themselves create or innovate, as this is a capacity enjoyed principally and fundamentally by humans. Consequently, no organisation or system can be innovative unless it has people within it that possess the various personal gifts that might, in an overall sense, be called 'innovation mindedness'. Even with such people present, it may still be possible that the organisation might fail to facilitate innovation if these human capacities are not properly harnessed and supported.

Typically, all innovations will have their beginnings in the way that a person reframes and resolves a problem. This fresh or innovative perspective is hugely people-dependent, insofar as the problem will not resolve itself without the presence of people with authentic innovation ability. It is people who ultimately have to have what it takes to generate a compelling innovation and there is nothing organisational in nature that can substitute for this ingredient, though there are many who still may believe that things like funding, policy, slogans and whatnot bring about innovation, but they are usually rather quickly revealed as ineffectual.

## Beneficial innovations will require adherence to ethics and values that uphold human dignity and well-being

It is quite possible for many innovative developments to have perverse consequences for human beings if there is no attempt made to test innovations against some standard of what is good for people. For instance, one sees many genuinely innovative forms of torture, yet the context and use of the human ingenuity involved is harmful and degrading to people and society. For this reason it is important to evaluate all innovations, not merely from the basis of their originality, but more fundamentally from the vantage point of whether they are in accord with how people should be treated in the most positive sense. In human service contexts, this would normally have to revolve around whether their enduring effect on service users is wholesome and beneficial.

Modern human services have, from their origin, engaged in all manner of experiments, usually in the name of human benefit, that have often had perverse results for the people that were their experimental subjects. Equally, where innovations have been responsibly conceived and carried out with rigorous attention to their ultimate consequences for service users, there have been many advances for which we need to be grateful. Even more to the point, if we do not pay enough attention to crafting beneficial innovations for and with service users, then many needs will go un-addressed, and at a cost to the life potential and best interests of service users. Thus, it is quite helpful to consider how this might be done more systematically and with careful consideration.

## The types of organisational investments that may eventually yield innovative results

It is axiomatic that simply waiting for innovation to occur 'naturally' would be an inferior strategy of innovation facilitation and cultivation, in comparison to one that created an intentional array of mutually reinforcing innovation catalysts. For this reason, it is useful to consider the many points that follow as being potential components for a multi-path investment strategy that could be adopted by sufficiently motivated and resolved organisations. Naturally, the thoroughness with which these are pursued would greatly influence the quality of the outcomes that might eventually be attained. Innovation must be earned, much as any other advance, and there must be an acceptance that a relation will exist between the adequacy of the investment made and the yield that can be expected.

### ◆ Attracting proven innovators with high values integrity

While it is vitally important to recruit, uphold and support people with prospective innovation potential, it is even more important that those with proven and well-tested histories of innovation serve as the core from which novices draw their leadership and character role models. Many organisational cultures suffer from an inhospitality to innovation-talented persons, such that they drive such persons away, rather than attract and nurture them. In the case of values-based innovations that might lead to principled organisational conduct it would mean the loss of people whose high levels of principles and integrity would serve as a key moral safeguard for the organisation's conduct. Naturally, it is equally possible to nurture, prize and search out values-based innovators, so the question would be why this is not done.

### ◆ Setting innovation as an enduring goal and priority

It is inconceivable that innovation would receive the necessary support in most organisations that it would require if there were not a special resolve taken and reinforced repeatedly, from the highest levels that innovation was a genuine priority, worthy of organisational sacrifice to achieve. In setting innovation as a serious goal it would mean that it would have visible priority, be supported by meaningful talent and resources, have enduring

organisational commitment and would attract noticeable and ongoing recognition from the organisation. If its support were just lip service, then it is likely that the organisation would support innovation sufficiently to make a difference in measurable innovation outcomes.

◆ **Creating concrete instances to define what innovations are most needed by service users**

It is difficult to use scarce innovation resources effectively if there is not an acute sense of where innovations are most urgently and fundamentally needed by people. However, once these needs are more clearly appreciated, then it is increasingly feasible to begin directing attention and resources to these directions. This deliberate linking of service user interests to a deliberate and continuously updated innovation agenda helps link organisational priorities to actual human need. Obviously, all of this is predicated upon a scrupulous attention, reflection and analysis on what is or is not happening in people's lives and where innovation is therefore needed.

◆ **Developing organizational leaders that can bring out the best in innovators**

It would be quite desirable that the managers in organisations and innovators share a common sense of purpose and urgency when it comes to advancing the organisation's innovation agenda. Were they to differ, it is quite probable that very little would be achieved. Consequently, the attraction of innovation-oriented and supportive leaders to an organisation can be very adaptive in cementing a working partnership between potential innovators and key organisational leaders. This does not require that all leaders be involved in innovation, but rather that the ones that are best suited to collaborating with innovators seek and be assigned this task. There is much that has to be resolved well to get the relationship right between innovators and an organisation and having the best leaders in place for this task greatly increases the prospect of a fruitful outcome.

◆ **Searching for relevant examples of needed innovations**

Often, much can be achieved by closely studying innovations that already exist that may be pertinent to what is needed. These examples can serve as both a guide to the further evolution of innovations and as a stimulus for the kinds of core insights that form the basis of needed advances. It is also helpful to try to define existing or otherwise well-known innovations that have already established a significant track record in terms of meeting unmet need. These innovations are often 'out there', but frequently go unnoticed or unappreciated, yet are well in advance of existing practice. So, the organisation or system that seeks these out is usually amply rewarded, as there is always something 'out there' that adds to what has been achieved by the organisation thus far.

◆ **Exposure of potential innovators to innovative thinking and personalities**

The process of innovation is essentially a human developmental process and is consequently helped by educational and consciousness-raising supports, such as contact with the thinking and people involved in innovations that are highly related to the kind that are needed. This means searching out such persons, evaluating their relevance to what is needed and important in people's lives and defining the type of innovation that is precisely needed. This process of analysis helps focus energies where they will do their most good and allows for the devotion

of prime energies to valid innovation priorities. It is often not possible, in advance, to be sure what precise advantages will most certainly flow from exposing potential innovators to already accomplished ones. Nonetheless, there will be advances, as such persons are ideally suited to learn from one another.

◆ **Consciously challenging and supporting innovative people to excel**

It is very helpful that innovative-minded people should be deliberately encouraged to experiment in needed directions. This reinforces the importance of innovation, the value of the innovators to the process of achieving service quality and relevance, and the commitment of the organization to 'getting down to business' in terms of innovations that actually change people's lives for the better. It also makes real the necessity for innovators to step up to the challenge of formulating innovations that will have an enduring impact on people's lives. Potential innovators could conceivably readily squander their inherent gifts with innovations that are trivial and inconsequential if they do not give some thought to the difference. So, a challenge must be present, not only for innovation, but more importantly highly relevant innovation.

◆ **The convening of innovators to act as catalysts with each other**

It can be expected that innovators will act to challenge and stimulate each other. Often this can result in many unexpected avenues being pursued that might otherwise have been discounted. Creativity is not merely a singular virtue, as it can be raised to new levels through the experience of small work groups, think tanks and teams devoted to advancement. There is most certainly something in the dynamic of innovators coming together that pushes them to levels that might not otherwise have occurred. In this regard, the act of convening innovators might be thought of as innovation enhancement in the sense that the resulting innovations will likely be a step or two further along the line than might have been the case were they not convened in a deliberate and intentional catalytic sense.

◆ **Creating experimental 'zones' within conventional agencies or systems**

If there are not specifically fashioned 'localities' or 'places' in the cultures of organisations or systems that permit the holding of dissident and 'unapproved' views as to what constitutes better practice, then it is predictable that orthodoxies and dogmas will take precedence over other possibly advantageous ways to do things. It is useful that these enabling opportunities be created somewhat deliberately with a view to ensconcing innovators into well-protected enclaves within and alongside existing systems that are properly constructed and nourished such that the innovators might flourish. The wisdom of doing this is that one can generate innovative results without the whole organisation or system having to be innovative.

◆ **Protecting innovations until they are strong enough to survive**

Innovations may well need to be incubated as they go through the often mistake-prone 'trial and error' period of their evolution. Few innovations emerge as fully polished and thus may need to be protected and defended until such time as they become more persuasive, mature and compelling. In effect, this means a recognition that innovations may need to be planted, sprouted and appropriately cared for until they are suitable for harvest. Metaphors aside, this means bringing an intentionality and patience to bear on whatever developmental requirements may

be necessary for innovations to emerge and evolve. Since innovations often take us into unknown territory, it may well mean a more open ended commitment to risk taking and learning than is typical in risk-averse environments.

◆ **Educating the uninformed or undiscerning as to the significance of important innovations**

Innovations do not usually get adopted by most people until they can see their relevance and practicality. Hence, it is often quite useful to prepare the ground for the easier adoption of innovations by educating people as to why a particular innovation is important and what its ultimate benefits might be. This cultivating of insight into innovation may seem merely supplemental to the core task of generating innovations, but this would be unwise when seen in the light of the need to get useful innovation adopted as practice at some point. If it is too readily assumed that 'innovations will speak for themselves' and thus generate their own adherents, this will prove to be quite delusional as the process may require more education and interpretation of the innovation than may be apparent to people who are already convinced about the inherent merit of the innovation. Innovations that threaten to overturn or disrupt long held patterns will most certainly have an even harder time finding acceptance.

◆ **Creating and maintaining the political, ideological and technical constituencies for needed innovations**

Innovators do not exist in a vacuum. They are as constrained by constituencies and vested interests as much as anyone else. By the same measure, their creative capacities are much helped and unleashed by the presence of supporters. Often, the politics of creating the support for innovations and an innovation agenda gets overlooked as a crucial part of the eventual outcome. Yet, eventual success is contingent not only on the validity and applicability of the innovation, but also whether people are resolved to support its potential. Innovations without backers are implementive orphans up until a constituency commits to it. Naturally, the more constituencies that show themselves in favour, the easier the transition from speculation into decision.

Additionally, the process of getting them to 'yes', might also mean keeping them in 'yes' if the trials and tribulations of innovation prove to be too demanding.

◆ **The devotion of sufficient fiscal and other resources toward innovation**

It has always been the case that one gets nothing for nothing. So it is with innovation. There will always be a need to divert some of the resources of an organisation, including non-cash assets such as time, talent and goodwill to supporting the work of innovation. Such an investment can certainly bring about returns to an organisation, though rarely in any short-term way, given the necessity to build quality solutions carefully. Not surprisingly, this requirement that innovation be supported beyond mere lip service will often be a test for those who are proponents of innovation since diverting crucial resources will often need compelling justification. Should the proponents not be up to the task of justifying why resources should be committed, then the failure to succeed in convincing people might well illuminate weaknesses in addressing the political and technical challenges inherent in having innovation survive as a key element of organisational life.

◆ **Capitalising on The success of already proven innovations to**

**further the innovation agenda**

It is certainly advantageous to use the precedent of prior innovations and their eventual demonstrable utility, to make the case for the potential of as yet unproven innovations. This is also part of the process of building an 'innovation culture' that reflexively tolerates a lot of short-term setbacks as being part of the long-term process of trial, error and innovation. It is very reassuring that prior attempts at innovation had eventually yielded good fruits and that their pathway had also had its share of setbacks and even defeats. This speaks to the confidence and credibility challenges that face all innovations, as they have to ultimately dislodge something that people are very comfortable with even if it is ineffective. So, being able to point to successes with prior innovations helps build faith in innovation itself, independent of the relative merits of specific innovations.

◆ **Linking internal innovators to the supportive networks of external innovators**

Not surprisingly, many innovators look to their 'peers' for affirmation, support and inspiration. Often these peers may be outside the organization and even perhaps at great distances from them. Nonetheless, they typically share deep passions for their work or subject and quite naturally seek out the company and stimulation of like-minded people. Supporting these networks reduces their isolation and brings them into contact with often the only people who can really challenge and excite them at the level of substance. This also acts as a kind of collective catalyst, since the interactions of innovators with each other helps raise the bar in terms of the eventual quality of innovation and push them to go further. Additionally, it helps with motivation, affirmation, critical evaluation, fresh insights and angles on a problem and assistance sorting out 'the wheat from the chaff'.

◆ **Increasing the appetite for 'significance' in innovation**

Innovations can be minor or significant in the impact they can have. The higher the quality and relevance of an innovation, the more value it has. Helping people discover what would constitute even greater degrees of 'significance' in innovation, helps them define and achieve 'better'. Not being clear as to what constitutes "'better' makes it less likely that people will achieve as much in terms of the quality of their innovations. Sometimes this can be helped by exposing people to exceptional examples of innovative achievement, as does the creation of occasions to critique and evaluate innovations. Significant discussions are a very valuable safeguard for people to question precisely what is and is not of meaning and value in a given innovation, as well as aiding the process of discerning just precisely how much faith and confidence one should place in a given innovation.

◆ **Maintaining an atmosphere of challenge to unthinking practice and thinking**

The culture of innovation is one in which there needs to be a great deal of questioning of 'status quo' assumptions or other apparent 'givens'. It is through the ability to look at practices with new eyes that the much vaunted 'paradigm shifts' become possible. Therefore, innovation is less likely to arise if people are punished for challenging practice and for introducing unfamiliar ways of seeing things. On the contrary, being contrary may actually be a safeguard, properly contextualised, if it helps people escape the many traps of group thinking, lazy conformity, superficiality and many other distractions from

genuinely original thinking. Creating this kind of mindfulness, can be very hard to do if organisational leadership are themselves trapped in and much too deferential to respectability and social approval.

◆ **Celebrating and recognising innovators and innovations**

Innovators are people like everyone else and therefore will normally respond quite well to being appreciated and valued, just as they will diminish in the face of hostility, derision and other detractions to their work. Thus, there is good sense in taking the time to recognise their contributions and to show a sense of how their efforts are valued. This demonstration of appreciation need not be elaborate or expensive, as many people simply want to have their contributions noted and valued. Should they not receive it after many efforts to excel, then it is understandable that they may leave seeking more hospitable environs. Driving out innovators is a destructive strategy, but the world offers many examples of how this error is so short sighted. On the other hand, when people feel that they are doing something of merit and significance and that others value and celebrate this, it is hard to walk away.

**Innovation, looking ahead and the question of human**

## Critique of 'Organisational and systems investments that can stimulate beneficial innovations', by Michael J. Kendrick

**H**istorically, in Ireland within the field of intellectual disability, volunteers, a great many of whom were members of religious congregations, provided a first basic level of service and advocacy for parents and their family members with disability, seeking to remove stigma and advocate for resources.

The growth of the Parents and Friends movement in the late 1950s, and particularly from the 1960s onwards, saw a major increase in advocacy at the political level and widespread citizen participation in the struggle to develop better resourced services, as close as possible to international best practice standards.

The voluntary sector at this stage had become the major provider and was dynamic, progressive, vocal in its advocacy and very much in touch with, and anxious to learn from, what was happening in the wider world—in order to further develop services.

Over this same period, however, the voluntary sector became increasingly reliant on state funding as the cost of provision escalated. Regrettably over this period also, the providing agencies were compelled to adopt in their entirety the conditions laid down by the state and, in particular, the terms and conditions of employment that were operative in the state sector. This effectively transformed these bodies into non-statutory arms of the statutory sector and has led to an escalating decline in the level of freedom available to the voluntary sector to pursue new initiatives that might be in advance of statutory thinking and regulation. This has ultimately led to the current situation whereby users of intellectual disability services are being forced to select from a very

### needs

We often cannot see the value of innovations in the present because we are usually so caught up in surviving the many responsibilities of the moment. Consequently, it is only by stepping back, and looking ahead, that we can bring perspective to bear on what might be important for us to do. This can take on a greater urgency in organisations founded upon service to others to reflect upon whether or not the people being served are properly aided by today's patterns of working. If their lives seem unchanged by what we now do, then perhaps our strategies are not as successful as we would have hoped or imagined. If so, it may well be that this very lack of success is the proper spur to get us to innovate in ways that might be more beneficial to the lives of the people. Innovation for its own sake is trivial in comparison to innovation that benefit's people and their lives. Hence, our unease with today's self-evident orthodoxies may well be the beginning of fruitful innovation.

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limited predetermined menu of rigidly defined service options—residential, day or respite.

While few could dispute that there has been significant investment into intellectual disability service provision over the past half century, and in particular over the past decade, one cannot but question whether in fact this investment has been targeted in the most appropriate way to meet the real needs of the citizens who should be the primary beneficiaries.

Within the Voluntary Sector, and indeed the wider community, there is a growing appreciation that what is currently on offer is not necessarily in the best interests of those citizens we claim to serve. There is significant conflict between current provision practice and the laudable rhetoric. While the spirit of recently enacted and emerging legislation is increasingly supportive of the concepts of person-centredness, practice is sadly at considerable variance with this.

Michael Kendrick's paper provides a further insightful perspective for stakeholders to consider in light of Ireland's growing political interest in, and emphasis on, the promotion of active citizenship. The intellectual disability sector should reflect on his perspective on innovation when revisiting its understanding of its role in a participatory democracy. The document could also prove helpful in a state examination of the extent to which it assists or hampers citizen participation.

**David Kieran**  
**CEO,**  
**St Anne's Services,**  
**Roscrea**

# Vigeland's Sculptures

The Vigeland Park is located in the centre of Oslo. It features many statues that were sculpted by Gustav Vigeland in the early 20th century. These statues offer a commentary on the human condition in all its wonderful variety.





*'These particular sculptures have been selected to illustrate human emotions such as anger, serenity and the call for help as well as the concept of caring'.*

# Health Matters!

Health is sometimes taken for granted. It's not until we become ill or don't feel quite right that we focus on what is wrong with our health. Fortunately there is a great deal that we can do. We are in a position to improve our health and we usually don't have to rely on others to do so. We may go to the doctor, pharmacist or other healthcare professional or use complementary therapies. The choice is always ours. If we have a predisposition to developing certain illnesses we can act accordingly and take the necessary steps to minimise the effects of the illnesses. If we are in pain we don't suffer in silence. Persons with an intellectual disability (ID) may not communicate verbally. They may be dependent on their carers to convey their wants and needs. Zwakhalen, Van Dongen, Hamers and Abu-Saad, (2004) assert that assessing pain can be problematic in persons who present with a severe or profound ID. In this instance the gold standard of pain measurement—self-report—is not appropriate. It has been stated that persons with an ID may experience 2.5 times more health problems than the generic population (Van Schroyen Lantman-De Valk *et al.* 2000). Evidence clearly indicates that the physical health and wellbeing of persons with an ID has not been promoted to the same degree as those without an ID (Marshall, McConkey and Moore 2003). Walmsley (2004) states that persons with an ID are considerably disadvantaged in a number of ways:

## 1. Weight

*Valuing people* (Department of Health (DH) 2001) states that good health is an essential prerequisite for achieving independence, choice and inclusion. It is noted that persons with an ID are more likely to die younger and to live with physical ill health when compared to persons without an ID. Following health checks in Wales (DH 2002) it was noted that persons with an ID were prone to be diabetic and obese. The figure for obesity stood at 35% (40% for women) for persons with an ID, in contrast to 22% for the general population; for diabetes 9% of persons with an ID compared with 4% or less in the general population. Drugs such as Amisulpride, Olanzapine, Quetiapine and Risperidone are known to trigger an increase in weight (Allison, Mentore and Heo, 1999). Furthermore 25-50% of persons with an ID who reside in institutions are prescribed neuroleptic [tranquillising] medication (Kiernan *et al.* 1995).

## 2. Vision

Cataracts often appear early in persons with Down Syndrome. The International Association of the Scientific Study of Intellectual Disability (IASSID) recommends that adults with an ID should be assessed for acuity, near vision, pressures and visual fields from at least 45 years of age and checked every 5 years thereafter. Persons with Down Syndrome should be checked from the age of 30 for cataracts, keratoconus and diabetic retinopathy. Regular clinical examinations would aid in the prevention of unnecessary visual impairments.

## 3. Hearing

Persons with an ID have higher levels of impaired hearing in contrast with the general population (Welsh Health Survey 1995). Yeats (1991) acknowledges that hearing loss is far greater in persons with an ID: 37% in comparison to 14% of those without an ID. Mencap (1998) emphasise that general practitioners are unsure as to when a hearing assessment is

necessary and frequently disregard carers' concerns.

Audiologists recommend that people with an ID, particularly children, should receive a regular hearing assessment every two years, especially for those deemed to be at risk (Roberts 2005).

## 4. Oral health

Local and regional studies in America demonstrate that persons with an ID and developmental disabilities have considerably higher rates of poor oral hygiene and periodontal disease than the general population. In the most recent study of children with an ID, 8% of these children who required dental treatment did not receive this service. Under the auspices of Special Olympics (America) graduates of dental schools must have sufficient skills to determine the dental treatment needs of persons with special needs (Waldman and Perlman, 2005).

## 5. Gastroesophageal reflux disease

In a study of 435 residents with gastroesophageal reflux disease living in institutionalised accommodation the following probable predisposing factors were offered to explain the occurrence of the disease in this cohort: nonambulatory, scoliosis, cerebral palsy, the use of anticonvulsant therapy and having a severe intellectual disability. Some of the symptoms were: persistent vomiting, hematemesis, (vomiting blood) rumination, regurgitation, food refusal and recurrent pneumonia. Persons who engage in rumination not only ruminate food but also gastric fluid inducing oesophageal damage (BCEhmer *et al.* 1999).

## 6. Mental health

In comparison to younger adults, older people who present with an ID are more susceptible to have mental health problems, especially depression, anxiety and dementia (Cooper 1997). This fact has been attributed to social, biological and medical factors, life events and specific syndromes (Tyrell and Dodd 2003). People with Down Syndrome are at an exceptionally high risk of developing dementia, with the age of onset 30-40 years younger than the general population (Holland *et al.* 1998).

## Conclusion

It is known that obesity is a major health risk. It is associated with several diseases including cardiovascular disease, diabetes, hypertension and various cancers. Unfortunately even when a person with an ID is deemed to be overweight or obese there is no guarantee that appropriate steps will be taken to control the person's weight (Marshall, McConkey and Moore 2003). Health promotion for persons with an ID should be pro-active rather than crisis- driven (Carlson 2002). There is a correlation between physical and mental health problems and challenging behaviours. Therefore it is imperative that these health issues are diagnosed and treated appropriately (Twist and Montgomery 2005).

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# General health issues of people with intellectual disabilities

This article by Professor Mike Kerr of Cardiff University has a look at how adults with an intellectual disability experience a complex set of problems with their health and health care, and some ways to meet these needs.

**P**retty much wherever you look in the world a similar pattern is seen: people with an intellectual disability have more health problems, a high level of serious conditions such as epilepsy and certain specific patterns of health needs associated with the cause of their disability. This pattern, easily recognisable by families and carers alike, is sadly complemented by an equally consistent pattern of a lack of appropriate health care. This can be summarised as poor health promotion uptake, inadequate care for serious chronic illnesses, unrecognised health need and poor access to health care. As such, people with a learning disability suffer great inequality in their health as compared with that of the general population.

## Are people with intellectual disability less healthy?

### *Common complex health problems in this population*

Some serious conditions are seen so much more commonly in this population that arguably special provision should be available. Of these some of the most common are (1) epilepsy, (2) sensory deficit, and (3) behavioral and psychological disturbance.

**Health problems associated with the cause of the intellectual disability:** An issue of increasing importance when planning an individual's care is recognising that having a specific cause of the learning disability, such as Down Syndrome, can predict potential health risks and that these should therefore be planned for. Clear examples of these would be how individuals who have Down Syndrome are prone to having an under-active thyroid gland or individuals with Rett Syndrome are prone to scoliosis, curvature of the spine. In these cases regular blood tests for thyroid function in people with Down Syndrome, or regular review for people with Rett Syndrome, may alleviate physical ill health.

**Unrecognised health needs:** A very consistent finding in the research is that when adults with an intellectual disability are offered structured examinations, as many as 50% will be discovered to have health needs not previously recognised. These will range from the relatively minor, but important, such as earwax; through to serious life limiting conditions such as cancer.

**An inequality in health?** Being healthy is a major component of a good quality of life and people with an intellectual disability have a right to a high quality of health. Of course, the general population is not always healthy either so our aim should be that people with intellectual disability are at least as healthy as their peers without intellectual disability. Table one highlights some areas of inequality in health experienced by PWID.

**Table 1: Health inequality in people with intellectual disability**

Area of potential inequality	Example in people with intellectual disability
Life expectancy	Lower life expectancy
Presence of major chronic illness	High level of epilepsy, sensory impairment, behaviour disorder
Increase in factors that may make you unhealthy	High levels of obesity and underweight Low employment Low level of relationships Low rate of physical activity
Getting proper access to health care	Low rates of uptake of health promotion
Quality of the health care experienced	High prescription rate of antipsychotic medication where no evidence of psychosis High unrecognised disease identified on health screening

## Are there any reasons for these inequalities?

Before thinking about how to change the situation, it is worth thinking about why the inequalities occur. Several reasons have been put forward:

**Poor physical access:** It has been suggested that inadequate access to GP and hospital facilities may affect an individuals' quality of care.

**Communication.** Most of us let our doctors know our problems verbally, individuals with major communication difficulties may have

great difficulty expressing their symptoms and this leads to problems making the diagnosis. A very clear example of this is that of problems associated with reflux oesophagitis and ulcer pain. We know reflux is very common in people with intellectual disability, yet it is very rarely presented as a problem. The condition is often only picked up when the individual shows other signs such as poor sleep, poor appetite, weight loss or vomiting, as compared to an individual with good language who would complain of discomfort and acid burn.

**Behaviour problems:** These have been suggested as a reason why individuals get inadequate, or no, physical examinations. This is probably a spurious complaint, but certainly for complex investigations such as brain scans this can be a real problem.

**The knowledge and attitudes of doctors and other professionals:** This is sadly a common complaint amongst carers and probably reflects, in some cases, a real issue of poor knowledge and attitude in a minority of professionals. There is certainly in most countries little specific teaching for medical students on intellectual disability, nor much more following their graduation.

## What can be done to stop these inequalities?

Whilst a constant drive to improve carer and individual knowledge, and in particular to ensure that those who advocate for individuals' health are skilled, these changes are small in comparison to the problems the system engenders. Thus the responsibility for changing this situation lies squarely on the shoulders of those who organise and deliver health care.

**Primary care:** Primary care is currently inadequate for people with an intellectual disability. Major changes are needed in the quality of care provision. The problem is that it is just not set up to meet individuals' needs. It relies too much on 'on-demand' access, often has insufficient time to address complex problems, and GP education rarely covers this population. Certain steps can be made by GPs or practices to organise care for this population such as recall and audit. However, a more fundamental change such as the provision of health checks, recently introduced in Wales, is the only way likely to make enduring and meaningful change.

### **Health checks-what, why, where, who and when?**

**What?** – a health check for an adult with an intellectual disability is a structured history and examination of the individual which must contain a detailed history of physical and mental change, a physical examination and precise questions on serious chronic health conditions seen in people with an intellectual disability. In Wales a structured format is followed by GPs who participate in health checking (<http://www.wales.nhs.uk/sites3/docmetadata.cfm?orgId=480&id=65346>) known as the Welsh Health Check.

**Why?** – It seems from the evidence that health checks lead to a reduction in the inequality in health care that I have discussed. They find unrecognised physical illness and they increase the amount of health promotion individuals get.

**Where and Who?** – In general practice by the GP and a practice nurse, if available.

**When?** – at present it seems they should be performed annually.

## Summary

It seems that despite our 21st century health care, adults with an intellectual disability can only aspire to 20th century health. Individuals, families and other carers can, and do, make great strides to reduce these deficits. The tools exist to reduce these inequalities through structured improved primary health care and efforts need to be made to make such an approach a reality for this population.

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# Fragile X Syndrome: a complex multigenerational condition

## Introduction

Fragile X syndrome is the most common identified inherited form of learning disability (Greco *et al.* 2002) and it has been identified in every racial/ethnic group that has been studied (Sherman 2002). The vast majority of males affected with Fragile X syndrome have a learning disability (Bennetto and Pennington 2002). For females affected by Fragile X syndrome, 50-70% will have a learning disability and the remainder may have more specific learning difficulties (Riddle *et al.* 1998). In the USA, the National Fragile X Foundation (2007) is currently quoting a prevalence figure of 1 in 3600-4000 for males and the prevalence rate for females is thought to be approximately half the rate for males.

## Inheritance Pattern

It is always from the mother that a child inherits Fragile X syndrome. Female carriers have a 50% chance of having a child with a Fragile X abnormality (i.e. their child may be a carrier or be fully affected by Fragile X syndrome). The daughters of male carriers will always be carriers, but will not be affected by the syndrome. Therefore, in some families male carriers may have grandchildren, but not children, affected with the syndrome. As Fragile X syndrome is a genetic condition, it is relatively common for more than one child in a family to be affected. It is also possible that there may be a number of generations affected in a family. In a recent Irish study involving twenty-two families affected by Fragile X syndrome, nine of the families had more than one child affected (Reilly 2006).

## Conditions associated with being a carrier of the gene responsible for Fragile X syndrome

As well as being at risk of having children or grandchildren affected by Fragile X syndrome, being a carrier of the gene responsible for Fragile X also places individuals at risk of being affected by either Premature Ovarian Failure (POF), in the case of females, and Fragile X associated Tremor/Ataxia Syndrome (FXTAS) in the case of males. Premature Ovarian Failure (POF) is defined as menopause occurring prior to the age of 40 (National Fragile X Foundation 2007). Sherman (2002) estimated the rate of POF among carrier women to be 21%. Male carriers are at risk of developing Fragile X associated Tremor/Ataxia Syndrome (FXTAS) (Hagerman 2006). FXTAS is a condition that may affect more than one-third of older adult male carriers (Jacquemont *et al.* 2003). Some female carriers may also develop FXTAS, although with much lower incidence than males (Hagerman 2006). In

addition to the core features of progressive intention tremor and gait ataxia, affected individuals commonly have parkinsonism, autonomic dysfunction, cognitive decline, emotional problems including disinhibition and apathy, and peripheral neuropathy (Jacquemont *et al.* 2003). FXTAS or POF has only been found in those who are carriers and not in those affected by Fragile X syndrome. A subgroup of male and female carriers may also have also mild cognitive, physical, and/or behavioural problems (Tassone *et al.* 2000). However, it is thought that these individuals are the exceptions to the typical lack of involvement in the majority of carriers (Hagerman 2002).

## Who should be tested for Fragile X syndrome?

The Task Force on Autism (Department of Education and Science 2001) recommends that all those who receive a diagnosis of autism should be tested for Fragile X syndrome. Hagerman (2002) recommends that any child who presents

with autism or autistic-like features, and/or learning disability without an identified aetiology, should undergo DNA testing for Fragile X syndrome. McConkie-Rossell *et al.* (2005) recommend that all individuals with a family history of Fragile X syndrome should be tested, but they caution that Fragile X testing for children less than 18 years of age must be approached carefully, with medical and emotional benefits weighed against potential harm.

## Physical and behavioural features of Fragile X syndrome

Common physical features which may be found in those (especially males) affected by Fragile X include large and prominent ears, a long narrow face, velvet-like skin, hyper-extensible finger joints, double-jointed thumbs, hypotonia (abnormal muscle slackness), flat feet and a single palmar crease (Hagerman 2002). The physical features of the syndrome may be present in females, but often to a much lesser degree. Individuals with Fragile X syndrome seem to be extra sensitive to sensory stimuli such that they are easily hyperaroused (overexcited) in situations with excess auditory, visual, or tactile stimuli, as in crowded and/or noisy environments (Hagerman 2002). This hyperarousal or over-stimulation in social situations is increasingly being recognised as a key characteristic of those of Fragile X and may be related to the display of challenging and atypical behaviours. Shyness or social anxiety is also a notable feature of children with Fragile X (Sobesky 1996). Difficulties with sensory integration are common among children with Fragile X (Schopmeyer and Lowe 1992) and these difficulties may need input from professionals with

*Individuals with Fragile X syndrome seem to be extra sensitive to sensory stimuli such that they are easily hyperaroused (overexcited) in situations with excess auditory, visual, or tactile stimuli, as in crowded and/or noisy environments*

knowledge of sensory integration therapy. The typical communication profile of those who have Fragile X syndrome may involve a combination of delayed early speech and language, attention difficulties, social anxiety and atypical language (Taylor 2004). Atypical language includes tangential language (off-topic questions and responses or comments), perseverative language (the reintroduction of favourite topics over and over), and repetitive speech (repetition of sounds, words or phrases). Approximately 20% of children with Fragile X will also have epilepsy (Musumeci *et al.* 1999).

Attention deficits, restlessness, hyperactivity and fidgeting have been described as some of the most striking and pervasive of the behaviours associated with Fragile X syndrome (Bregman *et al.* 1988) and may result in some of the children, especially males, receiving a diagnosis of Attention Deficit/Hyperactivity Disorder (ADHD). Girls with Fragile X and ADHD usually have less hyperactivity, compared to boys with Fragile X, but impulsivity and short attention span can also be a significant problem for girls (Hagerman 2002). Research has shown that autistic-like features, such as hand flapping, perseveration in speech, shyness, and poor eye contact are seen in the majority of individuals with Fragile X syndrome (Turk and Graham 1997). However, the majority of children with Fragile X syndrome do not demonstrate the core social deficits typical of autism (Hagerman 2002). The current view is that up to one-third of children with Fragile X syndrome may meet the diagnostic criteria for autism (The National Fragile X Foundation 2007), while others with autistic-like features may receive a diagnosis of PDD-NOS (Pervasive Developmental Disorder Not Otherwise Specified). The presence of autism with Fragile X syndrome is associated with severe language and social deficits, in addition to lower IQ compared with that of children with Fragile X syndrome without autism (Lewis *et al.* 2006).

### Challenges associated with a diagnosis of Fragile X syndrome

Dykens (1999) asserts that many families with children affected by genetic conditions may be relieved at finding a reason for their child's difficulties, but many will also receive the genetic diagnosis with a sense of guilt. The potential for self-blame may be particularly great for a condition such as Fragile X syndrome, given that mothers are carriers of the gene responsible for the syndrome. The comment of one mother in Reilly's (2006) Irish study highlights the potential for self-blame among mothers of children affected by Fragile X:

*...there was an awful lot of guilt lying around [at the time of diagnosis]...it is huge when know you are handing your own child a disability...*

As well as dealing with a diagnosis of Fragile X, Carmichael (1997) also identifies the burden which falls on the family member who is first in contact with the genetic centre, as this person will often feel responsible for contacting other family members. Some family members may react very badly to the news. They may be angry about being advised to go for testing and may be inclined to 'shoot the messenger'. Refusal of family members to cooperate with

testing may lead to resentment and anger. Some family members may be in denial and refuse to accept the information, or reduce or completely cut off contact with affected family members. The stigma associated with the condition and impact on family functioning was commented on by a number of parents in Reilly's (2006) study. One mother's comment highlighted the impact of a diagnosis and its repercussions on family cohesion:

*Telling the rest of the family was a nightmare. My parents would not talk to me for a while afterwards. It was all blame and 'it did not come from me' sort of thing. It was awful. It is hard to deal with the diagnosis but the aftermath was just as tough.*

The time of diagnosis is obviously very challenging for family members and, therefore, it is vital that the professionals involved deal with the issues in a sensitive manner. Asking questions about the family's history is vital, but yet may cause distress to a family who have recently received a diagnosis of Fragile X. Some parents may be in denial and be reluctant to discuss family history, and may choose not to take up the offer of genetic counselling. Genetic counsellors should be cognisant of the fact that, in general, families are initially overwhelmed, both emotionally and intellectually, by the complexity of the disorder and its implications for other family members (McConkie-Rossell *et al.*, 2005). The genetic counselling process with a condition as complicated as Fragile X should therefore be conceived of as a process involving contact over a period of time (Carmichael 2003). The idea that one grandparent may have passed the genetic mutation to the grandchild is a sensitive issue, and depression, sadness and guilt in grandparents coping with the news that they are carriers are not uncommon (Gane and Cronister 2002). As well as the affected child or children, families affected by Fragile X may have concerns about future children, grandchildren or the possibility of the occurrence of Premature Ovarian Failure (POF) or Fragile X associated Tremor/Ataxia Syndrome (FXTAS).

### Summary

Fragile X syndrome is a complex genetic condition that is likely to have far-reaching consequences for affected families. Its impact may be greater than other developmental conditions due to its genetic component, and potential impact on more than one generation in affected families. Families affected by the syndrome are likely to need, and benefit from, formal and informal support. In particular, the provision of genetic counselling and family therapy over an extended period may facilitate coping with, and understanding, the implications of a diagnosis of fragile X.

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#### For More Information on Fragile X Syndrome and Associated Conditions contact:

Irish Fragile X Society - <http://www.fragilex-ireland.org>  
[American] National Fragile X Foundation - <http://www.fragilex.org>  
UK Fragile X Society - <http://www.fragilex.org.uk>

# The management of menopause for women with intellectual disabilities

## Introduction

Cosgrave *et al.* (1999) have established that women with an intellectual disability experience menopause at an earlier age than women of the general population. It has been noted by McCarthy and Millard (2003a) that there is inadequate information and support available for women with an intellectual disability as they experience the onset of menopause. This is of particular concern when one considers that there are 4839 women with intellectual disability aged 35 and over in Ireland (Barron and Mulvaney 2004). Very little research has been carried out with regards to how the menopause affects the women with an intellectual disability (Martin *et al.* 2001). The purpose of this article is to provide information to assist carers to recognise the onset of menopause and to help with the management of the related symptoms associated with peri- to post- menopause in women with an intellectual disability.

## Definition of Menopause

The World Health Organization's definition (WHO, 1994)

- Peri-menopause: The time leading up to menopause with endocrinological, biological and clinical features of approaching menopause, ending one year after the last menstrual bleed.
- Menopause: Permanent cessation of menstruation resulting from the loss of ovarian follicular activity.
- Post-Menopause: The time following the date of last menstrual bleed, which cannot be determined until 12 months of spontaneous absence of bleeding has been observed.

## Causes of Menopause

In women, from around the age of 35 years, the reproductive cycle becomes less predictable and ovulation may not occur in every cycle (McKinlay *et al.* 1992). The levels of the hormone oestrogen fall and when levels fall too low to stimulate endometrial growth, bleeding stops altogether and the menopause occurs (Abernethy 2003). This erratic production and eventual decline in hormone levels in the blood are responsible for many of the symptoms of the menopause.

## Common symptoms arising in Menopause

It is important to note that women with learning disabilities experience the same range of symptoms as other women during and after menopause (Martin *et al.* 2001). In this article the short-term, intermediate, and long-term symptoms of this condition are highlighted, with suggestions as to how carers might respond to them. In many cases hormone replacement therapy (HRT) may help resolve the symptoms of menopause; this is discussed further below. In all cases a healthy lifestyle should be encouraged, a good varied diet and an appropriate level of exercise, to promote the best possible general health.

Typical Menopause Symptoms (McKinlay *et al.* 1992).

### Short term symptoms:

Hot flushes, night sweats, psychological symptoms e.g. depression, anxiety and panic attacks.

### Intermediate term symptoms:

Panic attacks, bladder symptoms e.g. incontinence.

### Long term symptoms:

Osteoporosis, and cardiovascular disease.

### Hot Flushes / Night Sweats

These are the most common symptoms of the menopause. When oestrogen production drops abruptly during the peri-menopause, there is a change in the brain's chemistry, which affects the temperature control centre in the hypothalamus. This causes a rush of heat over the face, neck and arms, followed by a profusion of sweating as the body attempts to regulate its' temperature. When these flushes occur at night they are known as 'night sweats' and can be very distressing as they can cause sleep disturbance.

How the carer can respond:

- ◆ The dietician may be consulted regarding the introduction of some foods; those high in magnesium, calcium, vitamin B6 (cereals), Vitamin E (nuts, almonds and avocado) and phyto-oestrogen (a chemical compound that occurs naturally in plants and has estrogenic properties) or restriction of some foods; caffeine, tea, red wine, refined sugar and spicy foods.
- ◆ Assist the client in choosing suitable clothing—e.g. wearing layers of clothes, especially cotton and natural materials.
- ◆ The use of bed linens which are made from natural fibres should be promoted. Plastic mattress covers and incontinence sheets should be avoided where possible.

### Psychological symptoms

Milner (1997) describes psychological symptoms such as depression, anxiety, panic attacks and changes in libido, which may accompany the other symptoms of the menopause. These may not be directly attributable to the decrease in levels of oestrogen, but may be as a result of all of the changes that occur during this transition.

### Depression

Depression during the menopause is most likely to occur during the peri-menopause period but it can last for weeks, months or years. At this time women may experience pain, disrupted sleep, loss of appetite, tiredness and sadness.

How the carer can respond:

- ◆ Be aware of any changes in the client's mood, for example she may experience feelings of sadness and worthlessness
- ◆ Observe the client's behaviour, she may become less motivated or change her routine.
- ◆ Observe her physical state—she may have physical pain, for example she may complain of headaches.

- ◆ The client should be encouraged to exercise as an increase in her level of activity will increase the rate of endorphins (the body's natural mood enhancers) produced in the brain. Regular exercise will also help maintain good circulation, mobility, bone density and wellbeing.
- ◆ Encourage the client to talk about her problems, encourage her to express her emotions.
- ◆ Antidepressants may be advised by the GP in some cases.

#### *Anxiety/panic attacks*

Women may experience episodes of anxiety at this time. This may take the form of generalised anxiety or in more severe cases may manifest as a panic attack; these are periods of acute and unremitting terror that grip the individual for periods of time, lasting from a few seconds to a few hours. The lifetime prevalence of a panic attack is estimated to be 4% (Katerndahl and Realini 1993).

Signs of generalised anxiety may include:

- ◆ Exaggerated worry and tension
- ◆ Expecting the worst
- ◆ An inability to relax
- ◆ Insomnia
- ◆ Physical symptoms: fatigue, trembling, muscle tension, headaches, irritability or hot flushes.

Symptoms of a panic attack may include:

- ◆ Shortness of breath
- ◆ Clammy skin or sweating
- ◆ Irregular heartbeats
- ◆ Dizziness
- ◆ Faintness
- ◆ Feeling of un-reality.

How the carer can respond

- ◆ Reassure the client
- ◆ Carers should assume a calm disposition
- ◆ Practice deep breathing exercises with the client (Eason Rowe 2006)
- ◆ Clients can be encouraged to talk about how they feel
- ◆ Carers should encourage clients to live an active and meaningful life, in order to develop a positive image of themselves, maintain or develop their self-esteem and promote physical wellbeing.

#### *Incontinence in women experiencing menopause*

Urinary incontinence refers to the involuntary loss of urine. It is not uncommon in adults, particularly women and the incidence increases with age (Milsom *et al.* 2001). During menopause, the decline in levels of oestrogen can cause changes in the lining of the vagina and bladder, which are heavily dependent on oestrogen to maintain its elasticity and health. Also the muscles of the pelvic floor may weaken due to these hormonal changes.

How the carer can respond

- ◆ It may be advisable for some women to attend their GP for advice with regard to incontinence (Brooker and Nicol 2003).
- ◆ Where incontinence remains an issue it is important that appropriate incontinence wear is provided for the client.
- ◆ At night, protect the mattress with a waterproof cover. However make sure that this does not come in contact with the person's skin, as it may cause irritation and soreness.
- ◆ Incontinence itself can also lead to skin irritation and soreness.

It is important that the person washes carefully in warm soapy water and dries themselves thoroughly prior to putting on fresh clothes.

- ◆ Pelvic floor exercises can also help to strengthen the pelvic floor muscles and may be appropriate for the client. (The Continence Foundation 2001)

#### *Cardio-vascular disease*

Cardiovascular disease—hardening of the arteries, high blood pressure, heart attacks, heart failure, and stroke (Preston 2006)—is thought to be linked to the menopause. For reasons not fully understood, oestrogen helps protect women against cardio-vascular disease during childbearing years. After menopause the incidence of cardio-vascular disease increases (Cornforth 2006). Cardiovascular disease often has no symptoms, but there are some signs to watch for including:

- ◆ Chest or arm pain/discomfort.
- ◆ A warning sign of a heart attack
- ◆ Shortness of breath, dizziness, nausea, abnormal heartbeats and feeling tired.

How the carer can respond

Clients should be encouraged....

- ◆ Not to smoke
- ◆ To exercise regularly
- ◆ To eat a healthy diet eg: fruit, vegetables, low fat dairy products and fish.
- ◆ To maintain a healthy weight.
- ◆ To have regular health screenings, eg: blood pressure, cholesterol levels etc.

#### *Osteoporosis*

Osteoporosis is 'a progressive systemic skeletal disease characterised by low bone mass and structural deterioration of bone tissue, with a consequent increase in bone fragility and susceptibility to fracture' (World Health Organization 1994). Osteoporosis may not have any symptoms until a fracture occurs.

How the carer can respond

- ◆ The client's diet may benefit from review by a dietician, who may suggest an increased intake of calcium, protein and vitamin D
- ◆ Some medications are available for osteoporosis. Clients should attend their GP for advice with regard to this.
- ◆ Gentle weight bearing exercises and an increase in general activity, all within the client's capabilities, may be advisable also.
- ◆ Clients should be advised about reducing alcohol intake and smoking cessation, as both in excess are associated with osteoporosis.
- ◆ Advice aimed at preventing accidents and falls will be of benefit also. (Brooker and Nicol 2003).

#### **Other issues of which carers need to be aware**

##### *Hormone Replacement Therapy*

Hormone replacement therapy (HRT) is 'the giving of prepared hormones as a substitute for those hormones that the body can no longer produce or that have been lost as a result of surgery.' (Weller 2005). Walsh *et al.* (2001, p.204) note that '... the frequency of oestrogen or hormone replacement therapy is much lower in women with intellectual disabilities than in

*Continued overleaf*

women in the general population.' This situation warrants further investigation. HRT is prescribed in many forms, depending on which suits the woman best. The options are; in tablet form, as a skin patch, pessary (a vaginal suppository) or as implants.

How the carer can respond

- ◆ An individual assessment of the degree of distress caused by the symptoms should take place. This should be weighed against the side effects and risks of therapy.
- ◆ The client should be facilitated to make an informed decision on which treatment to take (Whitehead and Godfree 1992). A number of consultations may be required in order for her to understand fully about HRT. Whitehead and Godfree (1992) suggest giving the person additional materials such as books or leaflets, DVDs and CDs and perhaps organising a counselling session with an experienced practice nurse.
- ◆ A 'trial of therapy' for three months should be offered. During these three months carers should assess the effects of HRT on the client and should ensure that these are reported to the GP.
- ◆ Carers can give information, reassurance and support to clients and help explore concerns and worries.
- ◆ The need for breast examination should be explained to the client and, where appropriate, the technique for self-examination can be taught (Alexander *et al.* 2000).

### Women's knowledge and understanding of the menopause

Traditionally little attention has been paid to the ways in which women with ID perceive the menopause, reproductive health care needs and age related concerns. McCarthy (2002) acknowledges that some women with intellectual disability may have only a limited knowledge of the menopause. The result of this is that older women with ID have not been adequately prepared for, or supported through what, for most women, is a significant 'change in life'.

How the carer can respond

- ◆ Recognise the importance of women with intellectual disability understanding the menopause.
- ◆ Training and education concerning the menopause will help client and their carers. Videos and adapted information sheets are available (McCarthy and Millard 2003b).
- ◆ Older female staff with experience of the menopause could share their experiences and feelings with women with ID to aid with understanding and acceptance of this stage of their lives.
- ◆ The changes that happen to a woman during the menopause are difficult for some women to acknowledge (e.g. weight gain, growth of facial hair, or thinning or loss of hair from the head) and therefore, sensitivity on part of the carer is required.

### Conclusion

In conclusion, it is important that carers of women with intellectual disability are aware of the signs and symptoms of menopause. Carers should also have a working knowledge of the range of treatments that are available to relieve the more distressing symptoms of this natural event. In this way women with intellectual disability can be appropriately supported through this natural transition in their lives.

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# Camphill: an anachronism in modern Ireland?



Camphill has recently celebrated its fiftieth birthday in Ireland. The first community, Glenraig, was established just outside Belfast in 1955. In the Republic, Camphill arrived to the Wexford coast at Duffcarrig, near Courtown, in 1976. Altogether, North and South, there are now seventeen communities of all shapes and sizes. Each has a distinct character, determined by the particular needs that it strives to meet.

This article is concerned with the role of Camphill in modern Ireland. I live in a community in Dublin, so most of my experience relates to the situation in the South of Ireland. However, many of the issues and trends are broadly relevant also to Northern Ireland.

## Background

Camphill is an international movement working with children, adolescents and adults with special needs. More than 5000 people live and work in over 100 Camphill communities in 23 different countries. As a pioneer movement in the field of social renewal, Camphill seeks to promote caring, life-sharing communities where children, adolescents and adults of all abilities choose to live, learn and work together, recognising the unique contribution made by each person.

Camphill as a movement is inspired by the philosophy and practical teachings of Rudolf Steiner (1861-1925) and of Karl König (1902-1966), the founder of Camphill. The character and purpose of each community is distinctively formed by the constellation of its members. Schools for curative education, centres for further education and training of adolescents and young adults, and life-sharing communities or working environments for adults each have their own distinguishing qualities. Central to all are certain ideals that characterise the Camphill approach:

- ◆ Mutual respect between individuals of all abilities
- ◆ Concern for the spiritual and mental, as well as the physical, health of each individual
- ◆ Recognition of the importance of setting the working life within a cultural and artistic environment, with a home life that is community-based rather than institutional
- ◆ Community life based on Christian values, celebrating the Christian festivals of the year
- ◆ A feeling of joint responsibility for all that occurs; and striving to place individual aspirations in a social context
- ◆ A social ethic of mutual support where each contributes according to ability and receives according to need. Most co-workers do not receive a wage or salary, but are supported directly from community funds.
- ◆ Recognition of the need to avoid isolation; rather to work in

the world, in partnership with others

- ◆ Concern for the protection and sustainability of the natural environment.

## How is Camphill different?

On the face of it Camphill is quite like any other service provider in the area of special needs. We contract with the health authorities to provide residential, day placement and respite services. We are subject to the same guidelines and legislative requirements as all service providers. As economic entities, we have our budgets and accounting mechanisms. Health and safety, insurance, vehicle management, etc. are part and parcel of our daily work.

However, referring back to the ideals that characterise Camphill, listed above, there are some fundamental differences between Camphill and many other service providers. A good place to start in examining these differences is with the very term 'service provider'. Not wishing to be too controversial, I think it's fair to say that a service provider implies an economic contract to supply certain services in return for an agreed payment. As the purchaser of the service, the HSE are obliged to look for value for money as defined by the efficiency and effectiveness of the service provider. In this particular relationship, the individuals with special needs are referred to as the 'clients'. Clients are customers of a service; their rights are safeguarded by the contractual and legislative requirements of the health authorities. Among the characteristics that define this system are professionalism, standardisation, specialisation and quality control.

Camphill, like all organisations, does, of course, need money to operate and it is appropriate to have a contract with the funding agencies. It is not the requirement for a contract of some sort that I am discussing, but rather the nature of the relationship formed by this contract. While Camphill's relationship with the health authorities is generally a good one, there is clearly a certain disparity between the role of a service provider and that of creating a life-sharing community. The focus of life-sharing is on the equality of rights and responsibilities, the endeavour to create an inclusive home and work environment, recognising the spiritual nature of all individuals and seeking to uphold this through mutual support. The life-sharing relationship is essentially voluntary. It is individually based and cannot be defined in contractual or legislative terms beyond that of a personal commitment. This focus on the individual applies to all members of Camphill communities. This includes people with special needs, both long- and short-term voluntary co-workers, a small number of salaried co-workers and co-worker children. It is a revelation to many people that the individuals with special needs are indeed the pivotal people in each community. They provide the social gel that facilitates a group of individuals to form a community.

I like to think of the ideals that are striven for in our relationships in terms of the ideals of the Enlightenment: liberty, equality and fraternity. High ideals indeed! But they have formed the basis of Camphill life in an ever-expanding movement for nearly



seventy years. Therefore they are eminently workable in real life and present a challenging basis for personal development.

Referring back to the characteristics of Camphill, there is another facet of our life that does not sit easily with the service-provider role. Camphill communities strive to be sustainable communities, defined as places that attempt to integrate the ecological, social, economic and spiritual aspects of life towards creating a harmonious and inclusive place to live. The role of living together with people with special needs has already been discussed. However, this role can be set within a broader ethic of seeking to create a society that cares for the individual and the planet. A truly sustainable society will seek to be inclusive, egalitarian and empowering. It will also endeavor to create economic relationships that don't undermine nature and that distribute goods fairly. A sustainable society will promote creativity and spirituality. By definition, these aims should not be confined to the members of particular communities but are part of a global endeavour. In the jargon of the environmental movement, society should develop in a way that promotes inter and intra-generational equity.

In Camphill, the realisation of creating sustainable communities is most obvious in the organic and biodynamic management of land, the efforts towards resource efficiency and recycling, the promotion and use of renewable energy, ethical purchasing and creating curative living environments. However, less obviously, there is an attempt to completely refute many of the trends in evidence in modern Ireland. For example, the economies of most Camphill communities operate on a needs-based system. This is to say, the community's resources are allocated according to the requirements of the individual, as expressed by them and in light of the needs of others in the community. If you think about this for a moment, it is a revolution in human arrangements. Just think how it would be if this concept were more widely applied! The same thinking applies to the financial arrangements between Camphill and the health authorities. The overall budget is worked out according to the community need and divided by the number of places. Whereas the usual economic law is one of maximising returns, the idea here is to provide for personal needs while being cognisant of society's ability to meet these needs.

Another aspect of Camphill life that runs counter to the norm is our attempt at non-hierarchical management. I say 'attempt' because it is an on-going striving rather than a definite procedure. This is based on consensual approaches and a wish to empower all members of a community to be able to participate to the best of their abilities. Responsibilities are allocated according to experience, ability and the wishes of the individual. There are no 'leaders' or 'managers' as such and most communities have a range of fora where views can be expressed and decisions made. The very act of life-sharing lends itself to an informal meeting of people.

### What is the role of Camphill in modern Ireland?

I would suggest that the disparity between the orthodox service-provider role and the ideal of a life-sharing community has been bridged to date by positive relationships between Camphill members (including the broader body of families and supporters) and health authority personnel. However, I would also suggest that the personal basis for the relationship is becoming increasingly problematic. On the one hand, the search for equality within Camphill does not lend itself readily to the emergence of strong leaders. Most agencies prefer to deal with designated managers rather than committees where the search for consensus



can delay decisions. On the other hand, within the health authorities, the place for personal discretion appears to be increasingly replaced by a raft of regulation, re-organisation and control mechanisms. This trend is, I believe, in part a reaction to the abuses that occurred in a hitherto relatively unregulated system and also a reflection of the liberal management orthodoxy that predominates in public service provision. Neither trend bodes well for the maintenance of good personal relationships.

This situation seems to mirror general trends in Irish society. When Camphill first arrived in Ireland it offered a completely different way to provide living and working opportunities for people with special needs. Over the years, many other organisations have emerged to also fill aspects of this need so that the difference between Camphill and other organisations has, in many ways, shrunk. Indeed, in some quarters Camphill is now viewed as an old-fashioned, institutional-type setting. In an age of 'mainstreaming' and 'care in the community', the traditional Camphill 'village' is deemed obsolete. This is so obviously a misrepresentation of the situation to those of us who know Camphill, but the suggestion seems to reflect the fact that the interpersonal relationships between members of the health authorities and the communities have reduced so that the 'system' no longer has personal knowledge of Camphill life. It also fails to take account of the fact that much of the new development in Camphill has taken place in urban areas and has sought to be innovative in meeting the needs of individuals in a modern, culturally diverse, country.

While societal trends do not appear to be working in Camphill's favour at the moment, I believe that Camphill has a vital role to play in modern Ireland. Without blushing, I can make a claim that the distinctive Camphill way of life offers an alternative in a society increasingly in need of such alternatives. This goes for people with special needs and all those others living in and affected by Camphill. In seeking to create a sustainable society, as discussed above, Camphill is part of a global movement that has sought to provide practical solutions to today's problems. Camphill has been among the pioneers in some ways, such as the development of small-scale renewable energy. The contribution that Camphill has to make in other ways has yet to be appreciated.

As mentioned earlier, a sustainable society is an inclusive society. In relation to special needs provision, I believe Camphill's role is to promote the life-sharing model. Far from excluding people from the mainstream, this is, in my opinion, meaningful inclusion. Not care in *the* community—as if the wider community by nature will provide the care needed—but care in a community, a particular community of people that have chosen to live together and care for one another.

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# Some reasons why becoming person-centred should be proving difficult

In what is seen as an ongoing effort to improve 'quality' and reflect a more modern approach to service provision, many of us in services are striving to become person-centred. The way this concept has been interpreted and applied seems to be variable or selective but few services fail to make reference to it in their mission and value statements. Indeed some services claim that their mission is accomplished and that their services are already provided in a person-centred way.

Without refuting the claims made by such services, this short article will consider why we are (or should be) finding it extremely difficult to become truly person-centred and some of the traps into which we appear to fall. We made need to carefully take stock of how far we have actually come in what is, if nothing else, a sincere attempt to do things better.

## What does person centredness entail?

Three essential aspects of person-centredness can be identified, although there are many more.

Firstly, a fundamental test of true person-centredness within a service is the extent to which transfer of power has occurred from the service system to those served. This implies a culture in which those served are seen as directors rather than recipients, players rather than spectators. It is, in essence, about the sincere adoption of a person-centred ethic and demands that we apply, rather than recite, our values.

A second feature of person-centredness is the extent to which services have supported people into valued social roles and the degree to which the client / professional role barriers have been breached. What roles are implicitly or explicitly assigned to the parties in the relationship? How are those served valued, viewed and—even—described?

Thirdly, person-centredness entails a sincere, sustained and authentic commitment to individual people's well-being and interests in the very broadest sense.

Unfortunately, there exists a widely held misconception that we will become person-centred, not by applying our values or attending to individual interests, but by the wholesale application of certain planning methodologies. In reality we could be person-centred without plans—and plans, however well intentioned, do not make us person-centred. It seems to be the case that many services are devoting their energy to person-centred planning, with much less attention being given to the real business of transferring ownership and control to those whom they serve. This misconception is compounded and reinforced by, amongst other targets, HSE 'performance indicators' which tell us nothing about person-centred practice, but only about the bald statistics of how many plans have been produced.

Perhaps the reason why services seem to have taken the 'planning route' lies in the view that it is easier to adopt a technology than it is to change a culture. We seem much more adept at devising systems, policies and procedures than we are at adopting new ways of thinking and acting. The concept of 'accountability' seems to fuel a need for easily measurable statistics, and 'productivity' while time spent working on 'ideas' or 'new ways of working' takes a far lower priority.

It is worth considering that if we became truly person-centred the need for formalised planning might very well disappear.

## The problem of design

One of the many simple definitions in the lexicon of 'quality' is that the quality of a thing may be measured by the degree to which it is fitted to its purpose. We need to remind ourselves that, for many of us, in asking our services to be person-centred

we are expecting them to achieve something that they were never designed to do in the first place.

The services in which many of us work came into existence specifically to take people out of their existing communities. Many services developed as focal points for what was seen as largely a homogenous group of people who were viewed as requiring 'treatment' which could only be provided by certain specialised 'professionals' and in isolation from mainstream society. These service's *raison d'être* was segregation and it is such designed and built-in segregation that we are now in the process of trying to dismantle. It should be no surprise that this has proven to be challenging.

As a consequence of historically segregating service design and ethos, an individual's identity was unlikely to extend beyond the presence of certain clinical conditions and the 'level' of one's perceived disability, etc. For many the huge challenge remains the recovery of this lost identity.

## The historical legacy

It is instructive to consider how the relict terminology occasionally used within services reflects their origins and stage of development (e.g. 'admission', 'discharge', 'absconding'). The so-called medical model has left us with organisational structures and systems that do little to further the cause of person-centredness. Hierarchical structures, professionalised roles and patterns of working remain largely unchanged. In some cases, a view persists that people with disabilities remain forever bound to a need for institutionalised medical care, which is rarely if ever the case.

Of greater concern, and at the heart of being person-centred, are the very poor levels of real empowerment enjoyed by most people. Decision making is still very largely in the hands of the service system rather than those served and few have an influence over the major decisions which affect their lives. This may well be the legacy of the 'patient' role who received, rather than controlled, the service that was on offer.

In a similar way there is still a tendency to focus on people's 'differences', when for many their overriding need and demand is to have ordinary lives, in ordinary places with ordinary people. We still focus on the 'special needs' of people rather than the common needs which we all share.

Professional vested interests as well as outdated views of disabled people were also inherited from the medical model. Again they form a barrier to the real change needed to become person-centred. This is not to say that on occasions we all don't need 'specialists', but what qualifications are really required to be someone's friend, to get to know them, to respect them and to share with them the experiences of a full life?

For some of us our other historical legacy is the negative and stigmatising view of disability perpetuated by the religious bodies who originally provided many of our existing services. Whilst their work was of enormous and enduring value, the devaluing images of unfortunate eternal children requiring care and protection were reinforced. Again, in order to become person-centred we are challenged to revise this view.

## Adopting a 'social model'

Most services claim to have rejected the medical model in favour of a social model of disability. Although we may have changed our model, we need to be clear how far we have given life to the changes that the model should imply. Some examples exist where we don't seem to quite understand either how far we have got or where we should be going.

Firstly, there is tendency to equate de-institutionalisation and

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community living with both person-centredness and evidence of the application of a social view of disability. The reality is that for many people, their lives remain largely segregated and they are apart from mainstream society and normal patterns of daily living. If you still attend a 'day centre' and live with other disabled people, what has really changed apart from your address? If we are adopting a social model, why are people still being moved into group homes? We may have removed some of the barriers to inclusion but this must be viewed as work in progress.

Secondly, most people remain supported by 'rented strangers' and the involvement of 'natural supports' remains largely unexplored. People are surrounded by staff, and those often described as their 'friends' tend to be housemates allocated by the service provider. Again there is little evidence here that we have breached the barriers.

We may need to consider that perhaps it is too early to make real claims that a social model has been successfully applied in advance of the real societal changes necessary to bring this about. A more authentic appraisal of how far we have actually come would keep us focused on the challenges yet to be faced.

### Organisational and legislative frameworks

Unfortunately, some of the highest barriers to becoming person-centred are located outside the control of individual service providers. Paradoxically, in some cases, it is the funding mechanisms used by the same controlling bodies who require us to become person-centred, which may actually stand in the way of this achievement.

Aside from the obvious issue of under-funding; inflexibility and a restrictive range of 'packages' form major obstacles to

being person-centred. Similarly, although the Health Service Executive may claim to assess individual need, what actually exists tends to be a 'foyer' system where individuals are matched to options rather than individualised options being designed based on real need. Evidence of a real understanding of person-centredness and its implications would be helpful here.

### Questions we may need to ask

In order to become more authentically person-centred it may be instructive if services were to consider the following five simple questions:

- 1) Do we genuinely understand the implications of being person-centred and applying a social model of disability?
- 2) Is there a gap between our claims to be person-centred and our actual practice performance?
- 3) To what extent are service users involved in making the decisions which affect their lives?
- 4) How do the lives of our service users compare to other, non-disabled, people of the same age and gender? and
- 5) Is there a balance between the energy we devote to planning and the energy we devote to changing our culture?

Only by such honest self-appraisal will we keep faith with those we claim to serve.

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## A typology of needs-led quality of life for persons with intellectual disability

### Introduction

Until the decade of the nineties, service provision for people with intellectual disabilities was directed through the normalisation philosophy. This centred on how people with disabilities should be cared for and, in particular, what types of services should be provided for them. While the normalisation philosophy has fashioned the type of services made available to clients, it is seen as being an ideology that is service-led as against person-led (Seed and Lloyd 1997). Within the current paradigm of service provision, normalisation has been superseded with the more person-led construct of quality of life. Sanderson (2003) sees this person-centred approach as being about the recognition and enhancement of the person's needs and in particular, their quality of life. The concept of quality of life with its components of subjective, objective and personal weighting to the individual is seen as both a replacement and advancement on normalisation (Brown 1996, Hatton 1997). It is grounded in the identification and satisfaction of personal needs of people and helping them achieve the lifestyle they want for themselves (Seed and Lloyd 1997).

Despite this paradigm of needs-led care and quality of life outcomes, the construct has as yet not been integrated within the thinking of nurses or their scope of practice (An Bord Altranais 2000, Northway and Jenkins 2003). More fundamentally, the majority of nurses working in residential services appear to limit their interventions on client needs to basic needs for physical care, safety and emotional support with little interventions surrounding growth or developmental needs (Redmond 2005).

This is not meant as a criticism of nurses, but a reflection of the more pressing and practical needs of clients with severe and complex disabilities. Failure to see and respond to other needs however means that holistic care is unlikely to be provided.

### Needs-led care

According to Ovretveit (1998), good quality care is concerned with meeting the needs of clients as the outcomes of service interventions. Mattiasson and Anderson (1997) have pointed out that identifying the needs of clients is a determinant of quality nursing care which can be determined as the extent to which needs are actually met. Within the general framework for nursing practice, the ability of nurses to recognise needs in clients is a fundamental requirement of nursing care since according to Holtkamp *et al.* (2001), the practice of nursing is about identifying and meeting needs in patients/clients, whether they are sick or disabled.

### Concept and theory of needs

From a conceptual analysis and clarification of the concept of needs and needs-led nursing, Stockdale (1989) advanced the following assumptions about human needs:

- ◆ All humans have needs that lead to outcomes
- ◆ Humans experience needs that have subjective meaning and importance
- ◆ Needs change and have varying degrees of urgency and strength
- ◆ Needs are not always recognised or acknowledged by the individual

- ◆ Significant deprivation of needs will result in physiological and/or psychosocial harm
- ◆ Nursing intervention has the potential to improve the well being of the human condition
- ◆ Needs theory is applicable to all aspects of nursing practice

There are several needs theories (Murray 1938, Maslow 1954, Alderfer 1972, Yura and Walsh 1988). The needs theory used in this typology is based on the theory of motivation developed by Abraham Maslow (1954, 1970). The reason for choosing this theory is that both nursing models (McKenna 1997) and quality of life models (Brown *et al.* 1994) have been developed from it. In this theory there are five broad groups of needs divided between basic or deficiency needs and higher order or being needs. Basic needs such as for food, water and sleep are deficiency needs because if the individual does not meet them, that person will strive to make up the deficiency.

Higher-order needs include intellectual, aesthetic and self-actualisation needs. According to Maslow, only when the basic needs are at least partially satisfied can the individual have the time, energy and motivation to devote to these higher order needs. Maslow described his needs theory as taking a holistic view of the person while being dynamic in view of the ever-changing needs of the person. A criticism of this theory is that it has little empirical foundation since Maslow developed his ideas based on interviews with a few select people whom he considered to have self-actualised. Another criticism concerns his needs theory being hierarchical. However, before his death, Maslow recanted his early assertion that basic needs had to be met before higher needs could be achieved and acknowledged that early needs would have to be at least partially met. Theorists generally agree that humans have basic and higher order needs and while basic needs are necessary for survival, fulfilling secondary needs leads to growth and development of the person

**Quality of life (QoL)**

The current paradigm of service provision to persons with disabilities is grounded in outcomes of service for clients and in particular, personal outcomes (Gardner 1997). These outcomes are related to needs and find expression in the construct of quality of life. In an early paper on the subject, Landesman (1986) argued that an undeniable goal of service provision for individuals with intellectual disability was to enhance their quality of life thus making the construct important to practitioners. Quality of life emerged as an important construct in disability research and an integral part of the current service paradigm during the decade of the eighties (Felce and Perry 1995). There is a substantial and expanding literature on the subject much of which is concerned with conceptual issues, dimensions and their measurement (Felce and Perry 1996, Cummins 1997, Schalock and Verdugo Alonso 2002, Rapley 2003). These continue to be the subject of debate and are beyond the scope of this paper.

While writers differ on how they define quality of life, most agree that it is multidimensional with subjective and objective components in the person's life weighed against their satisfaction with these. Despite its considered importance there is as yet no universal agreement on either the number or variety of dimensions that make up the concept (Rapley 2003). As intellectual disability nurses have been slow to integrate the construct into their thinking (Northway and Jenkins 2003) this may in part be accounted for by the lack of an agreement on definition and its dimensions.

This said, within the field of intellectual disability research, a level of consensus seems to exist on the definition and dimensions of the concept. Brown *et al.* (1992, p.111) for example, define quality of

life as 'the discrepancy between a person's achieved and unmet needs and desires.' Keith (2001) believes it to mean empowerment, autonomy, personal satisfaction and independence. Perry and Felce (1995, p. 60) define QoL as 'an overall general well-being that comprises objective descriptors and subjective evaluations by the individual of their physical, material, social and emotional well-being together with the extent of their personal development and purposeful activity, all of which are weighted by a personal set of values'. They see QoL as the interaction between the circumstances or mode of a person's life, their satisfaction with its various facets and their personal goals and values. Various writers have singled out different dimensions or components of quality of life. Schalock (2002) for example, identified eight components, which are listed in Table 1.

**Table 1. List of the eight dimensions (components) of quality of life (Schalock and Verdugo Alonso 2002, p.184)**

Physical well-being	Emotional well-being
Interpersonal relations	Social inclusion
Personal development	Material well-being
Self-determination	Rights

From their extensive review of key literature sources, Felce and Perry (1995, pp.60-2) identified the five dimensions of quality of life seen in Table 2.

**Table 2. Five dimensions of quality of life identified by Felce and Perry (1995)**

Physical well being	Material well being	Social well being
Development and activity	Emotional well being	

The areas identified by Felce and Perry (1995) are clearly not exhaustive but were chosen because they reflect the dimensions of a person's life seen as being repeatedly singled out in the literature and about which there was most agreement. Based on this, these five dimensions constitute the quality of life outcomes against which Maslow's five broad human needs are compared in the typology presented here.

**Activities and interventions for clients**

Nurses frequently engage clients in quite natural and normative activities, which they employ as therapy interventions with the expectation that they will meet particular needs in clients that in turn will lead to their growth and development. For example, nurses are likely to employ activities to foster speech and language in clients so as to develop their communication and self-advocacy skills (Grove *et al.* 2001, Ferris-Taylor 2003). They also use music, movement, art, play and leisure not just for the enjoyment these bring, but also for developing social skills, friendships, self esteem, physical coordination and various cognitive skills in clients (Slade 1995, Manners *et al.* 2003). In helping clients to live as normative a lifestyle as possible, nurses engage in disparate activities ranging from self-help, relationship and self-presentation skills. In addition, clients' have to be helped to master a range of psychomotor and occupational skills to participate in some meaningful employment (Bush 2003).

**Making connections between care interventions**

In reality however, different people may engage clients in particular interventions with little regard for what each is doing or with little consideration to how any one activity may impact on another. A nurse might engage a client in a range of activities, which although

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individually important, are not linked with each other. It is unlikely that these rather disjointed activities will facilitate or lead to achieving particular quality of life outcomes. What is important is not just the engagement in an activity but how and in what way this particular activity is 'connected' to others. It must be said here that pursuing and achieving a desirable outcome in any one domain of quality of life is complex. For this reason, Seed and Lloyd (1997) stress the importance of 'connections' between different needs and between different dimensions of quality of life. They point out that since a deficiency in one dimension of quality of life can affect other dimensions, considerations of outcomes in one dimension should be undertaken with respect to its connections with others. For example, if a person developed ill health (physical well-being dimension) this will be 'connected' to their ability to work and thus their income (material well being dimension) and probably their feelings and self esteem (emotional and social well being dimensions). Other micro-connections that apply to the individual include those of family, neighbourhood and workplace. Seed and Lloyd (1997) see more usefulness in connections between dimensions of quality of life network than in attempting to define discreet dimensions. For example, they suggest that rather than focusing on 'work' as a dimension, the important connections for this would include how work affects home life and vice-versa.

For a client to achieve a desirable outcome in any one quality of life dimension is, to say the least, complex. Seed and Lloyd (1997) stress that to facilitate a client to develop themselves in any one dimension requires not just that interventions be directed to several needs but that these needs-led interventions be consistently planned and integrated with the particular quality of life outcome in mind. Unless interventions are planned and organised to facilitate these 'connections' they are likely to amount to no more than fragmented time consuming activities.

**A typology of needs-led quality of life**

Table 3. A typology of needs-led quality of life for persons with intellectual disability (Redmond 2005)					
Human Needs Dimensions (Maslow 1954)	Quality of Life Dimensions (Felce & Perry 1995)				
	Physical well-being	Material well-being	Emotional well-being	Social well-being	Development and activity
Physiological					
Safety/security					
Belonging					
Self esteem					
Self actualisation					

A typology is a type of framework useful for illustrating the relationships between concepts as variables and is usually presented as a matrix with one lot of variables on the vertical axis and another lot on the horizontal axis. One can then consider how any one variable on the vertical axis can impact on any other variable along the horizontal axis at the point of intersection. While this typology does this it also uses two-way arrows to indicate the relationships between the variables of needs and quality of life. The arrows emphasise the complexity of the relationships between needs and quality of life outcomes and are meant to alert the user to how needs both affect and are themselves affected by quality of life outcomes. The typology is constructed from two broad theoretical positions of human needs and quality of life and the connections between them. It is descriptive as against being predictive but it should sensitise nurses to the range of needs that individual clients have and how

meeting these can help foster particular outcomes of their quality of life. Table 3 above is the typology of needs-led quality of life for persons with intellectual disability

**Applications of the typology**

The typology has many potential applications. It can help nurses and others in their thinking about how meeting different needs in clients can enhance their quality of life. It can assist with what Sanderson (2002) describes as the family of planning styles that includes person centred planning to achieve a better life for people with intellectual disability. It can highlight gaps in care provision, form part of records of clients overall development and assist with evaluation of care. In practice settings, the typology will have a number of uses. By presenting the typology in the form of an A4 or A3 sheet of paper to allow completion, it can form part of the client's care plan. Alternatively, it can be transferred to a computer where it can be incorporated as part of clients' computerised care plans. By observing how needs intersect with particular dimensions of quality of life, nurses and other service staff will be aware of how an individual client's needs may impact upon particular quality of life outcomes. In the grid space where specific needs and quality of life dimensions intersect, the nurse can do a number of things including:

- ◆ Note observations and then use these as discussion points with the care team.
- ◆ Comment on strengths, weaknesses, and areas for further development.
- ◆ Discriminate between those needs that are met and unmet in clients.
- ◆ Map the extent to which met needs are related to quality of life dimensions.
- ◆ Identify gaps in meeting particular needs in clients
- ◆ State goals or performance objectives to close gaps in clients needs.

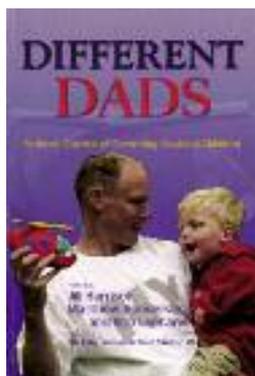
Added to these are the observations of Seed and Lloyd (1997), who see alternatives to scales and questionnaires for measuring quality of life including structured discussions and personal diaries filled out by the person or a personal carer. This typology can make a valuable contribution to any structured discussions about clients.

**Conclusion**

This paper presented a typology of needs-led quality of life for persons with intellectual disability. The typology was developed from two broad theoretical positions. A rationale is provided for the typology and its potential applications were discussed. Whereas the typology can make a contribution to understanding and thinking about how needs are related to achieving quality of life outcomes for clients, it is not intended to indicate that a linear relationship exists between specific needs and outcomes. The use of two-way arrows indicate that relationships of needs to outcomes are complex and it is likely that to achieve any particular quality of life outcome will require that many needs be met. Thus the typology recognises the connections between all the variables. Finally, while this writer sees these variables as important, they may be modified or extended to include others or, alternative needs theories and or quality of life dimensions can be substituted for the ones used here.

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**DIFFERENT DADS: FATHERS' STORIES OF PARENTING DISABLED CHILDREN**  
by Jill Harrison, Matthew Henderson and Rob Leonard. London: Jessica Kingsley. ISBN 978 1 84310 454 4

As a father of a 12-year-old son with Down Syndrome, I agreed to read this book with a sense of unease, wondering what feelings might emerge that had lain buried for so long. Initially I wondered how it

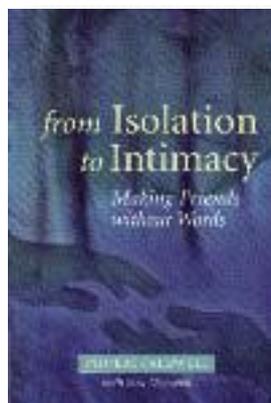
would apply to me? But I continued to read it to explore if it would be useful to other fathers in a similar position. The book contains 21 individual and quite different personal experiences; it is easily read and the glossary of terms is comprehensive. Although there is much variation between the 21 cases, there are some threads that are common to the emotional responses that one experiences in the aftermath of being informed that one's child has a disability.

The overwhelming need for information specific to the condition, regardless of the individuality of the circumstances, resonates loudly through each of the stories. It would appear that fathers still continue to feel as though they are the only person in the world that this has happened to. As long as health professionals continue to focus their attention on the mother, fathers will remain condemned to feeling as if their role is somehow secondary, and that they are in fact extraneous to the situation. These stories highlight that little if any support is given to assist fathers to cope with initial feelings such as rejection, tinged by despair at what their child will not achieve. Although each story is individual, there was one particular example that struck a chord. One father mentioned how attending one's church should be a supportive environment, yet the irony was that when his baby made noise during the service he received disapproving looks—an all-too-painful and familiar feeling. The wide variation in the experiences described serves to normalise the multiplicity of emotional responses one can expect to feel; yet each of the fathers described how over time they learned to celebrate their child's achievements and to bear intolerance with fortitude.

Although one could relate to many of the emotional responses put forward, this is where the similarities end. For example, many marital relationships failed and some fathers actually changed career and/or became fulltime carers. This seemed somehow to be the exception to the rule. Perhaps this is possible in the UK, because of specific financial and health benefits afforded to families in this situation. However, although geographically close, Ireland seems a million miles away, as simple supports such as access to respite care are unattainable for many.

There are many positive aspects to the book, most importantly that it highlights that one is not alone. However, one would suggest caution in recommending the text routinely, as it may raise concerns for parents that they have never yet considered—such as managing challenging behaviour. Therefore, if a health professional recommends this text to parents only recently informed of their child's disability, informational support should be provided to answer any questions that may arise. If I were offering this to a father, I would suggest that he read the conclusion first. That way he can get a flavour for the individual experiences described and can choose to read those that resonate strongly, rather than perhaps becoming overwhelmed by issues that may never arise in their own circumstances.

Paul Lalor



**FROM ISOLATION TO INTIMACY: MAKING FRIENDS WITHOUT WORDS**  
by Phoebe Caldwell with Jane Horwood. London, Jessica Kingsley (2007). ISBN 978 1 84310 500 8, £12.99.

This book looks at how people without disabilities communicate with those who have intellectual disability or are on the autistic spectrum. The book is divided into two sections, the first of which is entitled 'Learning the skills of

interaction'. This section examines what goes on as we interact with people who mostly do not use language and who view the world as a very different place to the way their carers view it. Caldwell understands that if you are on the autistic spectrum the world appears to you as wholly foreign and unpredictable; she understands that the capacity of many people with severe intellectual disabilities to comprehend the world in which they live is very limited. The author explains some of her theories about why this is so. In brief, she suggests that the way to communicate with such people is to use their utterances and body language as the starting point from which to develop a conversation.

Although Caldwell uses many case studies in the first part of the book, she relies heavily on stories of different individuals in the second section, which gives examples of how she has worked with people with autistic traits and people with intellectual disabilities to make contact with them and to use that contact as a way of communicating with them on their terms, and then of easing the anxiety that many suffer from in encountering the world around them.

Caldwell's theses is summed up in page 144, where she says: 'Whatever our state, we take it for granted that others experience the same as we do. It is one thing to be aware in our heads that another person's experience differs from our own, quite another to take this on board and understand what their experience feels like, how different their perceptions are in the flesh.' Caldwell thinks that we cannot communicate with people with autism or severe intellectual disability unless we try to see the world through their eyes. We can do this through closely watching the person we wish to communicate with, and by using imitation and intensive interaction as communication mechanisms that enable us to engage with others on their terms and to 'speak their language'.

The difficulty of the task is evident when one thinks of how easy it is to misunderstand our non-disabled peers who can communicate with words and gestures, let alone the immense difficulty that people with autism or severe intellectual disability present with.

If I have any criticisms of the book they are that Caldwell makes communication seem easy, which it clearly is not. She only describes her successes, never the people with whom she could not communicate. Furthermore, as she points out herself, there is little scientific evidence to support her theories. Hopefully that will come. Indeed it is important that her ideas are tested, quite simply because they are such good ideas. Caldwell makes it clear that if you perceive the world in a wholly distorted way you can only be communicated with by someone who understands that—obvious really. It is fascinating that in all her discourses regarding those on the autistic spectrum she does not mention Applied Behaviour Analysis once. In ways, this is not surprising because her approach is very different. She does mention the use of PECS as being helpful if used thoughtfully, but she does not regard the technique as a panacea.

In short, this is a wonderful book—it challenges current thinking, it makes you want to go straight up to the next person you meet who has communication difficulties and try out the approaches she suggests. It is early days, but if evidence can be produced to support her theories this may just come to be regarded as a book that changed the world.

Colin Griffiths

