

NO. 66
SUMMER 2006

the frontline

OF LEARNING DISABILITY



Early intervention
Community and rights
Person-centred planning
Personality and motivation

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Published by
The Frontline of Learning
Disability Ltd

Production
Niamh Power, Alicia McAuley

Subscriptions
Helen Dunne

Typeset by
Wordwell Ltd

Printed by
ebrook

ISSN 0791-1270
Published Quarterly



Cover picture: 'Drove the Chevy to the levee'. Sculpture by Séamus Leavy, Mullingar Resource Centre

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Letters to the editor are welcomed. Name and address should be provided; they will be published unless otherwise requested.

Articles may be submitted for possible publication in Frontline. Guidelines for authors are available from the editor.

Items on meetings, conferences etc. for Noticeboard should be submitted well in advance of events, to meet Frontline's publication schedule.

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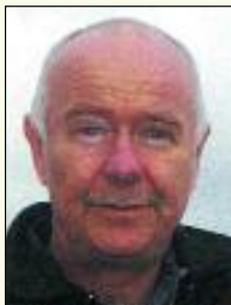
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Correction

On the contents page of Issue 65, Michael McKeon's article 'A constructive outlook for people with severe and profound intellectual disability' was erroneously credited to Andy Smith. Apologies all round.

editorial



Changing our lives

DUE TO THE LONG DURATION OF THE PRODUCTION PROCESS I am writing the editorial a few days after the Oscar awards ceremony—the ceremony at which, against all expectations, the film *Crash* eclipsed the favourite *Brokeback mountain*. This unexpected outcome—where the initial outsider becomes the favourite and then falls at the final fence—offers some food for thought. Why, I wonder, did this heartrending love story not make the impact that was expected of it? The thought that comes to mind is that a gay movie, even a gay cowboy movie, is still a step too far for Hollywood. Nevertheless the film has garnered three Oscars, won other awards as well as proving very popular in the cinema. As a genre, cowboy movies have rather passed their peak of popularity so it is interesting to see that putting a gay slant on an old love story has played some part in the popularity of the movie. Undoubtedly the fine story combined with the directorial talents of Ang Lee and the acting abilities of a superb cast also played parts in the movie's success. When I came away from the film I felt quite overwhelmed, I thought that the way the story had portrayed the eternal themes of love, deception, and fleeting happiness amid the storms of life was very powerful and that the question of the sexual orientation of

'Do we not seek a society where people with disabilities are integral but not necessarily central to the story of our world?'

the leading protagonists was not important—it was simply a good story. This led me to reflect that if movies can tell such a story about one section of society why can they not do so for others? There is a disability movie sector and some very good movies have been made that have told stories of people with disability. However, to my recollection there have been no disability movies that have made such an impact internationally, nor any where the disability has not been the main issue in the film. *Brokeback mountain* made the grade not because it was a gay movie but because it was a good movie with gay characters in it. To this writer the journey from the margins to full inclusion in society is a long one, a journey that has been made easier for the gay sector by the success of the film. We in the disability sector need our *Brokeback mountain*; we need a film that has a good story, is well directed and is acted by actors with intellectual and other disabilities who are integral but not central to the story. Indeed, is that not our aim? Do we not seek a society where people with disabilities are integral but not

necessarily central to the story of our world?

I am taking a break from the editorship of *Frontline*. This is due to the fact that I shall be taking a sabbatical in order to carry out research over the next few months. As a result I will be vacating the editor's chair for the next two issues. *Frontline* 67 will be edited by Kathy O'Grady-Reilly and Issue 68 by Michael McKeon. Both Kathy and Michael have been on the editorial board for several years and will bring wonderful experience to the role of guest editor. It is said that variety is the spice of life and as such the next two issues will have some different flavours, while firmly remaining in the tradition that *Frontline* has become.

Readership survey

There was a terrific response from our readers to our recent readership survey. We are very grateful to the very large proportion of readers who took the time to respond. The TCD team who undertook the work will be publishing an article on the results in issue 68. In the meantime we would like to express our gratitude to Lauren Kelly, Conor Brides, Eoin Dunne and Gary Notley of the Department of Statistics in Trinity College Dublin for carrying out the work and giving us much food for thought.

Colin Griffiths

Person-Centred Planning Seminar.

The National Disability Authority hosted a seminar at the Burlington Hotel, Dublin, on 30 November 2005, to support the adoption of its recently published guidelines on person-centred planning. An Tanaiste Mary Harney TD sent a message of support and encouragement for the occasion, noting that: 'One of the basic principles of the health strategy is that services should be "people-centred".' Her message was read at the opening of the seminar.

The seminar was attended by almost 100 delegates. Among those present and/or presenting were: people with disabilities and their parents, families, advocates and representative groups; service providers; various funding bodies; educators and employers; and representatives from the Department of Health and Children, the Health Service Executive and the Department of Justice, Equality and Law Reform. The event was opened by Siobhán Barron, Acting Director of the NDA and chaired by Mary Van Lieshout, Head of Research and Standards Development at the NDA.

The seminar began with a presentation of the new national guidelines by Dr Anne-Marie Rooney, Person Centred Planning Project Leader for the NDA. Her presentation was followed by a series of short presentations on the Irish experience of person-centred planning (PCP), by eleven guest speakers. The aim of the guest speaker series was to address frequently asked questions on the practice of PCP, with practical examples from current Irish experience, as a complement to the more general recommendations set out in the guidelines document.

Speaking in a personal capacity, Michael Corbett addressed the very important, fundamental question of why PCP should be considered, and how it could make a difference to the lives of people with disabilities and the services and supports they receive. Acknowledging the potential of PCP, Michael cautioned against the development of new systems, professions and bureaucracies, and urged intending practitioners to stay focused on the person and the whole point of PCP, which is to ensure better lives and services for people with disabilities.

Using practical examples, Karina Wallis, Head of Evaluation and Person Centred Training, SCJM Services, explored how a person-centred culture might manifest itself in services and the broader community, and how it might be experienced by a person with a disability. Karina then went on to describe, in some detail, how a more person-centred approach has made an enormous, positive difference to two people with disabilities with whom she is familiar, where other approaches, previously adopted, had not been found to be particularly useful to them.

Marie Therese Corbett, from Westmeath, described how her own person-centred plan is developing and how it is being implemented. This presentation was particularly valuable because of the fact that Marie Therese's plan is in no way standardised, but is very much her own, in terms of both content and form; it is also a very clearly action-oriented plan that is getting results.

Speaking in a personal capacity, James Rickard, Dublin, made a brief but significant presentation indicating the need to develop advocacy and other complementary skills alongside person-centred planning skills, so as to ensure that plans do, indeed, get put into action.

Professor Patricia O'Brien, Director of the National Institute for the Study of Learning Disabilities, Trinity College, Dublin, pointed out that effective relationships and alliances are equally essential to putting plans into action. Patricia defined these as



Dr Anne-Marie Rooney (NDA), Paul Cambridge (Tizard Centre) and Kathy O'Grady (SCJMS) at the launch of the NDA guidelines on PCP.

respectful, equal, trusting, caring, reliable and mutually supportive. Patricia described, in some depth, how such relationships and alliances could be forged.

Kathy O'Grady Reilly, Senior Psychologist with SCJM Services, gave some very practical and useful ideas on how to work out the level of supports required for PCP, based on her own experience in Valley Bungalows, Mullingar, and using the AAMR 'Supports Intensities Scale'.

Kay Downey Ennis presented the approach adopted by the Daughters of Charity Services in introducing PCP into one of its services. Kay's presentation was particularly helpful in that she described not only how each stage of the process has evolved, but also how each stage has been experienced by various participants. Kay summarised the lessons learned from her experience in the form of a general set of keys to success in establishing PCP in services. Significantly, the Daughters of Charity began their work in this area by developing their own definition of PCP. Management, staff and service users worked together to reach a good definition that made sense to them. In this way, everyone had a clear understanding and sense of ownership of the process from its outset.

[Ed's note: see full article on pp 26-27.]

Kevin Barnes of RehabCare described that organisation's approach to capturing key requirements of individual person-centred plans so that they might inform services' overall strategic plans. This is a significant issue, and not just for service providers. In order to be able to properly meet the demands made by each individual service user's person-centred plan, it is important for service providers to get an overall picture of what is being asked of them by everyone. In this way they can plan the best use of the resources that are available to them and begin to develop services that are better tailored to the needs of each-and-every service user. Kevin's presentation gave some very helpful, practical ideas on how to get started on this process.

John O'Dwyer and Anthony Kiernan, Gheel Autism Services, also made a significant contribution on change management to the seminar. They described Gheel's research and experience in supporting, tracking, applying and assessing ongoing learning

within services, as new forms of support are developed that are better tailored to individual requirements and preferences.

Geraldine Graydon, National Parents' Council, gave some valuable insights into a parent's experience of developing and championing a person-centred plan. She underlined the need for ongoing commitment to concerted action to ensure that plans are put into action. She also called for more person-centred, flexible and responsive systems of funding that would enable services to be more responsive to person-centred plans through requiring accountability for the deployment of funds to the people with disabilities and their families served by the organisation.

The keynote address by Paul Cambridge, of the Tizard Centre in Kent, complemented the presentation of lessons learned from the Irish experience with an international perspective on PCP in practice. Paul emphasised the need for person-centred organisations; circles and networks of support; advocacy and empowerment; independent location of PCP within or, preferably, altogether outside existing systems; communication and inclusion; links with wider systems; and competence at all levels, if PCP is to work effectively. Paul also emphasised the need to track progress and monitor the impact of PCP process-

es, plans and outcomes at individual, service and national levels.

A lively questions-and-answers session followed Paul's presentation. Matters of risk, responsibility, resources, choices and next steps were all discussed in some detail.

The seminar closed with expressions of thanks to all who contributed in various ways to a very interesting event and a word of encouragement to everyone to keep in touch with each other, so as to ensure that everyone wishing to pursue PCP further would be supported in realising this ambition.

The NDA's guidelines on person-centred planning may be accessed on their website: www.nda.ie or obtained in printed form (in regular, jargon-free plain English, easy-to-read summary and large-print formats), audio tape or Braille formats, by contacting the NDA at 01-6080400.

**Dr Anne-Marie Rooney,
Standards Officer,
National Disability Authority,
25, Clyde Road, Dublin 4.**

namhi becomes INCLUSION IRELAND

Throughout a long and distinguished history, namhi has played a proud role in representing people with an intellectual disability. Based on the principle of full and equal participation, the organisation never wavered in its determination to give a voice to Irish citizens who were on the margins, citizens who had no voice of their own. Our campaigns, services, research and publications all helped to start critically important debates and to contribute to them. Over nearly 45 years, namhi grew to become the largest and most genuinely national representative organisation for people with an intellectual disability, with 160 affiliated organisations throughout the country and hundreds of individual members.

namhi is, however, no more. No, it hasn't disappeared, or suddenly decided to give up the fight. Instead, namhi has changed its name to INCLUSION IRELAND. The main reason for doing this is because the people we represent—people with an intellectual disability—asked us to do so.

For several years, the name namhi was the acronym for an out-of-date concept. The letters stand for 'National Association for the Mentally Handicapped of Ireland'; the term 'mental handicap' is completely old-fashioned and offends a great many people, especially self-advocates.

As well as the new name, INCLUSION IRELAND has adopted an identity statement that will go on all our literature and material, and will be part of our new look. Reflecting the campaigns we have been involved in and what we stand for, the tag line will be 'Promoting Rights, Independence, Dignity and Equality'.

It is not easy to change the name of an organisation, especially since it has been in existence for over 40 years. However, after many suggested names and much debate (a lot of it quite passionate!) we succeeded, and the members of INCLUSION IRELAND were able to arrive at a democratic decision that will steer us into the future. Under the guidance of Katherine O'Leary, chair of the 'Name Change Committee', INCLUSION IRELAND was agreed by the general members at an EGM, and adopted

by the board.

In business, our old name would have been described as a 'very strong brand', with its long association and history. But the strength of any brand comes from much more than the name. It comes from the determination of the members to make a difference and the leadership given by people like former namhi president and long-standing disability campaigner Annie Ryan, and the leadership of our current Chairperson Stephen Kealy who has seen us through this change. We look forward to going from strength to strength under our new name with incoming chairperson Finula Garrahy and the unity of the whole organisation around our goals and objectives.

There are no labels in the name INCLUSION IRELAND. The name speaks for itself. INCLUSION IRELAND was decided on because there is a European organisation for people with an intellectual disability known as Inclusion Europe; the world-wide organisation is known as Inclusion International, and we are affiliated to both.

Our aims in INCLUSION IRELAND will be the same as they have always been—to fight for the rights of people with an intellectual disability. The team in INCLUSION IRELAND, led by our CEO Deirdre Carroll, will continue to work hard to ensure that the rights and needs of people with an intellectual disability are always high on the agenda. And we will continue to take great pride in our history and traditions, while we are looking to the future with confidence.

Side by side with the name change, INCLUSION IRELAND is changing offices, to an accessible and modern building close to the LUAS, Dart and Connolly Railway Station. Our new address is: Unit C2, The Steelworks, Foley Street, Dublin 1. Our other contact details are:

Tel: 01-8559891 Fax: 01-8559904

Email: info@inclusionireland.ie

Website: www.inclusionireland.ie

St Mary's Rochestown School Reunion



St. Mary's School in Rochestown (Cork) hosted a fantastic reunion on Saturday, 8 October last. This was a celebration of 30 years of special education at St Mary's School. 150 former students from Cork, Kerry, Limerick, Tipperary, Waterford and Wexford and over 50 former staff members arrived for the celebration.

A reception was held in the school during the afternoon. Michael Fitzgerald, the former chef to the school (and currently the manager of Caritas Training Centre in Cork), provided refreshments for the guests. A couple of chaps from Kerry could not wait for Saturday and they arrived at the school on the Friday! Mary Conroy (the present Principal) had the school in great shape. Photographs of students and staff from former years were displayed. It was wonderful to see how some people had changed so much over the years. It was also amazing how some others had hardly changed at all. Jim Ryng, a teacher since the school was first opened, acted as MC. Brother John O'Shea of the Brothers of Charity and Patron of the School, travelled from Galway to mark the occasion with some kind words. Una Nagle (Director of Services) also spoke and said that she was impressed by how well the graduates of St Mary's had turned out. Teresa Fitzgerald, a student in the 1980s and 1990s, thanked the staff at the school for helping her and others so much. The afternoon ended with Mass, celebrated by Fr Séamus McKenna.

About 400 former students were invited to the Reunion. It was difficult to contact everybody as many people have changed their addresses during the 30 years. Sadly, some former students and staff have died in the meantime and they were remembered at the Mass. Susan Ryan, a social work student to Deirdre Quirke (BOC/UCC), made a special commemorative booklet for the reunion and the current final year students provided the artwork. Shane O'Mahony at The Brook Day Service made beautiful bookmarks using a photograph of St Mary's and these were also given to guests as a gift. The local community also contributed with Douglas Credit Union kindly sponsoring bus transport from City Hall to St Mary's. Many more memories were shared later that evening, at a Supper and Dance held in the GAA hall in Douglas. The Reunion organising committee was chaired by Marie Kavanagh-Myers, Sector Manager; among the committee members were former students Beverly Smith, Michael Brown and Colm Hennessy.

The St Mary's Reunion was an idea that came from the Psychology Department. We have been concerned about the social isolation that many adults experience. We know

that the social needs of adults with mild intellectual disability are very important. Recreation or having something interesting to do in your spare time is important, but not the only social need. Our research has found that adults with mild intellectual disability have many other social needs. It is really important for some adults to have someone to talk to and to simply have company. Some of these adults are parents. Others have sexual partners and others would like to have a partner. For some people, it is a challenge to communicate with people in the community. In the world outside of services, some adults are being bullied and victimised. In addition to family members, the people who are most important to such adults are the staff who know them and who used to work with them. We want to make services aware of this problem of social isolation and to find ways of helping people make contact with one another.

The reunion at St Mary's was one idea for tackling social isolation. Reunions frequently occur in mainstream life and they are great for people to come together, to remember their shared history, and to celebrate that past. This Reunion gave many former staff and students something to look forward to, even though we were remembering the past. We hope that other areas in the Brothers of Charity services (such as hostels or group homes) will take up the idea of 'reunion' and reach out to former service users and staff, to celebrate our past times together.

St Mary's is a special school in Rochestown near Cork City, which opened with 15 pupils in the 1974/5 school year. The school is set on 26 acres of farm land. A boarding school to accommodate students was run at the school until 1987. Since that time, students who require accommodation stay in hostels run by the Brothers of Charity in Cork City. In 1979 there were 132 pupils attending the school. Pupil numbers have now been reduced to 58, as special schools have opened in other counties. Nowadays also, mainstream schools accommodate many students with mild intellectual disability. In addition to the academic programme, there is a strong history of physical and social education at St Mary's.

**Séamas Feehan,
Senior Psychologist**

Daniel McCarthy's story

My name is Daniel McCarthy. I went to school at St. Mary's, Rochestown. Now I work in Down's Supervalu in Ballincollig. I work in the storeroom and I collect the trolleys. I enjoy the work because I get to meet a lot of people. I am involved with Ballincollig GAA Club since 1992. I am actually a waterman there and I look after a lot of the teams in the club. I go to a lot of their matches and I enjoy it. I like to listen to music and I got an opportunity to go to see Christy Moore last year in concert in the Showgrounds. I really enjoyed his concert. I take two weeks' holidays in August and I go away on day trips—down to West Cork or anywhere really. I am 32 and so it's about 12 or 14 years since I was in St Mary's School. I was in St Mary's from the 80s and I left in 1991. It was a boarding school then because I used to stay there. I actually stayed there from Monday to Friday and I used to go home in the weekends. I didn't like staying at the school at first because I was away from my friends. But I got settled in, in the end. I got on well there. I got on well with the teachers there and I knew a lot of the staff. When I was 18, I thanked them for my time there.

I attended the school reunion on 8 October 2005. It was a great day. They welcomed us and we got booklets and on the back there was a history of St Mary's School. It was actually named St Declan's before it was called St Mary's. We also got a stone plaque that fits onto your cupboard. We got a bookmark as well with the name of the school and a photo of the building. I took lots of photographs and so did many others. It was a great day because it was nice to see all the staff and the teachers that we knew. We went around all the classrooms. We went into the kitchen and in to the dining area for a cup of tea or coffee and a chat. Then we went upstairs up to where the dormitories used to be and where the new classrooms are now. We had a lovely Mass there and afterwards we went down to Douglas GAA Club for a chat and a dance as well.



This is Michael Fitzgerald. He was the chef in the school and I got on well with him. He worked in one of the hostels that I used to stay in for a while.



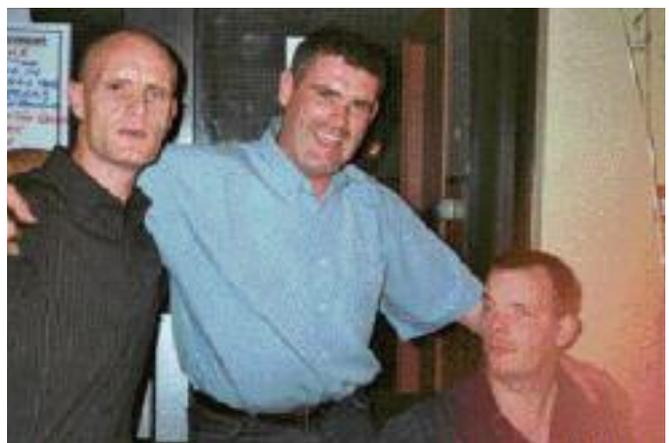
This is Jim Ryng with Una Nagle, Director of Services with the Brothers of Charity. I meet up with Jim Ryng occasionally at matches when we are playing Bishopstown. He was teaching in St Mary's.



My mum came to the Reunion as well. Here she is with the glasses, standing beside Marie Kavanagh-Myers who is now a senior manager with the Brothers of Charity. And beside Marie is Noelle Corkery who worked there as well.



This is a photograph of myself and Lily Hess. She used to be the Night Nurse. I didn't recognise her at first, but then she recognised me. She actually knew my name, so it was nice to meet her. It's been years since I last met her. I got on well with her.



Here I am again with Conor Hegarty and Michael Brown who is sitting down.

Daniel McCarthy

“Hi Everyone”

Nothing about us, without us!!

Who are we?

We are the **Union on the Hill Self-Advocacy Group**.

We are a group of self-advocates who want to make a difference for people with a disability.

We have a supporter, but we are independent!

What does the Group do?

We meet every couple of weeks in Dublin on a Monday evening.

We talk about problems in our lives.

We share stories.

We support each other.

We give each other advice.

We follow up on problems that people bring to the group.

We organise events – we will be soon be doing an anti-bullying seminar.

Who can join the Group?

Any person with a disability!

Any person with a disability who wants to learn how to speak up for themselves!

Any person with a disability that needs support!

Any person with a disability that wants to be more independent!

What the Group wants to gain

We want to make sure people with a disability have their rights respected.

We want to help people with a disability build their confidence.

We want to support each other.

We want to let people with a disability know that bullying is wrong.

We want to give people a voice!

We want to give people a chance!

We want to get people to listen!

Other information about Union on the Hill

We are open to all people with a disability!

Everything we speak about is private and will go no further.

Everything that is told in the group is confidential.

We will listen to everybody's story.

We are completely independent!

WE WANT MORE PEOPLE WITH A DISABILITY TO JOIN OUR GROUP!! DO YOU WANT TO JOIN?

If so, contact Phil Davy, Chairperson of the Group (Tel: 086-3797165) or Clíona Ní Chualáin, Support Person to the Group (Tel: 01-8559891)

The European Platform of Self-Advocates

The European Platform of Self-Advocates (EPSA) would like to invite you and your association to become members of the European Platform of Self-Advocates. EPSA is part of Inclusion Europe and consists of organisations of self-advocates. EPSA is run by a steering group made up of four self-advocates, who are elected at the general meeting every two years. EPSA is supported by the Self-advocacy Officer of Inclusion Europe.

EPSA and the Steering Group have several activities which include:

- ★ organising conferences to exchange experiences
- ★ publishing a newsletter *Europe for us!*
- ★ providing information to increase people's awareness of self-advocacy
- ★ publishing information about important issues at European level
- maintaining a list of self-advocacy organisations
- ★ publishing guidelines on topics that concern self-advocacy.

The following are some of the reasons why it could be good for your organisation to become a member of EPSA:

- ★ speak about your self-advocacy organisation in Europe
- ★ have contacts with other self-advocacy organisations
- ★ exchange information and experiences

- ★ receive information
 - about the work of other self-advocacy organizations
 - about the work of persons with intellectual disability
- ★ work together to help self-advocacy organisations
- ★ speak for all other self-advocacy organisations in Inclusion Europe

In becoming a member, you will also receive:

- ★ Addresses of self-advocacy organisations
- ★ Information about the work of self-advocacy organisations
- ★ Information about work done for persons with intellectual disability
- ★ All other documentation of Inclusion Europe

Furthermore, having become a member, it is possible for you to research information on the EPSA website as well as exchanging information with other members. You can also participate in the annual meeting of Inclusion Europe and other conferences organised by Inclusion Europe and the European Platform of Self-Advocates.

For more information on how to become a member, or for an membership application form, please contact **Inclusion Ireland**.

Ian Redmond

Early intervention in Ireland: a review of service provision

Infancy and early childhood are times of great importance for all children and their families. Current theories of human lifespan development suggest that many factors help to shape patterns of growth and learning: ‘the child’s temperament, parent styles, opportunities for learning and the family’s social and economic environment, among others’ (Santrock 1995).

Current service provision

The presence of a condition leading to disability is an additional source of influence on the development of some children. Early intervention programmes set out to ameliorate the impact of disability and/or disadvantage on children from birth to the time they make their transition to first-level schooling. These programmes have been very effective in changing the thrust of service development, not only for children but also for their families. For most parents, the birth of a son or daughter is anticipated with great joy and excitement. A child born with an apparent disability can readily challenge and alter parents’ expectation. Diagnosis of a disabling condition at birth is possible if an infant is born with an identifiable syndrome or medical condition. Other children may develop disabilities later and their needs will emerge only during or after the first year of life.

Meeting the needs of all children, not only those whose condition is recognisable at birth, but also those with emerging needs, has not followed any agreed national strategy. The availability of a service has for some families been a matter of where you live rather than automatic access to an integrated, well resourced and locally developed service based on national priorities and guidelines. Planning across administrative boundaries can be enormously difficult in large delivery systems (Mitler 1979). It can be equally challenging in some regional health services between community care areas. In Ireland, in the past, the delivery of an integrated, uniform and equitable service between community care areas presented Herculean challenges. One of the primary objectives of the Health Services Executive (HSE) is the provision of an integrated service based on quality and equity.

For some parents, their first contact with early services takes place in the hospital/maternity unit or when the birth notification reaches their local health board. Children aged up to 2 years, who have disabilities, are also identified to child surveillance provided by their public health nursing home visiting programme or by a general practitioner (primary care medical doctors) who refer some children for special intervention. Parents may also contact service agencies directly if they have concerns about their child’s development. The quality of that contact can very

often be a harbinger of what is to come.

Family composition today in Ireland reflects recent social change and greater cultural diversity. The family as a unit (father and mother as married partners and their children) is no longer the norm. In 1996, just 39% of Irish households comprised a married couple with children and 28% of all births in Ireland were outside of marriage—more than the average EU rate (Kennedy 2001).

Recently too, Ireland has been seen by women from abroad as a desirable place to give birth, and the number of infants born in Ireland to mothers from outside Europe has increased. Immigration into Ireland has generated cultural diversity not easily mapped onto the services provided to date by regional health boards. Whatever the composition of a family, its members must grapple with the presence of a child with apparent disabilities and what this means for them. Providers of special services and national associations are increasingly aware of cultural diversity and they also recognise the needs of brothers and sisters of a child with disabilities.

New developments in service provision

The literature on early intervention makes a distinction between first- and second-generation research on early intervention programmes. First-generation programmes focussed on the individual child. Second-generation early intervention programmes recognised that a child’s development takes place within a family context and is influenced by a relationship within the family

(Guralnick 1998). This understanding is beginning to be recognised in how early intervention services are delivered by the Health Services Executive, by highlighting the need for ‘a team around the child’ (Mid Western Health Board 2002). In the past understanding of a child’s needs was often based on individual assessment from different professionals, sometimes working alone, other times on an interdisciplinary, multidisciplinary (or more recently transdisciplinary) basis. Recently enacted legislation (Epsen Act 2001, Disability Act 2005) puts centre stage the assessment of need for early intervention; this means having parents as central and participative members of the process (Gallagher 2002). Participative interventions will involve family members and therapists to ensure a child is involved, encouraged and assisted to grow and develop to their full potential.

Second-generation early intervention research emphasises the importance of supporting the family around the child, while conscious of the need for a respectful and trusting partnership with parents. Such collaborative partnerships must take account of a child’s vulnerability (Ramey and Ramey 1998; Bailey *et al.* 1998).

‘All interventions must take account of parents’ needs in what is clearly a stressful period by listening carefully to their concerns and focus on supporting them around their child’s identified needs.’

Early Intervention programmes share a number of objectives, to:

- **Enable** parents to optimise the time spent with their children;
- **Complete** specific pieces of work based on identified need;
- **Develop** the relationship between parent and child;
- **Make** services more accessible;
- **Provide** a collaborative working structure for parents, professionals, service providers.

Nationally the HSE has committed substantial resources to children's services, although these resources are not always evenly distributed which makes for a compelling need to monitor and evaluate whether early intervention programmes are delivered to plan, implemented equitably and achieve a quality standard (Rush 2002).

This need was previously highlighted by a national survey on early intervention for young children with intellectual disabilities undertaken by namhi in 1995. Throughout the country many innovative approaches to service delivery are in place, but in the absence of any coherent national policy on the aims and outcomes of early intervention for young children with developmental delay. The strategic review of disability currently underway (Department of Health and Children 2006) is likely to identify the need for an integrated early children's service linked to disability legislative requirements.

Future service requirements

Regardless of the outcome of any review, the HSE has to ensure national operational policies can effectively address for parents what happens when a child with a disability is born in a maternity unit today:

- How is the information shared with parents?
- Do maternity units have in place agreed protocols for breaking the news?
- Are the protocols adhered to?
- Are parents linked with local services?
- Do local services assign a named person to work with the family?
- Is there clarity at a local level as to who does what?
- Is the local child surveillance service sufficiently well integrated to pick up children whose needs only unfold in the first and second year of life?
- Is there a home visiting programme available for a child with special needs?
- Are therapy services available?

Equity is a substantive underlying theme in all recent health and related publications (Department of Health 1994; Commission on the Status of People with Disabilities 1996). To achieve that equity, the HSE should:

- Ensure that resources reach parents as needed;
- Promote community awareness;
- Ensure a library of information is available to parents;
- Have in place individual programmes for each family;
- Source and, where necessary, support resources such as pre-school education in the community;
- Listen to parents;
- Ensure flexibility in service provision;
- Endeavour to customise the supports to a child in the family.

Conclusion

Early intervention services set out to:

- Enhance the development of children already exhibiting delays of known and unknown aetiology;
- Alter the developmental trajectory;
- Prevent secondary complications; and
- Prevent delays from occurring for children at risk (Guralnick 2004).

A child with special needs in the family presents real day-to-day concerns for parents. All interventions must take account of parents' needs in what is clearly a stressful period by listening carefully to their concerns and focussing on supporting them around their child's identified needs. Early intervention programmes are posited on the basis that there is a window of opportunity to optimise the child's receptivity and that an appropriate intervention will have long-term benefits for the child and the family. Clearly intervention services in the community must be adequately resourced and linked to effective follow-on educational programmes if observable gains are to be made, sustained and retained over time. The latter is far more problematic, given the absence of integrated accessible pre-school services.

Stephen Kealy

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St Catherine's Association Early Intervention Group

Introduction

In September 2004 the multidisciplinary team in St Catherine's agreed to run an Early Intervention Group for an initial block of six two-hour sessions on a weekly basis. We had identified a cohort of children who had similar communication and developmental needs. The speech and language therapist, together with the nursing department, designed the content of these sessions to facilitate development in the following areas:

- Early play skills
- Cognitive skills
- Communication.

A requirement for attendance in the group is that at least one parent/caregiver attends with the child. Following the initial group we requested feedback from the parents. Based on this feedback, along with our own evaluations on the children's progress, we continued to run group sessions throughout each term. In September 2005 we identified a need to run two separate groups because of the diverse needs and developmental levels of the children. The first group caters for seven children, all under three years of age. Three children attend the second group. We try to meet the varying specific needs of these children by the use of augmentative or alternative communication (AAC)—such as visual cues and Lámh. Evaluations are carried out at the end of each session.

At the end of a block of sessions we request parental feedback, comments and suggestions. These group sessions are supplemented with individual sessions as required.

Approaches used

The Hanen model is used. 'The Hanen model is based on the philosophy that language is best learned in the natural environment and that those involved with the communicatively impaired have continuous opportunities to promote the development of communication skills' (Watson 1994).

As the facilitators model the activities within the programme, the parents (who are the primary caregivers) are empowered to actually deliver the programme to their children.

The activities throughout each session aim to demonstrate how play and routines (which can also be practised at home) facilitate the development of the above areas. Play is one of the chief mediums for this.

Play is a powerful tool both for the development of cognitive skills and for communication. Maria Montessori described play as the child's work; Hanen's teaching reinforces this concept by use of the following:

- Getting down to the child's level
- Following the child's lead where appropriate
- Imitation
- Interpreting for the child
- Giving the child time to initiate or respond (Research has shown that it can take up to 14 seconds for our children to process incoming information.)

Through play children learn to:

- have fun, be sociable
- imitate
- problem-solve



- explore, and learn about the environment
- integrate many of the senses i.e., hear and see and feel.

Play offers opportunities for repetition and is not always dependent on words—gestures and actions can also be included.

Content of programmes

Socialisation

This encourages awareness of self and others, thus building self-esteem and interaction.

Listening and attention

This is a prerequisite for all learning. Activities include auditory attention, discrimination and matching games.

Pre-verbal skills

These include eye contact, imitation, turn-taking, joint attention and play.

All of the above skills are intrinsic to language acquisition and cognitive development.

Receptive and expressive language

The language targeted is taken from the Living Language Programme, commencing with single words comprehension. New vocabulary is introduced through the use of themes and reinforced through stories, pictures and games.

Books

It is widely recognised that books are a rich source of learning. Books encourage development of language, shared interests and bonding. Imagination, cognitive expansion.

In the group we encourage the parents to make a personal book for their child. This has proved a very successful activity. The children enjoy showing their book to the group. We also encourage adaptation of books to the children's language level.

Oral motor function

Strengthening of muscles in the oral area is vital for later development of sound production and verbal language. Fun exercises such as blowing, straws, blow football, banners and whistles are included in the group activities. Mirror work, including Mr Tongue story, licking exercises, humming and nonsense syllables are all included.

Sensory experiences

Children absorb concepts and information about the world around them through their senses. In the group

we encourage parents to allow the children to experience their environment through their senses. This fulfils the Montessori philosophy that the building up of intelligence is done through experience in the environment. We have done the following activities: tactile experiences with fabrics, sensory boards, play dough, brushing, painting, pouring and spooning. All our activities are visually stimulating; a favourite one which closes our sessions is 'the parachute'.

Auditory activities are included throughout our programme, including auditory matching and discrimination.

Movement is an integral component of the group. Children cannot sit still and must be allowed to move within a structured environment. We facilitate this by using motor activities and action songs. But mental development must be connected with movement and be dependent on it.' (Montessori 1949, p.130)

Taste and smell will be included in future sessions.

LÁMH

Lámh is a sign system designed for people with intellectual disabilities and communication needs in Ireland. The signs can be used to support a person's understanding of what is being said and/or as a means to express oneself or complement what one is attempting to say. Lámh can be used with both children and adults.

Research shows that the appropriate use of systems such as Lámh, accompanied by speech, improves communication skills in general (e.g. increasing interaction, developing language skills) and in many cases facilitates the development of spoken language. People will generally use speech if it is available to them.

Within the group activities emphasis is placed on the importance of routines. They provide opportunities for repetition of language and familiarisation with daily activities.

We have included time for a snack break in the middle of our programme to allow the children to rest. It is also a valuable time for the parents to chat. Staff supply the beverages and retreat!

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St Catherine's Association Ltd (formerly The County Wicklow Association for the Mentally Handicapped Ltd.) has provided Early Services since 1982. It now provides a comprehensive service to over 60 families in a variety of locations and settings. The service is for children from birth to four years, provided by a team specialising in the field of intellectual disability and developmental delay.

Referrals are usually made by a paediatrician, maternity hospital, public health nurse, area medical officer—or parents may contact the service directly. There is a referral policy in place.

Services are available at the following locations;

Bray Health Centre (first Tuesday of the month, 09.00–14.00)
Shillelagh Health Centre (second Tuesday of the month, 10.00–13.00).
Tinahely Health Centre (second Tuesday of the month, 14.00–16.00)
Aughrim Health Centre (third Tuesday of the month, 10.00–13.00)
Arklow Health Centre (third Thursday of the month, 10.00–13.00)
Wicklow Health Centre (fourth Thursday of the month, 09.00–14.00)
Donarea Lodge, Kilcoole, Co. Wicklow (This venue is designated full time to the provision of early services)

St Catherine's, Newcastle, Co. Wicklow (every Friday morning)
Additional services are home-based.

The service is provided by a multidisciplinary team:

- Psychologist
- Physiotherapist
- Nurse-Developmental Educator
- Speech/Language Therapist
- Occupational Therapist.

We are in the fortunate position of having the same therapists attend each of the clinics, thus enabling parents to have continuity, consistency and to build up a relationship of trust.

The available services include:

- Assessment
- Clinic- and home-based developmental programmes for infants and young children
- Information for parents—everything from information on disability issues to entitlements
- Swimming for parents and their young child
- Toy library facilities
- A named person available by telephone (24-hour service).

Susan and Saragh are part of the Early Services multidisciplinary team.

A review of early interventions for children with autism



For over 40 years there has been considerable interest in the provision of early intervention for children 'at risk' and for those with disabilities. The concept rose to prominence in the USA during the 1960s with the launch of the Head Start Programme that sought to enhance the development of young children from low-income families who were considered to be 'at risk'. In the areas of learning disability and autism various approaches make claims of almost miraculous cures for children with disabilities if they enter certain treatment programmes early. As with all such claims it is wise to proceed with caution and to look for the scientific evidence that supports these claims. If an approach sounds too good to be true, then it probably is not all that it claims to be. However, before I briefly review the effectiveness of some of the more commonly used approaches I first want to summarise the general beliefs behind the concept of early intervention.

The aim of early intervention is to enhance the cognitive, emotional and social skills of young children 'at risk' or with a disability such as a developmental delay or autism. Most of these children are known to have a developmental trajectory that is less than that of a normally developing child. For example, a child who is two years behind at three years of age, may be four years behind at six, and six years behind when s/he reaches nine years. In such circumstances the child at nine is said to have a mental age of three. The concept of mental age is not very useful beyond the teenage years, as people's mental age seems to reach a ceiling by the time they are 13–16 years of age. As is apparent, a relatively small difference between a child's actual age and his/her mental age early on is likely to become more pronounced with time unless intervention occurs. The hope of early intervention is to try and narrow this gap in development as soon as possible so that the child will develop along the same developmental line or trajectory as other normally developing

children. If intervention is delayed for one reason or another there is a belief that the gap may have become too wide to bridge. Also, there is a general assumption that the brain of a young child is far more amenable to change or has greater 'plasticity' than that of an older child. Most of the evidence for this assumption comes from research with animals where there are findings that suggest that early intervention can produce neurological changes in the developing brain. Based on these assumptions there has been an increased demand for the early recognition of developmental disorders, coupled with the delivery of effective interventions. The challenge, therefore, is to determine if these assumptions and beliefs are correct and to determine whether children who are diagnosed early and get interventions fare better than children who don't.

Obtaining valid and reliable answers to the above questions is a complex matter. The challenge for all of us who are interested in promoting the abilities of young children with disabilities is to distinguish between claims about interventions that work from the many false or essentially unverifiable claims. This has been the focus of scientific enquiry. There are various accepted scientific methods that enable us to determine whether a treatment is effective or not (see Bristol *et al*, 1996; Lonigan, Elbert and Johnson 1998; Green 1996).

Fortunately, a number of people have reviewed the existing literature on the effectiveness of different approaches commonly used with children with autism and have provided simple synopses of their findings. In 2002 Dr Linda Finnegan and Professor Alan Carr at University College Dublin (UCD) reviewed the literature concerning effective treatments for children with autism. Prof. Patricia Howlin, who is an advisor to the UK National Autistic Society, gave a summary of the current literature at the

NAS International Conference in London last September in her presentation on 'Assessing the effectiveness of early intervention programmes for young children with autism'. The last source is Prof. Richard Simpson and his colleagues at the University of Kansas who conducted a recent and detailed review of 40 commonly used approaches in the field of autism. Below I have attempted to summarise the evidence from the above sources concerning the most widely cited treatments. While each of these reviewers used different methods to determine the effectiveness of various interventions, there are, however considerable similarities in their conclusions.

Interventions and treatments are divided into those that are supported by good scientific evidence, those that show promise—but where the evidence is still limited, those where there is little or no convincing evidence to support them, and those that have tested negative or are clearly ineffective.

Treatments that are supported by good scientific evidence include various Applied Behavioural Analyses (ABA) approaches, such as Discrete Trial Teaching (DTT) and Pivotal Response Training, and Learning Experiences: an Alternative Programme for Preschoolers and Parents (LEAP). DTT came to prominence in the area of autism through the work of Prof. Ivar Lovaas at UCLA. DTT involves breaking tasks into small steps and then systematically teaching each of these steps using reinforcement until a certain criterion is reached before moving to the next step. Pivotal Response Training typically involves the careful selection of socially valid behaviours, which may be taught by modelling and their imitation reinforced, so that they are likely to help promote other skills not specifically taught. LEAP is an integrated 15 hours per week programme that uses behavioural techniques and which aims to develop play and interactional skills between preschool children with and without autism.

Interventions and treatments that show promise include Picture Exchange Communication System (PECS); incidental teaching; structured teaching; TEACCH (Treatment and Education of Autistic and related Communications handicapped Children); speech and language programmes, Circle of Friends; Hanen; augmentative alternative communication; assistive technology; joint action routines; play-oriented strategies; cognitive behavioural modification; cognitive learning strategies; social stories; social decision making strategies and sensory integration.

Limited or no supporting quality evidence exists for the following practices: Gentle Teaching; Option method (also known as the Son-Rise programme); Floor Time approach by Greenspan; pet/animal therapy; relationship development intervention; Van Dijk curricular approach; Fast ForWord; cognitive scripts; Cartooning; Power Cards; Scotopic Sensitivity Syndrome (Irlen lenses); Auditory Integration Training; megavitamins; special diets; herb, mineral and other supplement; music therapy and art therapy.

Treatments and interventions that are not supported by evidence or that have been shown to have a negative effect and accordingly are not recommended include Holding Therapy; Facilitated Communication and the use of the drug secretin.

In summary, the evidence indicates that early interventions that are based on behavioural principles, applied preferably both in preschool/school and at home, and that focus on a child's educational development can have a marked impact on the cognitive, behavioural and social adjustment of children with autism. There is no conclusive evidence to show that any

one behavioural approach is better than another, or to indicate the optimal level of intensity, duration, structure or age of onset. Prof. Howlin advocates that for early intervention to be most effective it should last at least six-months; involve at least 15 hours per week (though 20–30 hours may be optimal); have a high adult-staff ratio; involve specially trained teachers; and begin early (perhaps at 2 to 3 years of age). In addition, Finnegan and Carr (2002) recommend that there should be a highly collaborative working relationship between parents, teachers and clinical staff; that the educational programmes should be tailored to the child's individual needs; and that they should be well structured. Also, effective programmes should focus on enhancing skills in five key areas: 1) attending to aspects of the environment essential for learning, 2) imitation; 3) language usage; 4) imaginative play; and 5) social interaction.

Furthermore, the behavioural research literature indicates that slightly under half of the children who receive intensive early behavioural intervention will show very substantial gains in IQ and many will also show a substantial reduction in the expression of autistic behaviours. Most improvement in intellectual functioning, when it happens, seems to occur during the early stages of the programme (i.e., the first few months). Those who are most likely to make substantial gains appear to be children whose level of intellectual functioning was relatively good prior to the commencement of intervention (i.e. have an IQ of approximately 50 or higher). However, there is evidence to show that older children aged 4–7 years (Eikeseth et al. 2002) and a small number of children with very significant developmental delays do benefit considerably from early intensive behavioural intervention.

Mitchel Fleming

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Midlands artists MAKING FACES



Artists' names (clockwise):

- John McNally, Collinstown, Co. Westmeath
- Gareth Rynne, Castlepollard, Co. Westmeath
- Barry Lynch, Grouse Hall, Co. Cavan
- Tracy Maher, Ballynacargy, Co. Westmeath
- St Brigid by a group from St Peter's Centre, Castlepollard





Discourse and dialogue at Trinity

An exploration of contemporary Irish research in intellectual disabilities

Introduction

The School of Nursing and Midwifery of University of Dublin Trinity College held its 6th Annual Interdisciplinary Research Conference *Transforming Healthcare through Research, Education and Technology*, on 2–4 November 2005. The peer reviewed conference attracted a substantial range of international and inter-professional presenters and delegates. A full day's concurrent session on 3 November was devoted to contemporary research in intellectual disabilities.

This article summarises seven of the research studies that were presented at the conference and discusses common emerging themes.

The implementation of person-centred approaches to care in a residential setting in the Mid-Western region of Ireland (Carey 2005)

This paper described and analysed the processes devised and utilised by staff to implement a person-centred approach to care in a residential service in the Mid-Western region of Ireland. The degree to which the spiritual needs of the person are realised was also examined. The research design was mainly quantitative and informed by a qualitative component. From a population of 250 healthcare employees, 168 were sampled. A focus group interview and pilot study enabled the adaptation of an instrument devised by Holburn *et al.* (2000) and the development of an Indicators of Processes of Person-Centred Planning Scale (IPPCPS). The final draft of the IPPCPS was distributed to 147 healthcare employees.

Carey found that core systematic processes conducive to person-centred planning are operating in the residential centre. Systematic processes are in place to meet some of the spiritual needs of the person. However, she found there was a substantial lack of consideration for identifying the preferences and perspectives of people in relation to their quality of life issues. The residential centre is now challenged to move beyond their traditional approaches to care, i.e. 'protection' and 'mothering', to develop good practice guidelines ensuring person-centred care. To provide a holistic approach to care, staff need to ensure that care processes and practices embrace the person's perspective, preferences and aspirations, as defined by them in the context of quality living.

The attitudes of primary care givers to sexuality and people with intellectual disability (Drummond 2005)

This pilot-study that used a quantitative descriptive method investigated the attitudes of primary carers towards the sexuality of people with intellectual disability. The research focused on people attending two day-service sites run by one care provider in Ireland.

Drummond's review of the literature indicated that, whilst attitudes towards sexuality for people with intellectual disabilities have become more open in the past three decades, considerable barriers remain for those with intellectual disability in experiencing their sexuality positively. Staff consistently fail to facilitate these needs (Meera 2000; Walmsley 2000; Wolfe 1997; Aunos and Feldman 2002; Hamilton 2002; Johnson *et al.* 2000; Evans *et al.* 2003). This is confirmed by those adults with

intellectual disabilities who have demonstrated an understanding of personal relationships and sexuality (Caffrey 1992; Murray *et al.*, 2001; Christian *et al.*, 2002).

Forty-five primary carers (i.e. parents, siblings and care staff) of people with intellectual disabilities who attended rural and urban day services were sampled, using a self-administered postal questionnaire. Their attitudes were measured by the Sexual Attitudes Questionnaire-ID (the adapted GSAQ-LD developed by Karellou (2003a)). The instrument demonstrated good internal consistency and test-retest reliability.

Results from the study indicated that primary carers' attitudes were significantly influenced by their age, level of education, marital status and attitudes to religious attendance. Primary carers' who were younger and had a higher level of education tended to hold more open attitudes to sexuality generally, and for people with intellectual disability specifically. However, respondents tended to discriminate between groups. Primary carers who were single (i.e. 12 of the 45 people sampled) were less likely to discriminate than their non-single counterparts (i.e. 33 people). A clear relationship was also found between attitudes and religious attendance where more open attitudes were associated with lower levels of religious attendance. Primary carers were also found to vary in their overall acknowledgement of the sexuality of the person with intellectual disability, as compared to the general population, and they differed in their attitudes towards same-sex relationships for people with intellectual disability as compared to the general population. Contrary to findings in other research studies, gender, level of intellectual disability and geographical location were generally found to be insignificant.

Carers' perceptions of the support they provide to service users at the time of, and following, bereavement (Gilrane-McGarry 2005)

This study investigated the perceptions of the types of supports provided to an intellectual disability population at the time of, and following, bereavement by formal carers. Eleven participants took part in semi-structured interviews. The practical supports they provided to individuals (i.e. involvement in events surrounding the death and access to the rites of passage) were reported to be positive interventions, whereas the provision of emotional supports by staff (i.e. formal and informal supportive counselling) were cited by the participants to be sporadic. The use of alternative approaches (i.e. reminiscence work; the creation of a life story book/family tree, the use of art therapy and pictorial material) were also reported to be lacking. The findings highlight the need for education/training and leadership to provide staff on an ongoing basis with the insights, knowledge and skills necessary to practically and emotionally support people with intellectual disabilities who are facing loss and bereavement. In addition, these training needs should be aligned with ongoing managerial and specialist organisational support so that the specific needs of each member of this bereaved population can be fully addressed.

Meeting the mental health needs of people with an intellectual disability from a nurse's perspective (Hardy 2005)

The presence of mental health problems in people with learning disabilities is a relatively new concept. Historically it was not recognised that people with learning disabilities suffered from the same psychiatric disorders as the general population (Gravestock 1999). Though studies over the last thirty years have generally found higher rates of mental health problems in this population (Taylor *et al.* 2004; Borthwick-Duffy 1994; Corbett 1979), this increased prevalence is due to a combination of complex vulnerability factors including biological, psychological, social and developmental.

According to Hardy, the assessment of mental health problems in people with learning disabilities is fraught with difficulties. These difficulties include communication impairments, suggestibility, acquiescence and third-party reports. Care planning and treatment often need to be adapted to the particular needs of the person and his/her level of ability. The mental health care of this vulnerable and complex group is challenging and their needs are best met within an interdisciplinary framework, of which nurses are an integral part.

The role of the social model of disability in Irish intellectual disability nursing (Hartnett 2005).

The role of the social model of disability in Irish intellectual disability nursing from the perspectives of ten practitioners from the specialism. To generate deep rich data, in-depth interviewing was used. This data was then analysed utilising constant comparative analysis. The results showed evidence of aspects of the social model in participants' outlooks and work practices, but that the term 'social model' is not one which the majority used to describe this. Participants were able to identify limitations of the social model, in addition to ways in which the social model could further enhance intellectual disability nursing.

The study concluded that adopting aspects of the social model could facilitate Irish intellectual disability nursing to address some of the contemporary challenges it faces such as professional role confusion, and to maximise its contribution to disability service provision through a clear language, clear underlying values and networking with organisations supporting the social model (including the National Disability Authority).

Nurses' perceived and actual methods of communication when interacting with people with severe and profound intellectual disabilities who communicate non-verbally (Healy 2005).

For all people, developing and maintaining interpersonal relationships is vital. Individuals with severe/profound intellectual disabilities are likely to experience communication difficulties that impede such relationships. Investigators studying staff – service user interactions in settings for people with intellectual disability have generally found very low rates of interaction between individuals and staff members (Hile and Walbran, 1991). In addition, very little information is available about how nurses in day and residential services typically communicate with adults who have an intellectual disability.

An exploratory research design was employed using purposive sampling. Nurses perceived by the researcher to be knowledgeable about communication with persons with a severe to profound intellectual disability were invited to participate. The ten participants were asked to choose a person with whom they were familiar. A combination of data collection tools were

used, namely structured observation, individual interviews and focus group interviews. Thematic content analysis was utilised to analyse the individual and focus group data. SPSS (Scientific Package for Social Sciences) was used to analyse the observational data.

Healy (2005) found that the majority of staff felt continuing education and training in the area of communication would increase their confidence and competence. Staff used similar amounts of verbal and non-verbal methods of communication when interacting with people. Interestingly, some staff members were able to predict their method of communication, however, their actual use of communication appeared to be strongly influenced by the use of a 'teaching strategy'. In addition, the majority failed to recognise their use of some verbal and non-verbal signs of communication and also failed to adjust their language to meet people's needs. Environmental factors were highlighted as having an impact on communication. Negative and positive aspects of communication were also identified. Alternative methods of communication were examined and many participants suggested that these methods could be used in addition to verbal means of communication.

The intellectual disability nurse's knowledge and experience of interdisciplinary care (Hughes 2005).

This study examined what contribution(s) Registered Mental Handicap Nurses (RMHN) (now Registered Nurses – Intellectual Disability) (An Bord Altranais 2000) perceived they made to intellectual disability services. Within this study she explored their understanding and experience of interdisciplinary working and how this could be developed.

A qualitative approach was taken (Morse, 1994) using semi-structured open-ended interviews with 14 intellectual disability nurses (eleven women and three men) working in Irish intellectual disability services.

Eleven themes emerged from the data including: their meaning(s) of being an intellectual disability nurse and what distinguished them from other nurses working in intellectual disability services; their understanding of interdisciplinary working and the roles of other disciplines; the requirements for successful interdisciplinary working; the benefits and drawbacks of interdisciplinary working; pre-registration preparation for interdisciplinary working; the contribution of intellectual disability nurses to interdisciplinary working; and how they could enhance this.

More than half of the participants identified having a wide range of particular suitable skills for assessing the needs of people with intellectual disabilities and for providing holistic care. The diversity of RMHNs roles and role components were commented on and this was reflected by the composition of the sample of participants, their respective backgrounds, work experience and settings in which they were currently working and had worked previously. However, the participants did not articulate unequivocally the contribution that RMHNs have made to intellectual disability service provision. Similarly, there were few substantive comments about what distinguished RMHNs from other nurses working in the same field, even though most had worked with other nurses.

Most participants understood interdisciplinary working to mean different health and social care professionals working together. Some identified the professionals and non-professionals with whom they actually worked or envisaged as potential members of an intellectual disability team. However, with one exception, none spontaneously included the person

with intellectual disabilities.

The interchangeable use of the terms *interdisciplinary* and *multidisciplinary* by several participants, may indicate lack of knowledge of the differences in meaning. Many of the participants appeared to understand interdisciplinary working to include or to be synonymous with interdisciplinary team-working. However, formalised team-working structures and other strategies for promoting interdisciplinary working (Barr, 2001) did not seem to be in place in some of the services where participants worked, or were in place within particular settings within a service but not in others. It also appeared that the participants had few opportunities to work directly alongside other professionals or grades of staff other than care staff, especially those participants working in residential settings. Nevertheless, more than half of the participants stated that different opinions and expertise was enhancing the holistic, person-centred approach of service provision.

Hughes (2005) recommends the need to enhance interdisciplinary working in intellectual disability services. One way this can be achieved is by enabling staff to become more familiar with the terminology and concept of interdisciplinary working. The formalisation of team-working structures and other strategies for promoting interdisciplinary working should also be considered (Barr 2001). Increased opportunities to work with and participate in continuing education/training activities with other disciplines may also help to achieve mutual understanding of others' roles and develop skills of interdisciplinary working. RMHNs should consider how they can better articulate their role. This may be achieved through the development of assertiveness and confidence. Finally, at a policy level, there is a need to develop an agreed definition of interdisciplinary working, and further research to be undertaken into existing interdisciplinary working practices.

Discussion

Much of the research summarised above speaks for itself. While the issue of 'generalization of findings' may be problematic, a number of common themes are worth analysing further. For example, 1. the evidence of best practice and 2. people with intellectual disabilities are not always at the centre of their care. The latter is discussed first.

Carey (2005), Drummond (2005), Hughes (2005) and Gilrane-McGarry (2005) all highlighted areas where there was a limited focus given by carers to facilitating active participation by people in their own lives in ways which are defined by and meaningful to them. Among other things this raises fundamental issues about their human and other legal rights.

Hughes (2005) finding that only one of the fourteen Registered Nurses – Intellectual Disabilities mentioned the client as central to interdisciplinary care is concerning. Interdisciplinary working, or ideally inter-professional collaboration, involves different professions working and learning together in alliance with the client and significant carers / others with the primary purpose of facilitating the client to maximise, maintain or slow down the deterioration of, that person's well-being. There is a need for carers to further seek out and respond more effectively to the perspective(s) of the person's experience and aspirations.

Drummond (2005) implies that unless people with intellectual disabilities are included in discussions about their sexuality then the possibilities of addressing their needs effectively in this area are lost and their human and other legal rights with respect to intimate personal relationships and sexuality education are infringed.

Future Trinity Conferences are keen to attract a wider range of professionals and non-professionals, such as carers, parents / relatives and significant others to their prestigious and highly successful international conferences. Central to future conferences is their aspiration to engage people with intellectual disabilities more actively in the process as organisers, presenters and delegates.

Academics (myself included), service managers and carers appear better able to 'talk the talk', but their ability to 'walk the walk', appears to be lagging 'a little bit' behind. But perhaps there is a natural time lag in these matters. One can be heartened by the range of developments going on in services and the clear evidence of good and best practice identified in the research studies above. Examples include Carey (2005) and Gilrane-McGarry (2005). Carey (2005) found that core systematic processes conducive to person-centred planning are operating in a residential centre in the mid-west of Ireland thus ensuring that the foundations and processes exist for fostering and nurturing high quality individualised care. Secondly, Gilrane-McGarry (2005) found that a wide range of appropriate practical supports were evident when meeting the needs of people through the bereavement process.

Conclusion

The quality of research currently undertaken in the field of intellectual disabilities and the high level of dialogue it generated during and since the conference is commendable. This adds to the evidence that Irish researchers, in this case mainly RNID nurses, play a pivotal role in reaffirming, questioning and increasing the evidence / research base underpinning, reinforcing and developing practice.

The challenge for many researchers, whether academics or clinical practitioners, is to ensure that their work is not only published and scrutinized within renowned peer reviewed journals, but also made accessible to people with intellectual disability and their carers in ways which are meaningful and useful to them. Secondly, we have a responsibility to ensure findings and recommendations enhance education and training, policies and processes, management and leadership, so as to facilitate people in living the lives they choose to live and aspire too. This can only lead to developments in high quality person-centred care for this group of people. Secondly, this partnership between research and practice will go some way towards enhancing carer accountability i.e. their ability to describe what they do and do not do; their ability to provide appropriate rationale(s) for what they do or do not do and; their ability to articulate the research / evidence base underpinning and guiding their professional knowledge, practice and values, not just the common, shared knowledge/practice/values, but that which makes them unique from other carers – a uniqueness that is valued and necessary.

Further Information

Further research studies contained within the conference proceedings with relevance to Intellectual Disabilities include: Griffiths and McCabe (2005) on Communication; Gormley (2005) on Epilepsy; Harnett and Walls (2005) Development of Irish national best practice guidelines and training for informing families of their child's disability; and Keenan (2005) pre-registration intellectual disability nursing and social work education and training.

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Community and rights

Based on a keynote presentation given at the 'Rights and Responsibilities', 7th Annual Conference of the National Advocacy Council, Brothers of Charity Services, 8 November 2005, Galway Bay Hotel, Salthill

Background: The rise of rights as a remedy to societal mistreatment

The vocabulary of rights is all around us these days, as rights become more and more heralded as the antidote to all manner of injustices and oppressions of people. So, it should not surprise us that these are looked to by many groups seeking emancipation, be they women, minorities, immigrants, people with disabilities, abused children, the overweight, unemployed and so on. In some instances, these rights have even been transferred to animals. The basic theme is that the possession, assertion, clarification and education about or the enforcement of rights will empower and liberate sufficiently to overcome whatever societal devaluation and mistreatment of persons or groups has taken place.

Although many may not appreciate it, most formal charters of rights have only appeared and been promulgated in the second half of the twentieth century, beginning in the West, though some do go back into the time of the European Enlightenment period and even earlier. This assertion of the rights of the individual was deeply influential in the French, American and Russian revolutions. Rights in Judeo-Christian cultures were originally thought to be bestowed upon humankind by the Creator, in that humans were thought to be a reflection of the glory of God, and thus had an inviolable innate sacred value and worth, no matter what their standing in society. In this regard, the possession of a soul gave to each person a transcendent, indissoluble and eternal spiritual identity and responsibilities, the foremost of which was freedom and will, including the ultimate liberty of being able to turn against the Creator.

With the fall of God as the source of life and authority in the increasingly secularised affluent societies of the West in the twentieth century, there nonetheless remained an ongoing cultural legacy of Judeo-Christian values and outlooks in regards to how human beings were thought of, what was believed to be moral and just in their treatment, and a recognition of the need to anchor this perspective in law. The absence of a transcendent source of authority for such law, such as God had provided in earlier times, was resolved by the creation of the idea of 'natural justice'. 'Natural' justice was not specifically codified, as it remained obscure as to its origins and doctrines, yet its precepts were that human beings ought to be treated morally and largely consistently with earlier religiously sanctioned imperatives such as those contained in the Ten Commandments.

A kind of mystified Nature then served as an acceptable substitute for the fallen God's authority, and could become the morally legitimating basis for law, providing that the endowments of inherent and inalienable rights would underpin the worth and value of people. Anchored in national constitutions and various Bills of Rights, rights had both cultural and legal meanings, as is seen in the subtle distinctions between human and legal rights. People of other centuries would have been puzzled by these supposedly eternal 'rights', although they could easily understand them as claims upon common decency and fairness.

So, we now have a world in which many are persuaded that they have rights, that these should be exercised and respected, that social institutions ought to be tasked with upholding and respecting these, that the laws should entrench these, that they be enforced and that their simple assertion

will somehow automatically trigger the right response. These demands that rights ought to be respected are often more than just a claim that the law should be upheld, and may well mean a demand for people to be treated respectfully and with presumed entitlements that often go much beyond what laws actually require. In essence, these are cultural, rather than legal, claims. This is often seen in claims that service users ought to be listened to and taken into account. Few laws actually demand very much in this regard, but such claims coming from advocates may have significant moral, cultural and political weight, as they have the potential to morally embarrass officials who are seen to unduly leave people out of important public processes.

The capacity of communities to meet the demand for rights

An interesting question that many may not always consider in their enthusiasm to be sure that they become the champion of oppressed people, is whether communities can or will actually respond to such challenges, as it should be relatively obvious that the assertion of rights is often quite successfully ignored or subverted by many social institutions and the community as a whole, even in instances where the law technically upholds such claims. In some instances, the response to rights may be expedient, token, minimalist, uninspired, very grudging and spectacularly unrepentant, even in the face of otherwise logical and rationally persuasive evidence that people's claims to have been mistreated had absolute merit. Even genocidal killers and regimes have often complained that it is they who have been mistreated rather than their victims.

So, what may be at issue is the assumption that there is an inexorable linkage between the assertion of rights claims and a community's adherence to them. In other words, vigorous rights advocacy is, clearly, not always rewarded by an equally spirited compliance with rights. In fact, many skeptics undoubtedly believe that the same perversities simply continue, but under a new regime of making it appear that rights are being nominally respected, without addressing the actual essentials at issue. The capacity of communities and social institutions to self-correct and rehabilitate themselves in the way that advocates imagine should happen, may not fully take into account that what it would take to respond appropriately to rights demands, may not yet be present in sufficient force to guarantee the desired outcome.

In other words, it is suggested that communities and social institutions have not adequately cultivated within themselves that which would be foundational to the respect of rights. Therefore, any amount of external pounding on such entities will fail to yield what is sought, since it either does not exist, or exists in too weak a form, and cannot thus express itself in the manner that advocates would hope for—as the saying goes, 'One cannot get blood from a stone.'

Another way to look at this is to try to imagine a community in which advocacy would not normally be needed because people are temperamentally inclined, in most instances, to do and be the right thing. In such a community, obviously something has been nurtured in people, within its history, that renders them to be predictably and reliably disposed to treat people well over and over again, even in very trying circumstances, such that challenging them to do so becomes unnecessary. In essence, such communities will have embedded in themselves a culture of authentic respect for

people, so that their behavior is not one of possibly reluctant compliance to an external mandate to do the right thing, but rather a genuine building into people's character, of a possibly unconscious, but genuine, predisposition of respect for others, that may even appear to be instinctual rather than learned.

Communities, as described here, would be a delight for advocates to work with, because virtually all advocacy demands would elicit reasonable and constructive responses, and pledges made to improve conduct and performance would be pursued earnestly and in good faith. People and institutions would no longer have to be cajoled, persuaded, pressured or even threatened to do the right thing, as there would exist a bias towards upholding rights if at all possible.

If one could suspend judgment momentarily regarding whether such an idealised community appears too utopian or virtuous to even merit consideration as a realistic prospect, it would be worthwhile to first consider whether virtue can be cultivated in oneself or others. Much as there can be communities that expunge virtue and encourage malfeasance, decadence and disregard for the respectful treatment of human beings, there must be at least some where the opposite qualities have been upheld in people. Clearly, in the case of hugely oppressive communities, we are very aware of locations and times when communities have nurtured and given expression to the worst instincts in people, and have accordingly defamed and destroyed those who have attempted to uphold the right treatment of people. What may be less clear are the many communities in which the right thing occurs, but goes unnoticed and unappreciated because nothing dramatic or even miraculous is thought to have occurred. After all, why would anyone comment on the pleasing and commendable lack of sectarian killings, when such acts have been unheard of for generations.

This simply proves the point that virtues can be cultivated, internalised and institutionalised to such a degree that behaving in non-virtuous ways becomes rare and exceptional, much as we see vast differences in recorded levels of crime and antisocial conduct from one society to another. Logically, the underlying human nature of people, with its varying capacities for good or ill, will obviously remain a constant. Nonetheless, the precise expression of this nature will undoubtedly be shaped and fashioned by the values and outlook of that society, thereby strengthening some aspects of character and discouraging the growth of others. If this premise holds, then we would be in a position to identify what would be the traits and conduct that are consistent with respecting people's rights, and thus be able to self-consciously 'grow' them, much as the Japanese and Germans nations have, for several generations at least, hugely and measurably curbed their prior tendency towards imperial militarism by very deliberate strategies of changed conduct and outlook.

What is it that should be cultivated to enable rights to be sincerely respected?

It is essential to answer this question of what helps nurture and strengthen a disposition towards respecting and upholding the worth of people, particularly in regard to those people and groups who may face disproportionate risks of being socially devalued. If this tendency to devalue goes very deep, and with great antiquity in a culture, then its amelioration will need to be equally profound and long-lasting in order to counterbalance this tendency, substitute beneficial ones and nurture these into a critical and defining mass. What follows are some suggestions of what these 'desiderata' might be, and why this is so.

The cultivation of identification between people

People can identify with each other only when they can see something of themselves in others, particularly in others who may differ from themselves in significant and possibly very uncomfortable ways. To be able to be in the shoes of others, both imaginatively and practically, makes it far more likely that the 'other' becomes one of 'us'. Each is inherently eligible to become one's brother or sister.

The cultivation of compassion for (all) others

Compassion goes beyond seeing oneself in others, because it involves an obligation to act with kindness, concern and instrumental solidarity with others. Compassion is not simply a matter of feeling the pain of others, but rather it contains an imperative to act, where one can, to undo the suffering of others. One has compassion for others when one is part of healing the suffering of people much as in the commandment to love one another.

The cultivation of authentic supported social inclusion of potentially rejected people

If individuals and groups are so devalued by a community that they are not welcomed in all of the core social institutions of the society, then it is not hard to imagine that their rights will have little standing. On the other hand, if their place at the heart of community is assured beyond a doubt, then respect will flow as it should. Thus, social inclusion cannot be seen as a superfluous 'frill', as its presence is a necessary expression of what it means to truly belong.

The cultivation of values that emphasise a shared, universal and equal humanity

Whenever communities begin a process of dividing people into 'worthy' and 'unworthy' humanity, they inevitably begin to assign to some a sub-human status, with all of the inevitable detrimental effects that come with people's humanity being artificially lessened by cultural biases. At the same time, whenever people's identities and worth are perceived as inherently valuable, simply by right of being human, then it becomes impossible to abort girl babies in preference for males, to reward one class at the expense of another, and to waste the life potential of people whose impairments may require that communities adapt to their presence and needs.

The cultivation of 'right relationship' social ethics

'Right relationship' is a term drawn from Buddhist social ethics that refers to the obligation to be in relationships with people that are both ethical and honourable in how people are treated. In formal institutional and structural terms it means the presence of ethicality in the conditions of these relationships. Even if the organisational relationships are impersonal and distant, it is possible for these to nonetheless be ethical. These social ethics are deeply consonant with respect and rights, such that it is difficult to imagine rights thriving without them.

The cultivation of close personal relationships between potentially socially devalued people and those who are at less risk

If people are to be bound to each other, there must be very strong bonds formed between them. These cannot be achieved if people stay at a distance from each other, sequestered in isolated realities from each other. Personal relationships can offer a way to transcend huge differences between people, often in seemingly miraculous ways that permit a depth of knowing of the other that can overcome huge barriers. When people can respectfully become significant parts of each other's lives, it is hard to maintain an attitude of otherness, even when such relationships may be difficult.

The cultivation of a commitment to the common good

It is extremely common that when there is no restraint on people to take into consideration the wants and needs of others, then narrow, well positioned and selfish interests can well prevail over those who are vulnerable, easy to neglect or exploit, and who are comparatively without allies. An overarching commitment to the presence of an ethic of the common good helps constrain those who might act without regard for others. When this ethic is part of the operating obligations of community institutions, governments and others who operate in the public square, it constitutes a very useful safeguard for those whose status at the heart of society may be in question.

The cultivation of moral leadership

The good functioning of human affairs will always involve significant needs for leadership to be present, engaged and effective, whether this leadership is individual or collective. It is also critically important for the fate of vulnerable and disadvantaged people that society's formal and informal leaders are anchored in a compelling commitment to fairness and respect for vulnerable people. With such persons present, it is much more likely that our social institutions will do the right thing, whereas with unprincipled leaders, it is easy to imagine the unleashing of impulses that will harm people who are vulnerable.

The cultivation of substantive supports that would enable people to succeed

It is one thing to create a level playing field where opportunities are largely equally present for people to achieve their potential in life. However, if people do not have the practical supports they need to succeed, then such opportunities are nominal rather than functional in practice. A community that prefers actual progress for people, rather than symbolic gestures, would see great value in linking the crucial supports to opportunities that will make such opportunities bear fruit. A genuine respect for people means authentically engaging the practicalities of what ensures success, and doing what is required to sincerely overcome such difficulties, at least where there are efforts that are feasible.

The cultivation of an ongoing dialogue on what now constitutes a just society

Without regularly revisiting questions of values, respect, fairness and equity, it would be difficult for a community or society to continually re-examine itself and make corrections in its future course that would uphold its highest ideals. Such occasions may become pervasive in a community, and reflect an awareness and concern for the state of the people in its midst who may be detrimentally harmed by mistaken choices and directions. Unlike communities or societies where the claim is that 'there is no society', it is possible to have one where obligations to consider the well-being of others is seen as a logical part of the brotherhood of human beings and the creation of a commonwealth in which respect for people is foundational.

Communities need not be perfect nor ideal

It may be assumed by many people that the foregoing virtues and ideals are utopian, as actual communities and the people in them are far from ideal. This would be a realistic reservation because it would be unwise to ignore how fragile human beings and communities are in living up to their principles. So, asserting that they must be perfect is simply untenable given human history. Consequently, such a strategy of cultivation of respect for rights cannot be predicated on unrealistic

expectations of human nature and conduct. The same might be said for any number of other features of communities such as the presumed assumption that they are committed, clear, coherent, passionate, inspired, conscientious, dependable, flawless or whatever, as these wishful fantasies will only lead to disillusionment. Those who overstate or romanticise the virtues of communities must be careful, as they may well be looking at the world they prefer rather than the world as it really is. Such persons will ultimately mislead and disappoint.

The good news is that respect can be generated in individuals and communities even in the face of these and innumerable other limitations. This can be said because the strengthening of respect for others, if genuine and ongoing, will have effect even in the presence of these and other constraints. Put in another way, these barriers need not be fatal for the overall effort, as their effect may simply be to make the effort to invest in the good nature of people to be more difficult, rather than impractical in an absolute sense. The only way that such an investment would be fruitless would be if there were no good to build upon. It is inconceivable that no good whatsoever exists in both individuals and communities, so it is always a matter of building upon what is actually there to be built upon, irrespective of what will limit and constrain such good.

Providing that at least some people are genuine about core matters of respect for others, both individually and collectively, then their many errors, limitations, lapses and perversities can conceivably be absorbed and countered, such that vulnerable people are not placed in the kind of perpetual, unrelenting and damaging jeopardy that would quite properly provoke people into rights-based and other social justice movements.

Conclusion

It would have merit to investigate investments that lead to the strengthening of the 'right' things in people and communities that result in an ethic of respect for others, even if such communities start from a very degraded base. Even if these efforts are not substantial enough, even when linked with other independent efforts to achieve similar aims, this is not a reason to cease and desist, as even small initiatives are capable of a wholesome impact, providing they stem from genuine concern and commitment. Failure to fully transform society cannot be the basis for selecting strategies of change, as this may be impossible in any case. Rather, the real test should be genuine and specific beneficial impact rather than hoping for some sort of global and comprehensive panacea. Surely, this would be making the perfect, the enemy of the good.

The promise here is not some transcendental triumph, but rather that of taking actions in the real world that are intrinsically morally relevant, and which deeply confront our nature and institutions, and that challenge us to show the respect that we are capable of. It not an outrageous and unfair burden to place upon us, that we treat each other with respect, concern and fairness. So, those who dismiss investments in the improvement of our character, as being immaterial and ultimately futile, clearly do not recognise that humans have the capacity to be and do good, and should not be excused from this expectation.

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Personality and motivation in people with intellectual disabilities

If you ask any counsellor or psychotherapist who works with people who do not have intellectual disabilities what influences the behaviour and decisions of the people they work with, they will probably mention a number of factors including the person's relationships with other people, their personality, upbringing and their family history. It is unlikely that they would say 'cognitive functioning' or 'IQ'. And yet there is a widespread assumption that the behaviours of people with an intellectual disability are primarily the result of cognitive deficits. Furthermore, the dominance of behaviourism and behaviourally derived approaches to working with people with intellectual disabilities has tended to emphasise a 'one-size fits all' approach, the theory being that people's behaviour is most strongly influenced by external environmental contingencies and reinforcement, rather than anything internal to the person. Yet in the general population individual differences are seen as key issues in matters such as career choice, job satisfaction and relationship formation.

In the past four years there has been a small but growing body of research into the area of individual differences in people with intellectual disabilities. This is leading to some interesting developments in the area, including the assessment and prediction of compatibility of housemates with intellectual disabilities. For instance, Wiltz and Reiss (2003) found that they were able to distinguish between compatible and incompatible housemate pairs on the basis of their scores on a measure of motivation (Reiss Profile).

Research into the relationship between personality traits and particular psychiatric and behavioural disorders has also highlighted the relevance of personality and motivational assessment. Lecavalier and Tassé (2002) identified a group of people with intellectual disabilities who had psychiatric disorders such as anxiety and mood disorders or behaviour disorders such as self-injurious behaviour, using a high score on the Reiss Screen for Maladaptive Behavior. Secondly, they

identified a similar control group who had only an intellectual disability. They compared the two groups using a measure of personality and motivation and found significant differences in the two groups on eight of the fifteen subscales.

One of the most useful possible areas of development is in the analysis of motivation of challenging behaviours. Traditionally used methods such as the Motivational Assessment Scale have been hampered by difficulties such as low inter-rater reliability (different staff/family members not being able to agree on the motivation for the behaviour). It also allowed for only four possible interpretations as to the functional motivation of the challenging behaviour. The development of the Reiss Profile offers a more finely-tuned and individualised analysis of the motives of the individual who is being assessed that may be informative in interpreting the causes of the challenging behaviour. Though this work is still in its early stages and requires further validation and reliability analysis (and, in particular, the use of longitudinal studies), it does suggest a new and interesting development in work with people with intellectual disabilities.

The work on individual differences in motivation may help yield useful and practical insights in how to effectively reduce the incidence of challenging behaviour and increase the degree to which people with intellectual disabilities can lead full, integrated and rewarding lives.

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NATIONAL FEDERATION OF VOLUNTARY BODIES

Providing Services to People with Intellectual Disability

The National Federation of Voluntary Bodies is the national umbrella organisation for 61 voluntary/non-statutory agencies who provide direct services to over 20,000 people with intellectual disability and employ approximately 14,000 staff across a wide range of disciplines. The National Federation Research Sub-Committee was established in 2003 to promote applied research among the member organisations. The Research Sub-Committee aims to encourage inter-disciplinary and inter-agency research, and to disseminate the results so as to improve services and benefit people with disabilities and their families. In support of this goal, the National Federation Research Sub-Committee has agreed to provide research articles for each issue of *Frontline*, starting with the present issue. **Janet Swinburne**

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The introduction of formalised person-centred planning on a pilot basis in the Daughters of Charity Service

Introduction

A significant development and challenge in intellectual disability services is 'person-centredness', however, it is becoming widely recognised as a vital component of the overall quality of life for people with intellectual disability. Person-centred planning (PCP) is a concept that was developed in the late 1980s, designed to assist individuals with disability to achieve their dreams and aspirations (O'Brien and Lyle 1987). Person-centred means activities which are based upon what is important to the person from their perspective and can be simply defined as a way of discovering how a person wants to live their life and what supports they require to make this possible. The following is a reflective account about the development of person-centred planning on a pilot basis in the Daughters of Charity Service since June 2003.

Service context

The Daughters of Charity deliver services to people with intellectual disability through a mix of residential, respite, early services and day activation across ten sites in two separate geographical regions of Ireland. The decision to take the person-centred approach was made following an extensive review of the literature on quality of life in intellectual disabilities, culminating in the recommendation that PCP provided a framework for eliciting service users' personal dreams, aspirations and wishes, together with a means of working towards their achievement.

The PCP Journey

Following the decision to embark on person-centred planning, a project group was enacted with the goal of constructing a model/framework for its implementation. This process, which was guided by the seminal work of Sanderson (2000) and McIntosh (2004) led to the development of eight key principles to underpin the model.

Organisational awareness sessions were then undertaken for all stakeholders to:

- a) describe the concept of person centredness
- b) explain the key principles
- c) gain support for the process .

These sessions were undertaken at times to facilitate as many people as possible to attend. A significant number of stakeholders attended, which indicated to the service the great interest in PCP and it was encouraging that many family members attended.

The next step was to establish a steering group to guide and oversee its implementation. A project plan was developed and decided to embark on the following actions:

- define person centredness
- appoint project manager
- select pilot sites
- establish awareness campaign for all stakeholders in the

selected pilot sites

- identify essential system supports for pilot site/s
- agree documentation/tools
- identify development needs for pilot site run pilot.

While many definitions exist for PCP within the prescriptive literature, the following definition, which received widespread agreement, was developed in conjunction with service users as being the cornerstone of person centred planning within the service:

'Person centredness is about me, my life, my choice. It's having an action plan for my life where **I AM THE BOSS**. It's about focusing on my abilities, not my disabilities, and it is about finding out where I need help and support and getting my circle of friends and family to help me.'

A project manager was appointed whose main remit was to work towards the completion of the remainder of the action plan in conjunction with the steering group.

The selection of sites then began with some units/departments/service users indicating their immediate willingness to become involved, while in others a random selection of service users across the life span was undertaken. Specific targeted information sessions were held in all selected areas for service users, which were supplemented, as appropriate, with story boards/pictures to ensure that the sessions were user friendly. Each service user was then supported by a member of staff to select their circle of friends and facilitator to support them with their plan. A suite of established tools (such as Maps, Path, Essential Lifestyle Planning) were used to aid the development of the plan; however, each plan became unique to the individual service user. In total 35 service users are now engaged in developing their own person-centred plan.

Conclusion

The above is a short reflection of how this service undertook the concept of person centred planning. The concept has been embraced well within the service and is congruent with the core values of the Daughters of Charity service; however, like many other initiatives, some challenges emerged as the process developed. The difference between the already developed individual programme plans and the new concept was at times difficult for staff to identify. A specific concern for facilitators was the issue of ensuring that they truly represented the person and that their own aspirations for the person did not cloud their judgment. There was some caution if this process would be highly dependent on both human and financial resources. A further challenge emerged in that staff had concerns about facilitating the wishes, dreams or aspirations of service users who could not readily express their wishes, owing to communication or other difficulties. The process also highlighted the importance of allowing enough time to build relationships if plans were to be successful. Despite these challenges to date, one can confiden-

tially argue that the plans in progress currently do not require significant extra resources, but that on-going support and time for the process to evolve are essential. However, the project is new and we eagerly look forward to the final evaluation of this pilot project.

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Service: Daughters of Charity Service for Intellectual Disabilities, Dublin and Limerick.

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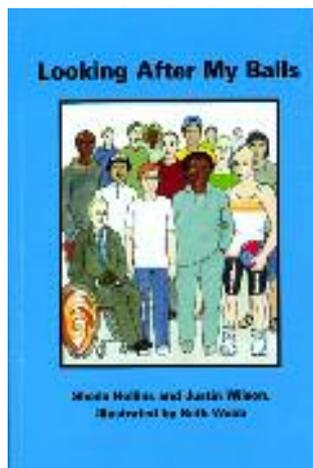
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LOOKING AFTER MY BALLS,

By Sheila Hollins and Justin Wilson

(Books Beyond Words series for people with Intellectual Disabilities)

Illustrations by Beth Webb.

(2004) Gaskell/St George's Hospital Medical School, London. Paperback ISBN 1 904671 05 5, £10.00.

This book received a commendation in the 2005 British Medical Association Awards.

In a world that is predominately visual, it is interesting that the written word is often valued as superior and bestowed a much higher status. This is not the case in *Looking after my balls*, an informative book designed to help men with intellectual disabilities to know more about their 'balls' (testicles) and about how to best care for them.

The book has two sections. The first 31 pages use colour illustrations only to tell the story of Tom, a young man with intellectual disabilities who discovers a lump while carrying out a routine testicular self-examination when in the shower. He seeks help immediately and attends the doctor. Following tests and an ultrasound scan, he is informed that the lump is benign. Section two of the book provides useful guidance on looking after one's testicles and what changes to look for. The book does not cover treatment for cancer. (This is addressed by *Getting on with cancer*, another very informative book in the highly praised *Books Beyond Words* series for people with intellectual disabilities.

The book is ideally suitable for anyone who prefers information conveyed through pictures or understands illustrations better than words; people with learning or communication difficulties; people with literacy problems and people for whom English is a second language where an interpreter is not available.

Good use is made of vivid colour and mime to display the changing emotions of each character as the story progresses. Although this is used to very good effect in the majority of pictures, there is one where this is not the case (page 31). This comment may seem petty, but it is an important one as the final illustration tells of Tom receiving the good news of his test results and therefore a critical climax to the story. While in the illustration the doctor is clearly pleased to inform Tom that the lump is not malignant, Tom's expression of relief is perhaps too subtle for the average reader, let alone a reader with intellectual disabilities. Tom's carer Danny looks gormless, apathetic and distant throughout some of the story, and is not an appropriate stereotype of support workers or professionals (although some readers may be able to identify one from their own caring experience!).

By using only illustrations, a carer is encouraged to sit down

with the person with intellectual disabilities and assist them to take the meaning they need from each picture. The carer is encouraged to allow the reader time to set his own pace and not necessarily go through the whole book on one occasion.

After the reader with intellectual disabilities discloses what they understand is going on in the story, the carer is encouraged to prompt the reader to explore each picture in greater depth so that a richer understanding is developed and enhanced. The authors suggest such prompts as:

- Who do you think that is?
- What is happening?
- What is he or she doing?
- How is he feeling now?
- Do you feel like that?

One may include one's own verbal prompts based on the assessed needs of the person being assisted, e.g. Have you ever felt like that and if so when?

For those readers and their carers who would rather not tell their own story of the pictures, an easy ready-made story is provided after the pictures.

Some people with intellectual disabilities may lose the thread of the story as they move through 31 pages. However a creative and sensitive carer should have no difficulty selecting a carefully chosen handful of manageable pictures to meet the reader's assessed needs.

Looking after my balls is culturally sensitive to the world in which people with intellectual disabilities live. A useful glossary of medical words is also provided near the back of the book.

While most symptoms of testicular cancer are covered in the book, a number of key symptoms are not highlighted, i.e. a build up of fluid within the scrotum, or blood in the semen which the person may notice when ejaculating; rarely, some men experience tenderness around their nipples. This may be due to the release of hormones that are produced by some testicular tumours, or because the cancer has spread to the chest area (NHS Direct 2006).

Pages i-vii, entitled 'How to look after my balls', are copyright-free and may be photocopied (provided the copies are used on a not-for-profit basis). I would strongly recommend that the editor of *FRONTLINE* and his board give serious consideration to publishing these pages within the magazine, to ensure this important health promotion material is seen by a wider audience. It is also available free of charge in a pdf leaflet format on

http://www.intelluadisability.info/leaflets/booklet_forweb.pdf

Professor Hollins and Consultant Wilson have, in collaboration with the illustrator Beth Webb, produced an excellent, informative testicular awareness book. They have tackled a complex issue clearly, sensitively and with considerable professional expertise. One of their primary intentions is to actively empower and engage the young person with intellectual disabilities in the health surveillance and health promotion process. They are to be commended for this. As noted above, this book is suitable for people with intellectual disabilities, their relatives, friends, supporters and advocates, teachers, social workers and health professionals, such as community nurses and GPs.

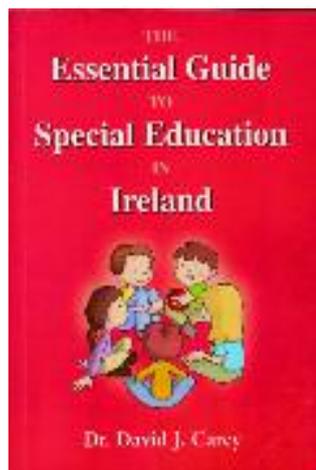
Reference:

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www.nhsdirect.nhs.uk/en.aspx?articleId=85§ionId=6138.

**Paul Michael Keenan, Lecturer,
School of Nursing and Midwifery, Trinity College Dublin**

THE ESSENTIAL GUIDE TO SPECIAL EDUCATION IN IRELAND,
by David J. Carey. (2005) Primary Abercorn House. Dublin ISBN 0-9545837-2-8 €15.99



At a period of rapid change in the area of special education in Ireland the publication of this reference book is timely. It takes a comprehensive look at special education from the assessment and identification of a child with special needs, through planning and teaching, to a review of new structures, new Department guidelines and new legislation which will define the area for years to come. It is written

with parents, teachers and students of colleges of education in mind. It does not assume previous knowledge; terms, special education conditions and a wealth of relevant information are explained in simple language. Furthermore, the layout of the book allows the reader who needs to access specific information to do so easily.

Following the Prologue, this guide is laid out in eight parts, dealing with assessment and planning; special education conditions; understanding special education; understanding the context of special education, using the curriculum and interventions; legislation, guidelines and structures; special education and the courts; reports of the Task Forces; and author's recommendations.

The process of establishing the specific nature of a child's special education condition or learning difficulty is set out by means of a staged approach to assessment. This is a clear guideline of good practice. In a case where referral to specialists outside the school is necessary, the referral process is clearly explained, including the roles of parents, principals, special education teachers, the SENO and the psychologist. Teachers will find the section on referral information particularly useful as Carey sets out a series of questions that need to be considered when referring a student for assessment.

The author then considers how assessment information is translated into educational practice with the drawing up of an Individual Education Plan (IEP). He lists nine points which, as a matter of best practice, should be contained in the IEP. Planning for children with behavioural problems is considered separately by means of a series of questions that the IEP team need to ask.

A detailed description of the nature, characteristics, signs and symptoms of the various special education conditions that are recognised as having an entitlement to special education in Ireland is set out in Part Two. This will be a useful reference for teachers as well as for parents. In each case the setting in which students with these conditions may receive support is detailed. Guidelines for the differentiation of instruction of students with exceptional ability/giftedness are also included in this section.

The focus of Part Three is understanding the student with a special education need and it goes on to consider the most appropriate response to that need. Carey discusses mainstreaming, integration, inclusion and segregation in the Irish context and concludes that the principle of least restrictive environment is central to appropriate special education provision. There fol-

lows an article that aims to help understanding of challenging behaviour and two articles specific to adolescents—on development, and on the occurrence of 'hidden disabilities' at secondary level.

The chapter on differentiating the curriculum is signalled as a 'need to know' for teachers. The principles outlined relate to differentiating the learning environment, the content, the process and the product for students with special needs. The author intends this to be a 'guide to thinking about special education rather than a reference guide'.

In the following three chapters, Carey provides a comprehensive review of recent legislation and Department guidelines, special education and the courts (detailing the O'Donoghue and Sinnott cases), and reports from the Autism Task Force and the Dyslexia Task Force.

The author's recommendations are offered in the final chapter. His recommendation that teachers must be given adequate time for planning, meetings and review of special educational provision during the school week will be welcomed by those who are attempting to provide an appropriate, quality education for students with special needs.

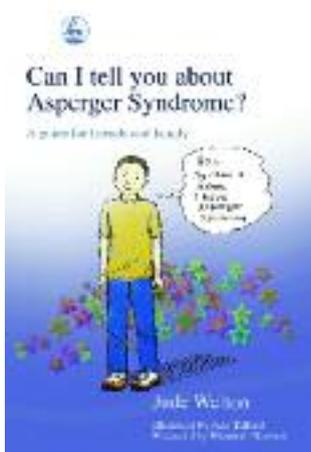
This is an informative guide to the area of special education in Ireland that will give a breadth of understanding to all interested readers. It is predicated on the author's uncompromising view that 'nothing is more important than children and that the needs of the children supersede the needs of the system and the people employed within the system.' This will, I have no doubt, encourage debate on existing processes and systems and the context in which they exist. It is important, I think, to question the rationale behind the system and to investigate if it serves students well.

Much of the information contained within the book relates to both the primary and secondary sectors. There are, however, fundamental differences between the sectors which I believe need to be debated. Some of these relate not only to provision of education to students with special needs, but to all students. Society has, by and large, defined success at second level in terms of academic achievement only, and this view is rarely challenged. In such an atmosphere the nurturing of the whole person needs to be supported by a strongly held philosophy, and systems and resources need to be put in place to support it. In relation to students with special needs, Carey acknowledges that 'the inclusion debate is as much a social debate as it is an educational debate'.

The chapter on using the curriculum contains many principles which should underlie the teaching of students at both primary and post primary level. It is based on the primary school 'child-friendly' curriculum and it raised many questions for me about how it might be applied effectively in the much more complex world of the post primary school. These questions relate to the ethos of the secondary system, the appropriateness of the curriculum to effect real development, both intellectual and social, and the commitment to supporting teachers to provide an integrated education to students with special needs. This book will have done students with special needs in post primary schools a great service if it raises these questions.

I would like to recommend this practical guide as one that is presented from a partnership perspective. Parents, teachers, and all involved in special education will find in it a philosophy which, if adopted, will improve the lot of children with special needs in Ireland.

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CAN I TELL YOU ABOUT ASPERGER'S SYNDROME? A guide for family and friends, by J. Welton (illustrated by Telford, J.) (2005). Jessica Kingsley Publishers, London. ISBN 1-84310-206-4.

This is a well-written and accessible volume. The author and illustrator achieve a pleasant balance with the use of simple language and a range of everyday images. As a parent of a child with Asperger's Syndrome (AS), I think that this book is a useful tool for other siblings, classmates and other members of the family—the text is specifically targeted at children aged 7 to 15 years of age. In some ways other siblings and cousins are forgotten in the everyday experience of AS. From my own parental and professional experience, siblings and other extended family members are very much affected by the Asperger's family dynamic, and this book goes a long way to include them in the explanation of the condition.

The book is divided into a number of two-page segments dealing with different aspects of the condition. Many of the issues addressed ring true to life—the author addresses the issues of dealing with loud noises, special-interest talents and difficulties. The book addresses the problems people with the condition have in dealing with change and the need for others to understand the special challenges they experience when working in groups.

The book closes with a section on 'how teachers can help', which is useful for professionals, family and friends alike, in trying to develop strategies to help a person with AS achieve their full potential. This is an excellent resource for anybody who may come into contact with AS and I believe parents of children with this condition should be guided to this volume before seeking answers on the internet or elsewhere. The book includes a catalogue of resources detailing further reading, websites and organisations that may be of help in learning to live with AS. This book makes an ideal companion to Jude Welton and Jane Telford's *What did you say? What do you mean? An illustrated guide to understanding metaphors*.

Paul Horan

LEARNING DISABILITY – A life cycle approach to valuing people, edited by Gordan Grant, Peter Goward, Malcolm Richardson and Paul Ramcharan (2005). Open University Press, Maidenhead. ISBN 978 0335 21439 6, Paperback. 7 978 0335 21826 4, Hardback.

The authors explore people's strengths and needs in the context of their natural bio-psycho-social growth and development through the lifespan. This is an important departure from the traditional textbook approach, which has generally focused narrowly on areas of specific need, such as challenging behaviour or epilepsy. By presenting knowledge in this way, Grant *et al.* provide the reader with a more holistic and authentic knowledge base for understanding people with intellectual disabilities.

The five sections are built round a small, but significant, number of narratives from people with intellectual disabilities. This rare and bold approach provides a richness and depth that most academic writing lacks. The juxtaposition and integration of carefully selected extracts with 'academic text' acknowledge the long ignored validity of this legitimate genre as an essential and valuable source of knowledge. What we as readers gain is a greater insight into the wide range of perspectives and experiences expressed by people with intellectual disabilities themselves.

While one would have liked to see a number of areas developed further—e.g. meeting the person's medical/surgical needs and the final section on care of the older person with intellectual disability—it should be acknowledged that research in these areas still remains limited. Secondly, even within a book of this size (757 pages), it is not always possible to give the same breadth and depth to each area. In saying that, the book is crammed full of useful research and references which guide and encourage the reader to seek out further material in special areas of interest.

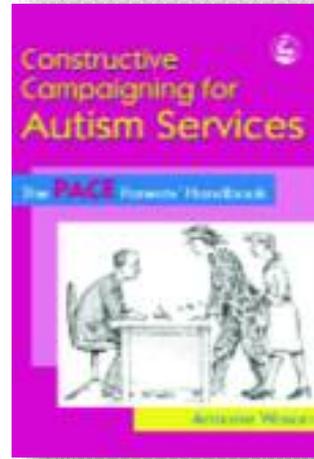
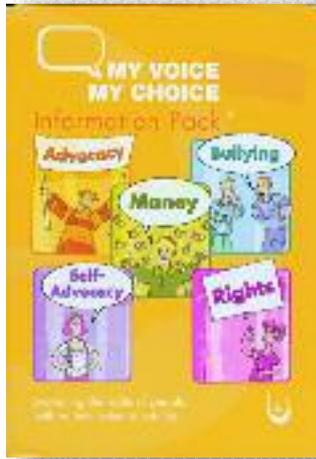
The authors state their primary aim is to serve two audiences: professionals updating their knowledge and understanding, and students new to the field. While the former group is well served by a wide range of contemporary source material, the latter group is less so. The book is pitched in parts at a level that assumes prior knowledge by the reader, which many students new to this field may not have. The oscillation between meeting the needs of both groups is not always successfully achieved, nor, it should be recognised, is this task normally easy to achieve. However, the authors have produced a major scholarly work that is clearly written and generally accessible. Read in conjunction with Gates' (2003) fourth edition *Learning Disabilities: Towards Inclusion* (a marked improvement on the third edition), both the student and professional are now well served with two core texts in this area.

The authors are to be highly commended for the depth and breadth of their work and for the rare achievement of successfully placing the perspectives of people with intellectual disabilities at the centre of our learning. I highly recommend this book.

**Paul Keenan,
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Trinity College Dublin**

Reference

Gates, B. (ed.) 2003 *Learning disabilities: towards inclusion* (4th edition). Edinburgh. Churchill Livingstone.



MY VOICE MY CHOICE: Information Pack published by namhi (funded and supported by Comhairle.) Illustrations by Steve Simpson, designed by the Newworld Group. €50.

My Voice My Choice is a series of five, 6-page booklets on advocacy, self-advocacy, money, rights, and bullying, with an accompanying CD-ROM. The aim of this publication is to promote the rights of people with an intellectual disability.

The CD-ROM and booklets are colourful, helpful, precise and concise. They are a good investment for any service setting for people with intellectual disabilities who endeavour to promote advocacy and self-advocacy and self-determination in their settings.

The CD-ROM is responsive and easy to use, as well as being fun and informative. Congratulations to namhi for producing this important document at a time when the NDA has launched guidelines in person-centred planning and there is a spirit of unison on the importance of civil rights and upholding self-determination. This information pack was given to a group of service users to elicit their feedback, which included remarks such as:

'I really liked working with the CD. It helped me learn that the DA is my money and I can have it if I want to', 'I don't like it when people shout at me ... that's bullying, like it says in the blue book.'

'I have my rights too, and now it is my turn to say so.'

Kathy O'Grady,
Senior Psychologist.
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CONSTRUCTIVE CAMPAIGNING FOR AUTISM SERVICE: the PACE parents handbook, by Armorer Wason. Jessica Kingsley Publishers, London. ISBN 1-84310-387-7 £11.99

'I heard a parent give a talk on "managing challenging behaviour". She was talking about the challenging behaviour of the professionals. She described how parents have to cope with a triad of impairments: health, education and social services, and gave some excellent examples of what the challenging behaviour of professionals can lead to.'

The above extract is taken from the book *Constructive campaigning for autism service*, a handbook written primarily for and by parents of children with autism living in England and Wales. The book contains examples of how parents have successfully campaigned for services, as well as problems and failures experienced by others. Effective communication and respect between professionals and parents is highlighted.

This book is simply written and shows how parents can make a difference. It explains that campaigning is not a negative word, but rather an organised and positive course of action.

Don't let the facts and figures applicable to England and Wales put you off, as the author does offer excellent advice on campaigning for services, no matter where you live. If you are a parent of a child on the autistic spectrum, and you want to fight for change, this book is for you.

Helen Doyle

frontline
reviews

EUROPE IN ACTION 2006

This year, the *Europe in Action 2006* conference was held in Brussels (Belgium) at the Tulip Inn Boulevard Hotel from 18–20 May 2006. Together with ANAMH asbi / NVHVG (Inclusion Ireland's equivalent in Brussels), Inclusion Europe hosted the three-day conference. The theme of this year's conference was "Learning all our lives: Continuing learning opportunities for adults with intellectual disabilities as a step towards non-discrimination".

The conference identified objectives and needs of adult education. Different models of adult education were presented at the conference, enabling those attending to

learn from positive experiences and best practices in the field. The conference also paid special attention to the needs and situation of people with intellectual disabilities in central and eastern European countries where people with intellectual disability are often excluded from primary school education.

Special care was taken to make the conference accessible for people with intellectual disabilities. A detailed programme, and all practical information are available on the *Europe in Action* website at www.europeinaction.org.

Ian Redmond, Inclusion Ireland.

