

# the frontline

OF LEARNING DISABILITY



Team Ireland at the Special Olympics  
*Jonix Educational Services*  
Cautionary Tales

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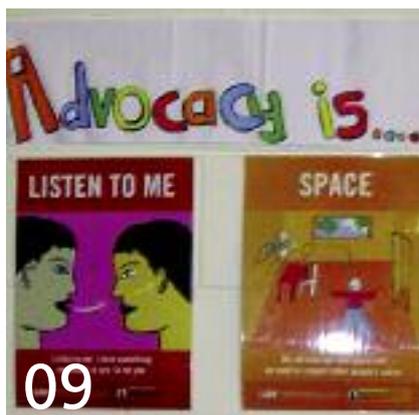
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## Times of change



*“The issue includes two academic articles—one by Steven Gannon exploring the complex attitudes in schools to children with Down Syndrome, and one by Michael Kendrick challenging the authenticity and success of the person-centred approaches in fashion today.”*

THIS ISSUE OF *Frontline* has advocacy as a central focus throughout. The main advocacy pages report on the successful National Advocacy Conference in Clonmel, which called for the closure of institutions, and a more localised project: IAM (Interagency Advocacy Movement), which is aimed at teaching service users to become advocacy champions. Another form of advocacy is reported in ‘Cautionary Tales’—Mary de Paor’s summary of Inclusion Ireland’s Parents’ Seminar last November.

Two articles provide insights into the demands facing young families today—the Jonix pre-school service (a private venture) that caters for children with ASD, language or developmental delay; and an article from the US exploring parenting and employment.

The issue includes two academic articles—one by Steven Gannon exploring the complex attitudes in schools to children with Down Syndrome, and one by Michael Kendrick challenging the authenticity and success of the person-centred approaches in fashion today.

We have a report on Team Ireland’s participation in the Special Olympics World Summer Games in China—with some ‘exclusive’ photos.

New ideas in this issue include ‘Changing Places’ toilets to provide improved access for people with intellectual disability, and Áthas Creative Art Therapies which are not for ‘art’, but a triangular relationship between therapist, client and invoked images.

Given the recent concerns at national level about breast cancer services, Liz McKeon’s article (Looking after your breasts) provides a to-the-point outline of health care in this important area—too often overlooked for people with intellectual disabilities. There are reviews of two Irish publications—one on Mothering Special needs, by Anna Karin Kingston, and one describing Avril Webster’s series of ‘Once upon a time—Off we go’ books.

Finally, the usual subscription details have not been included on the back cover of this issue. After two decades with publishers Wordwell, the magazine needs to find a new home. Our sincere thanks to our Wordwell, who have indeed been valuable friends. The appearance of Issue 72 may be delayed as we finalise new publishing arrangements, but all current subscriptions will be honoured—and we hope to attract many new ones!

**Michael McKeon**

## Law relating to people with an intellectual disability must be updated

Ireland's position regarding capacity and people with an intellectual disability dates back to the Lunacy Act of 1871.

Cases concerning sexual assault of people with an intellectual disability are not brought forward for prosecution because of capacity issues and people with an intellectual disability giving evidence.

Person with an intellectual disability cannot currently have their child adopted. 'Legal issues surrounding consent and people with an intellectual disability must be immediately examined by the Government,' says Inclusion Ireland CEO, Deirdre Carroll. Ms Carroll was speaking following the launch of the Law Reform Commission's Third Programme of Law Reform 2008-2014 which, among other issues, proposes to examine the law surrounding consent to sexual contact, how people with an intellectual disability are dealt with in the court process, and standards for carers.

'I welcome the Commission's latest Programme of Law Reform. The relationship between people with an intellectual disability and the law is outdated in many areas. Ireland's current position in relation to capacity and people with an intellectual disability dates back to the Lunacy Act of 1871. While the Mental Capacity and Guardianship Bill 2007 was introduced as a private member's Bill in the Seanad in February 2007, it has not yet been finalised. Lack of progress in this area means Ireland may be out of line with the UN Convention on the Rights of Persons with Disabilities, to which Ireland is a signatory.

'The issue of consent and sexual contact must also be urgently addressed. Every year we see cases concerning sexual assault of people with an intellectual disability being brought to the attention of the DPP, which are not brought forward for prosecution because of capacity issues and people with an intellectual disability giving evidence and this should be urgently examined.'

Inclusion Ireland campaigns for the law to be updated in many respects. Staff member Sarah Lennon is currently working on a project looking specifically at the area of legal capacity and consent. She says: 'The law relating to sexual relationships and people with an intellectual disability must be urgently updated. The Criminal Law (Sexual Offences) Act 1993 Section 5 criminalises certain consensual sexual acts. The extension of the law to those who cannot live an independent life is overly restrictive. On the other hand, the failure of the provision to criminalise acts up to, but not including, sexual intercourse may fail to protect the vulnerable groups to which the act pertains. Also, the current situation whereby a person with an intellectual disability cannot have their child adopted (as they are deemed to lack capacity) is causing distress to many people. This issue is especially pertinent as it is not covered in the Mental Capacity and Guardianship Bill, nor is it addressed in the Programme for Law Reform.'

Deirdre Carroll adds, 'We simply cannot afford to wait any longer. The law must be updated now and it is the Government's responsibility to make sure this is done.'

### Extracts from the Law Reform Commission Report: Third Programme of Law Reform 2008-2014

*(Section C: Criminal Law, p.13)*

#### 12) The law of Sexual Offences

This project will involve a general examination of the law of sexual offences. It will build on previous work by the Commission, which resulted in some legislative reforms. The project will include an examination of consent to sexual contact and whether there should be a statutory definition of the term 'consent'. The project will also explore the extent to which the law in this area can be consolidated.

#### 14) Vulnerable Persons and the Criminal Justice System

This project will examine how vulnerable persons, including those who are vulnerable arising from limited intellectual capacity, are dealt with in the criminal justice system in Ireland. The project will examine how vulnerable persons are treated before, during and after the court process.

*Section F: Specific Groups in a Changing Society (p. 16)*

#### 29) Legal Aspects of Carers

This project will examine the extent to which the current law ensures appropriate standards for professional carers, in particular those engaged in the provision of care to vulnerable persons. The Commission will ensure that this project takes full account of the work of the Health Information and Quality Authority (HIQA).

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## National Intellectual Disability Database: Summary of annual report 2007

The National Intellectual Disability Database was established in 1995. The information stored on the database is intended to assist the Health Service Executive and non-statutory agencies in Ireland when making decisions regarding services for people with intellectual disability. Currently there are over 25,000 registrations on the database. The type of information stored includes personal details, current service provision, multidisciplinary support services and future service requirements. Since its founding, ten reports have been published and this summary intends to give an indication of some of the main findings of this year's report. These findings should be read keeping in mind the changes in Ireland in recent times. For example, the 2006 census showed that Ireland has had an increase of over 8% in population in four years, the largest of any EU country. As Ireland's population is increasing in size, so are the numbers of people registered on the database. We also have an older population and we can see this trend mirrored with people with intellectual disability who are living longer owing to improved health and general well being.

This year the Annual Report of the National Disability Database Committee utilises data collected during 2007, thus providing the most recent data available to assist in decision making. The main findings of the report are in relation to the provision of day care and full time residential services. The

provision of full time residential services is the highest since 1995—up 3% on 2006. However, there is still a large demand for residential places, with 2118 people waiting. It is expected that this need will continue due to our population growth, high birth rates in the 1960s and 1970s, and the fact that people with intellectual disabilities are living longer. In relation to day services, the news is good in that very few people are now waiting and the numbers of day places required are reducing each year. With regard to future needs, there are 2430 people who either do not have a service at the moment or who need additional services; this represents a 2% increase since 2006. So despite recent efforts to improve and increase services, the demand has still not been met. The rate of increase is not keeping pace with the increased needs of people with intellectual disabilities.

In the area of residential support services, again we see an increase in the number of supports available, but also an increase in demand. There has been a 7% improvement in the availability of services such as respite and emergency residential care. While 5000 people currently have access to these services, a significantly larger number of people will require these services in the next ten years. Generally speaking those who have a current respite or emergency service will still need it and a significant number will require a changed or enhanced service. In relation to those people inappropriately placed in mental health services, the report has identified that 207 people need to be transferred to a location which offers them accommodation suitable to their needs.

In summary, this report has highlighted both the increase in service provision, but also the increase in service requirements for people with intellectual disability. Full reports can be downloaded from the Health Research Boards website, <http://hrb.webhost.heanet.ie>.

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#### Reference

Kelly, F., Kelly, C. and Craig, S. 2007 *Annual Report of the National Intellectual Disability Database Committee 2007*  
Dublin: Health Research Board.

## Inclusion Ireland's 2008 AGM and annual conference

ICTU General Secretary David Begg, Tánaiste Brian Cowen and RTÉ's Seán O'Rourke will be among those taking part in Inclusion Ireland's 2008 AGM and Annual Conference in the Tullamore Court Hotel, Tullamore, Co. Offaly on 11-12 April 2008. Mr. O'Rourke will chair a panel of local politicians from across party lines on Friday evening, 11 April, following the official opening of the conference. Politicians taking part will include front-bench opposition spokespeople as well as government TDs who chair Oireachtas committees.

The theme of this year's AGM will be 'Is it getting better for people with a disability?' The conference keynote speech,



Ms Finula Garrahy will open the 2008 Inclusion Ireland AGM & Conference.

at the Saturday morning session, will be given by David Begg of the Irish Congress of Trade Unions. Other speakers will include Brendan Broderick, Chairperson of the National Federation of Voluntary Bodies, who will make a presentation on 'best practice guidelines for informing families of their child's disability', as well as a series of four speakers on the theme 'From service user to citizen'. These speakers will include Karina Wallis, Sisters of Charity of Jesus and Mary Services; Alicia Woods, Associate Consultant, Paradigm, UK; Kathryn Stiles, Principal Psychologist, KARE; and Mildred Dillon of the County Offaly Parents and Friends Association. Media and Advocacy Awards will also be presented, as will the 'John Ryan Award'. The AGM will close with a dinner dance on Saturday evening.

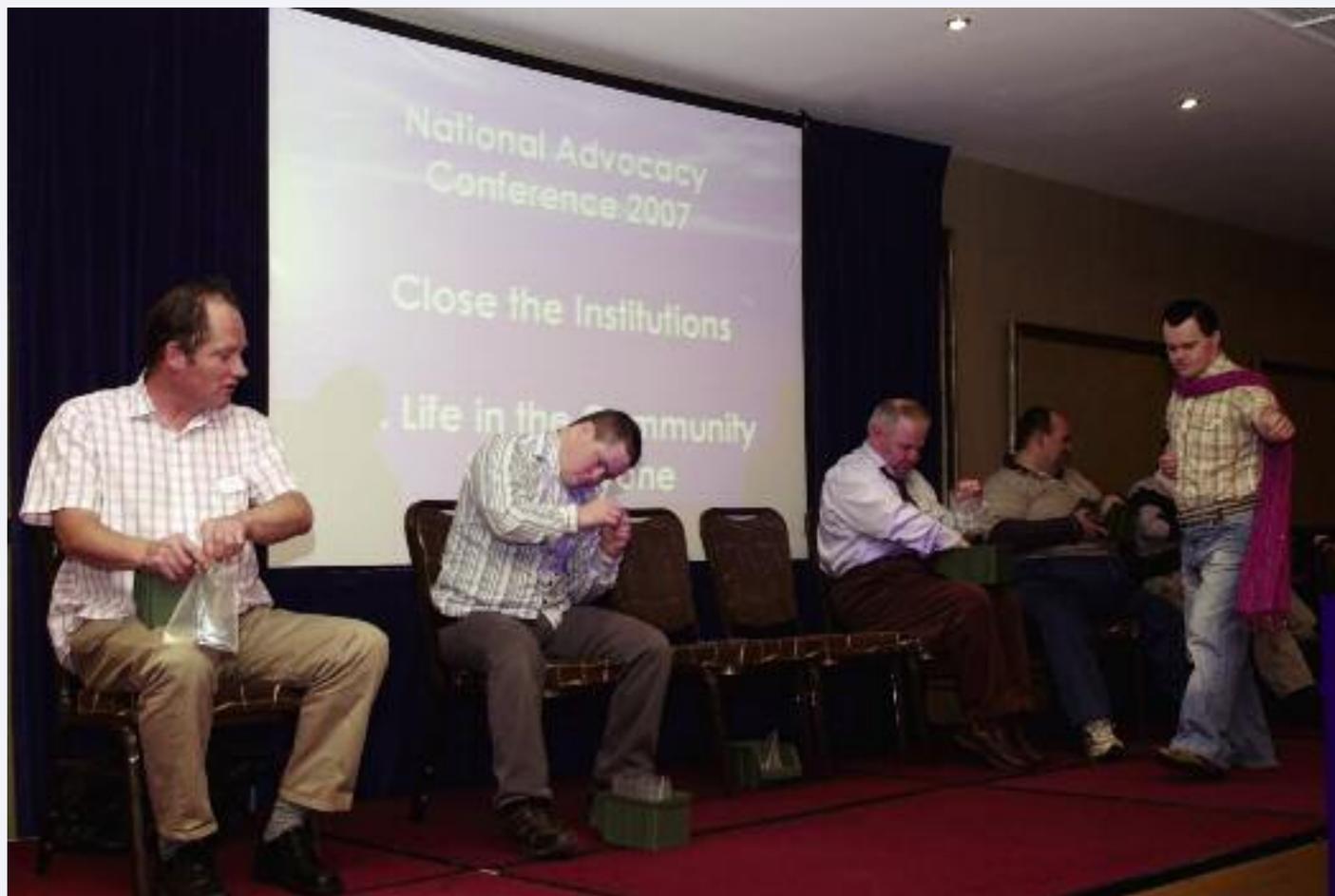
## Advisory group on standards in service

Inclusion Ireland is a member of the Standards Advisory Group which has been set up by the Health Information and Quality Authority (HIQA). The establishment of this advisory group on standards in services for people with an intellectual disability is a very welcome development. This follows the completion of draft standards for services for people with an intellectual disability, which were produced by the Department of Health and Children and the National Disability Authority (NDA) in March 2005. The consultation process on these draft standards was initiated by the NDA in 2002. However, no standards are currently in place in services.

Deirdre Carroll of Inclusion Ireland says 'we cannot afford to wait any longer for standards to be implemented. If we are to ensure that people with an intellectual disability are to have a decent quality of life in an environment where we can ensure they are safe and protected, then standards are vital. Inclusion Ireland again raised this issue in December when a report on abuse in a Galway service was published. Consultation on standards was initiated six years ago, but still no standards are in place. Inclusion Ireland has been calling for the introduction of national standards and inspection of residential centres and community homes for children and adults with disabilities since the mid-1990s. We welcome the development of the Standards Advisory Group, but we will continue to push hard for standards to be implemented as soon as possible.'

**Siobhán Kane,**  
Communications & Information Officer,  
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# *National Advocacy Conference calls for closure of institutions*



The Brothers of Charity Services' National Advocacy Conference in Clonmel has highlighted the wishes of intellectually disabled people to live full and independent lives as active members of their local communities. The conference, which had as its theme 'Close the institutions: A life In the community for everyone', took place over two days at the Clonmel Park Hotel and was attended by over 300 people with intellectual disabilities. During the conference, delegates heard from other people with a learning disability who shared their stories and experiences of living both in institutions and in communities.

The conference was opened by Dr Jimmy Devins, TD, Minister of State at the Department of Health and Children with

special responsibility for disability and mental health. He spoke about the importance of advocacy for people with disabilities who need support from time to time to voice their opinions. This, along with the need to close the institutions, was a theme that ran throughout the conference, with service users reiterating that they want to be heard and have the right to make decisions about their own lives.

Brian McClean, Principal Clinical Psychologist with Brothers of Charity Services Roscommon, and John Caslin, who is supported by Brothers of Charity services in Roscommon, together presented a film John had made as he revisited the various



institutions where he had lived throughout his life. During his introduction, Dr McClean highlighted the extent of the problem of institutionalising people in Ireland: according to a recent study, 49 per cent of Irish people with intellectual disability who currently live in residential services are in large residential centres. In England, Scotland and Norway, all such institutions have closed. Dr McClean pointed out that in England, people with intellectual disabilities and their families prefer residential care in small houses, as it allows people to live within a community and to benefit from the wider social networks. It was also found in England that more medication was used in large institutions, where the treatment is less personal and more routine-based.

During the conference, the delegates heard from many people with a learning disability about their experiences, and how they can become active citizens and self-advocates. Among the presentations was one by Larry O'Bryan, who receives supports from Brothers of Charity Services (Clare). Larry moved to his house in Kilrush from Bristol in the UK. Larry, who has autism, used to live in big institutions in the UK, which he described as 'sheer hell', before moving to smaller residential care in the UK. After visiting Ireland on holiday, he decided he wanted to live in West Clare.

Although he does not communicate verbally, Larry is now happy living as part of the local community in Kilrush and Kilkee, where he is a member of the church choir and the Clare Poets Circle. As Larry spelled out on his keyboard: 'There is a light at the end of the tunnel for me when people listen.'

The Conference closed with a question-and-answer session chaired by RTÉ chat-show host, Ryan Tubridy. The panel included Winifred O'Hanrahan, National Director of Services, Brothers of Charity Services Ireland; Carol Moore, HSE South; Niall Byrne, Cheshire Ireland; Cllr Richie Molloy, Mayor of Clonmel; Derek Watson and Timothy O'Connell, Seasamh Parliament; Claire Maher, joint Chair of the Regional Advocacy Committee; Mary Meaney, NDA, and Brian O'Donnell, National Federation of Voluntary Bodies. They answered questions which had been submitted by service users ahead of



the conference. Ryan Tubridy gave the audience an opportunity to ask questions directly to the panel. The questions served to demonstrate how passionately service users feel about institutionalisation and advocacy. They sought information about when all institutions in Ireland would be closed, why some community houses are almost like institutions, when service users will be paid a fair wage for the work they do, and how to get people to listen to their opinions and make changes.

Those attending the conference were told that one step towards getting the opinions of people with intellectual disabilities heard was by forwarding the lobbying cards supplied at the Conference to the Taoiseach Bertie Ahern, calling for an end to institutions. Cabríní de Barra, Advocacy and Evaluation Training Officer with Brothers of Charity Services South East, said:

*'The conference was a great success and once again goes to show that people with intellectual disabilities just want the same opportunities, rights, and access to service as everyone else. The conference is also a great way for our service users from around the country to meet together and swap ideas, experiences, and hopes for the future.'*

The Brothers of Charity Services continue to strive towards supporting people with a learning disability to live full, independent lives as active members of the community. 'Ending the institutional practices, structures and supports in Ireland would create an opportunity for people with disabilities to live ordinary lives where they can contribute to the life of local communities,' Cabríní de Barra said.

**Liza Kelly**  
**Advocacy Officer, Inclusion Ireland**



# I AM: Interagency Advocacy Movement The Advocacy Champion Programme

*'When people who are not used to speaking out are heard by people who are not used to listening, then real changes can happen'* (John O'Brien).



This innovative project, funded by the Citizens Information Board (formerly Comhairle) commenced in September 2006. It is aimed at up-skilling service users to become 'Advocacy Champions'—agents of change within their own organisations, with a view to contributing to the further development of systems and cultures of advocacy within each agency. The programme involves members from the Interagency Advocacy Movement, which over the last three years has organised a variety of initiatives including conferences, research, the development of an educational ten-poster set, an advocacy charter, advocacy workshops, and a series of education sessions in Trinity College for people with intellectual disabilities.

As part of the current project, training is being offered to service users (advocacy champions), their staff supports (mentors) and to members of agency management teams. The Advocacy Champions training is being provided by staff and students from the School of Occupational Therapy in Trinity College, Dublin, and is focussed on developing problem solving, team building, listening and critical analytical skills, as well as inter-agency networking for service users. One outcome of the training to date is that many of the Advocacy Champions have commenced challenging some of the existing ways that they have been able to voice their satisfaction and complaints. There is also a reported increase in peer advocacy, with some service users gaining confidence and skills to think beyond their own individual needs to include those of their peers.

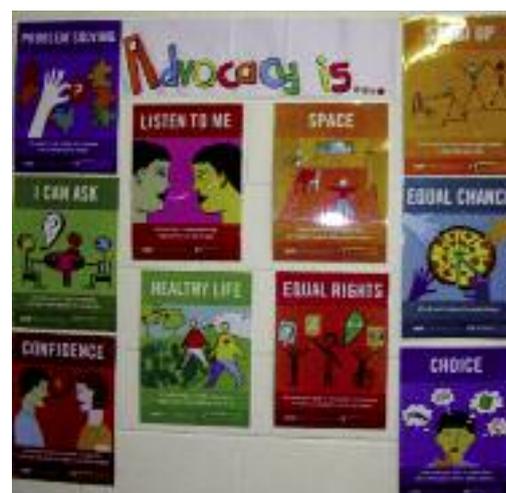
Training for advocacy mentors, which is being provided by Gogarty Consulting, is aimed at enabling staff to lend further support to the Advocacy Champions, to up-skill staff in their knowledge of advocacy, and to challenge thinking and ways of operating, while also allowing a forum to network and share ideas, problems and constraints with other mentors. Management training, provided by Gogarty Consulting and Inclusion Ireland, is focused on providing a detailed examination, practical understanding, knowledge and insight into the area of advocacy, with specific emphasis on agency or organisational advocacy-related change. In addition to the provision of advocacy-related training, another aim of the project is to examine existing advocacy models, using published literature and research, and to relate such models to current practices in the participating agencies.

A variety of challenges have emerged as this project has progressed. These challenges relate to:

- ◆ The provision of support and assistance for service users who are non verbal,
- ◆ Progressing a change from staff-led advocacy models and practices, to service-user led advocacy,
- ◆ Assisting Advocacy Champions to use and apply recently learned skills, while extending the opportunities to put them into practice,
- ◆ Influencing existing management structures and cultures of the participating agencies,
- ◆ Promoting participation of Advocacy Champions in organisational decision making in true and meaningful ways.

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# Jonix Educational Services

## — A specialised pre-school service

It is commonly accepted that an early diagnosis of an Autistic Spectrum Disorder (ASD), coupled with the right intervention, improves a child's chances of overcoming the obstacles accompanying autism. With this in mind many parents whose children have an ASD are often faced with decisions regarding early intervention strategies. Jonix Educational services offers early intervention in the form of a specialised pre-school service. The service is a private venture and caters for children of a pre-school age with an ASD, language or developmental delay.

### Where did Jonix come from?

The Jonix service began as an agency providing home tutors to children within their home. These tutors were sourced to provide a programme for a specific child. Soon the number of children needing the specialised service grew disproportionate to the amount of tutors available, and Jonix faced a dilemma. Parents were being forced to wait and their children received no intervention, even though they may have received grant approval. It was decided that it would be mutually beneficial to the children and the tutors if a small group of children could be taught together in a class setting environment.

The first small class was set up in the beginning of 2005 in Lucan, where Jonix rented a room from an existing crèche. This was a start, but Jonix soon sought their own premises. A waiting list was developing and later that year, Jonix rented an additional small purpose-built crèche in Enfield, Co. Meath, where they now had two classrooms and an office. The school filled quickly with referrals from other services in the area. The original school in Lucan eventually moved to a purpose-built crèche in Castleknock. Leasing two purpose-built crèches (each catering for 12 children), Jonix then opened a third class in Malahide in February 2007. The fourth class in Kill, Co Kildare, was opened in September 2007. The classes opened in 2007 each cater for 6 children.

### What is Jonix?

Jonix operates a pre-school service for children unable to learn and flourish in typical pre-school settings which may have large groups and activities that are unstructured. Staff may also not have the relevant experience or qualifications to facilitate the development of children who have communication difficulties. Within the Jonix schools, data is taken on a daily basis. Tutor and teacher record each child's daily progress. This information is then used to formulate educational and behavioural plans. High staff to child ratios ensure the child receives 1:1 interaction during the day. Classes generally run in the morning, though some parents have booked their children in for additional afternoon classes.

Currently Jonix operates 5 schools (the fifth opening in early November 2007). Jonix has a team of dedicated and enthusiastic staff. Teachers generally have a psychology or teaching qualification. Teachers within the schools set up the programs and then monitor each child's program. Jonix receives referrals from other early intervention or diagnostic services that do not have, or have only limited, pre-school facilities. Children attached to other services may receive occupational, speech and language and psychological support from their primary service.

### Where is Jonix now?

With all 5 schools up and running at capacity, Jonix is providing a service to 42 pre-school children and employing 30 staff. The children range in age from 2–6 years. The class structures were loosely based on the outreach classes set up by the Department of Education and Science (DES), however, Jonix added an additional staff member with a ratio of 4 adults to 6 children.

At Jonix the goal is to provide a learning environment that is fun and stimulating. Many of the children within the service have had no previous access to a pre-school setting. As much as possible typical pre-school activities are carried out within the day, such as music, art, PE etc. Elements from the Junior Infant Curriculum are also incorporated into programmes, as appropriate.

### Challenges

In order to fund the pre-school fees, parents avail of a home tuition grant issued by the Department of Education and Science. The grant is approved on a yearly basis; this therefore poses a big challenge for Jonix. The fact that parents must reapply for the grant each year, negatively impacts on the running of the schools (e.g. staff are on yearly contracts). In order to ease the financial burden on parents, Jonix will be seeking recognition on a more permanent basis and direct payment from the Department of Education and Science.

Another challenge for the service is family support outside school hours. Many of the families within Jonix request and display the need for some form of respite support. Most families would see this as a form of short-term respite within and outside the home. Jonix plans to investigate establishing respite homes; currently the service is only able to conduct short home visits.

### Strengths

High calibre staff and staff training are important issues within the Jonix service. Two members of staff have completed the BCABA (Board Certified Associate Behaviour

Analyst) certification through Trinity College Dublin, and one teacher is currently on the course. Various staff members have also completed a TEACCH course and training in the Picture Exchange Communication System (PECS). Last summer all the staff attended a 4-day training course delivered by a leading behavioural expert. Handleman and Harris (2001) state that with the continuing developments and changes in educational methodologies for children with autism, in-service training is crucial in maintaining an effective programme. Jonix adheres to this rationale and views staff training as essential to the continued success of the service.

According to the Department of Education and Science Autism Task Force (Department of Education and Science 2001, 137), 'In all cases, a proven, well-defined and well-delivered method of instruction should underpin all educational interactions with children with an ASD'. Within the Jonix schools each child has a personalised programme. The child is assessed and various goals are then devised. Applied Behaviour Analysis principles are used within the schools. Visual schedules also form an integral part of the child's day. Sign language and the use of PECS support the children's communication abilities. Each child's programme is reviewed and new goals are devised when necessary. It is vital to ensure that the child's progress is measurable. This ensures that the school programme is transparent and therefore accountable. Goals which are evidenced based ensure that the child has a programme that is flexible and up-to-date.

The Task Force Report (Department of Education and Science 2001) also lists what it considers to be the components of a pre-school programme that is effective. Jonix recognises these components and has successfully implemented them within each school, as appropriate. A large part of each child's programme is communication and play. These areas are vital for the child in his interaction with his family and peers.

Within the schools, family involvement is encouraged in relation to each child's programme. Each day a communication diary is sent home. Meetings are held within the school year to discuss each child's progress. New parents also attend an introduction meeting. After observational assessments, as well as probing various skill levels, the teacher proposes a programme for the child. Parents decide what the priorities are for them as a family. This meeting also provides an opportunity for parents to understand exactly what happens throughout the day, and how the day is structured.

Jonix is a private venture and therefore can determine its own admission policy. A parent may enrol a child within the school without a formal diagnosis. If, after visiting the school and meeting teachers, the parent feels their child will benefit, the child is enrolled at the school. The parents and teachers then review the situation in a month or two to assess if the placement is appropriate. This flexibility has on many occasions allowed children to access a service, while in the middle or beginning a diagnostic assessment. The child's early intervention begins without the delay of waiting for reports. A number of the children have benefited from this.

## Future

Jonix intends to expand the services that it provides to other areas of Ireland, by building on its brand of providing a quality educational pre-school service for children with an ASD. After a service review recommendations included that

Jonix should conduct suitable risk analysis assessments and expose the children to more community events. This has begun to be implemented and outings to the zoo, local playgrounds and farms have begun and will continue in the future. Another area that Jonix would like to explore is integration with other pre-schools, forging links with pre-schools in surrounding areas. Children could attend these pre-schools for periods of time with support from experienced Jonix staff.

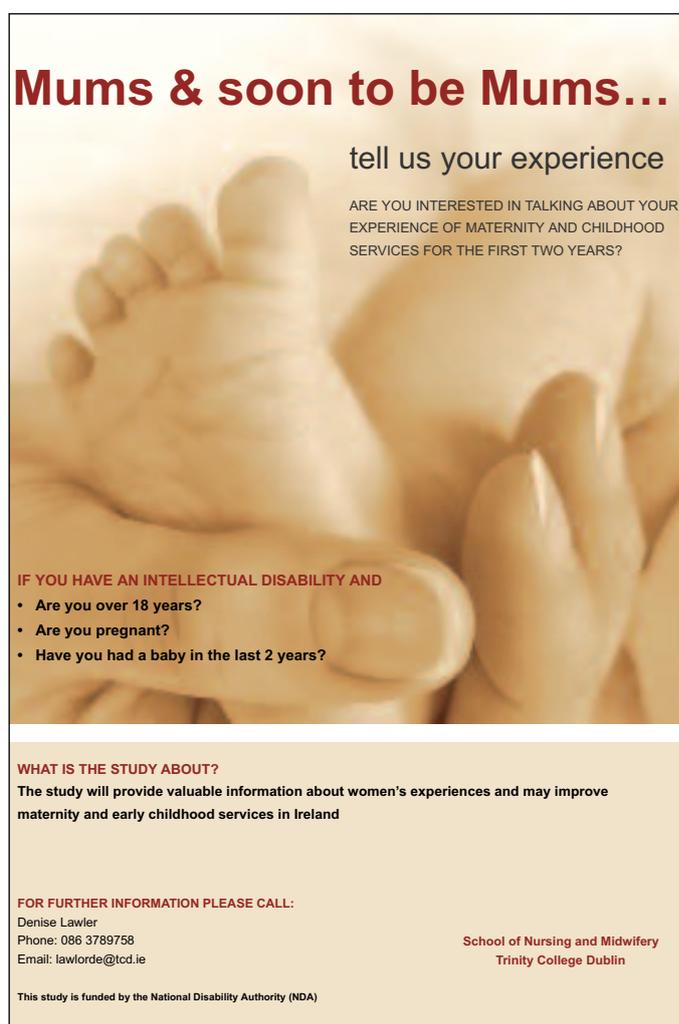
## Conclusion

Jonix is a unique service provider of educational services in Ireland. It has grown since its inception in 2003. In order to ensure that the children receive the best educational services possible, Jonix must remain updated and skilled in the best and most effective teaching methodologies. Jonix must also ensure that the families within its service feel supported and 'part of' their child's educational development.

Nicola Hansen  
email: nicola@jonix.ie

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- Department of Education and Science 2001 *The report of the Task Force on Autism*. Dublin: Stationery Office
- Handleman, J.S. and Harris, S.L. 2001 *Preschool education programs for children with autism*. Austin TX: Pro-Ed.



**Mums & soon to be Mums...**

tell us your experience

ARE YOU INTERESTED IN TALKING ABOUT YOUR EXPERIENCE OF MATERNITY AND CHILDHOOD SERVICES FOR THE FIRST TWO YEARS?

**IF YOU HAVE AN INTELLECTUAL DISABILITY AND**

- Are you over 18 years?
- Are you pregnant?
- Have you had a baby in the last 2 years?

**WHAT IS THE STUDY ABOUT?**

The study will provide valuable information about women's experiences and may improve maternity and early childhood services in Ireland

**FOR FURTHER INFORMATION PLEASE CALL:**  
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Email: lawlorde@tcd.ie

School of Nursing and Midwifery  
Trinity College Dublin

This study is funded by the National Disability Authority (NDA)

# Taking steps towards inclusion: Assessing the attitudes of schoolchildren toward their peers with Down Syndrome

## Introduction

The social relationships of a child with Down Syndrome or other Special Educational Needs (SEN) often constitute the single area of school life about which parents and carers are most concerned (Cuckle and Wilson 2002). Therefore, it is perhaps not surprising that exposure to peers and opportunities for friendships in the local community are frequently the main reasons why parents send their children with SEN to the local primary school (Nakken and Pijl 2002). However, these pupils belong to a vulnerable population of young people with learning disabilities who are more likely than their non-disabled peers to experience peer rejection, depression, anxiety, behavioural and conduct problems, delinquency, school dropout and poor academic adjustment (e.g. Sinson and Wetherick 1981; Weiner 1987; Werner, 1993; Guevremont and Dumas 1994; Laws, Taylor, Bennie and Buckley 1996; Wenz-Gross and Siperstein 1996). Furthermore, the extent to which these young people experience fully inclusive education has been the subject of considerable debate in recent years.

Despite a recent increase in research investigating the social relationships of pupils with Down Syndrome (eg. Murray and Greenberg 2006), studies of the attitudes of non-disabled children towards their peers with Down Syndrome are in their infancy and very little research of this kind has been conducted in Ireland (Gash *et al* 2000). The primary aim of the present study was to assess the attitudes of non-disabled children in several rural mainstream primary schools toward children with Down Syndrome. A secondary aim of the study was to examine the impact on attitudes (if any) of administering a video designed to promote inclusive attitudes toward children with Down Syndrome.

## Research methodology

A convenience sample of 118 children (comprising 54 males and 64 females) was drawn from six rural mainstream primary schools in North Kildare. Participants were recruited from twelve Third and Fourth Classes and were aged between 8 and 11 years ( $mn=9.35$ ;  $sd=0.72$ ). Classes which included children with learning disabilities (LD) were excluded from the study due to ethical reasons. The research was conducted during the Social Personal Health Education (SPHE) class in each school. Specific objectives of this module for Third and Fourth Classes involve acknowledging the importance of friendship and the practice and recognition of the value of care and consideration, courtesy and good manners when interacting with others (Government of Ireland 1999). The sample size and age-range of the children were considered appropriate in view of other similar studies in this area conducted elsewhere (Laws, Taylor, Bennie and Buckley 1996; Gash *et al* 2000; Gash, Romeu and Pina 2004; Roberts and Smith 1999).

Prior to commencement of the study, a letter was sent to the parents/guardians of all potential participants informing them about the study and seeking their consent for their child

to be involved on an 'opt-out' basis. Participants were first asked to complete a brief *Background Questionnaire* (BQ) which was devised to elicit details on age, sex, number of children in family and position of the child in family. Information regarding the participants' experience of a friend or relative with Down Syndrome was also obtained. It was thought that some or all of these kinds of variables might be linked to overall attitudes.

Following this, participants completed an *Attitude Questionnaire* (AQ) at two points in time and each on a group basis. The AQ was based on a slightly modified version of a questionnaire devised by Gash (1993) to examine attitudes towards children with special needs. For purposes of the current study, the term 'mental handicap' was replaced by 'Down Syndrome'. This 20-item measure comprises 10 items relating to the sociability of non-disabled children toward their counterparts with Down Syndrome (Scale One) and 10 items that assess the views of non-disabled children on the inclusion in schools of children with Down Syndrome (Scale Two). The children answered 'yes' or 'no' to each statement. A 'yes' response was scored as '1'; a 'no' response was scored as '2', so that higher scores reflect more negative attitudes.

A brief excerpt from a video entitled *Including children with Down Syndrome in your school* (Down Syndrome Ireland 2004) was shown upon completion of the first AQ. This 10-minute excerpt depicted children with Down Syndrome in an inclusive classroom participating in everyday school activities such as reading, writing, spelling and singing. This video was sent to every school in the Republic of Ireland in 2004 by Down Syndrome Ireland in cooperation with the Department of Education and Science in order to promote the inclusion of children with Down Syndrome in Irish primary schools. The literature accompanying the video provides general information on inclusion strategies and benefits, the learning profile of a child with Down Syndrome (e.g. reading, writing, phonics and numbers) and on the motor skills and behaviour of these children. Once the videotape had concluded, the class were invited to complete the AQ for a second time (also on a group basis). Upon completion, the participants were fully debriefed and thanked for their co-operation.

## Key findings

The mean AQ scores obtained on each scale at both Time 1 and Time 2 are shown in Table 1, alongside the background data. As shown in the table, the pattern of scores was broadly similar across both time points in relation to all key variables, although scores on Scale Two (attitudes toward inclusion) were consistently higher than those for Scale One at both time points. It can be seen that those who were middle children had the lowest mean score on Scale One (at both time points), while those who were only children obtained the highest mean scores overall. The youngest children in the group ( $\leq 9$  years) also attained marginally higher (i.e. more negative) scores than those aged 10 years and over. Closer inspection revealed the

following key findings:

- ◆ *Sociability versus inclusion*: Scores on Scale Two were consistently and statistically higher than those on Scale One, indicating more positive attitudes toward sociability than toward inclusion in general.
- ◆ *Gender differences*: Males and females did not differ significantly in terms of their Scale One and Scale Two scores at baseline (Time One).
- ◆ *Most sociable group*: Females in the over 10 years group were found, statistically, to be the most sociable toward their peers with Down Syndrome. No statistically significant differences were found for the effect of age on attitudes toward inclusion for either males or females.
- ◆ *Role of familiarity*: Those who had a relative or friend with Down Syndrome did not differ significantly from those without such contact in sociability or in attitudes toward inclusion in this study.
- ◆ *Position in family* (i.e. oldest, youngest, middle or only-child): This was not shown to play a role in children's levels of sociability and attitudes toward inclusion as measured by the AQ.
- ◆ *Analysis at Time 2*: This revealed that there was no statistically significant change in Scale One or Scale Two scores between the two time points.

**Table 1: Mean AQ scores by background variables**

Background Variable	Time 1		Time 2	
	Scale 1	Scale 2	Scale 1	Scale 2
<b>Gender</b>				
male	12.46	16.07	12.39	16.20
female	12.16	15.55	12.16	15.75
<b>Age-group</b>				
9 years and under	13.17	16.50	14.83	16.83
10 years	12.28	16.19	12.33	16.58
Over 10 years	12.80	15.80	12.60	16.20
<b>Position in Family</b>				
oldest	12.55	15.95	12.45	16.10
youngest	12.19	15.58	12.02	15.65
middle child	11.93	15.72	11.83	16.03
only child	13.17	16.50	14.83	16.83
<b>Number of children in family</b>				
1	13.29	14.86	13.86	15.57
2-3	12.19	15.84	12.19	16.01
4-5	12.32	16.02	12.26	16.30
<b>Friend/Relative with Down Syndrome?</b>				
Yes	12.24	15.76	11.95	15.47
No	12.33	15.80	12.41	16.19
<b>Total (group as a whole)</b>	12.30	15.79	12.26	15.96

## Commentary

The finding of greater sociability amongst the older females in the group is consistent with other research showing females to be generally more sociable than their male counterparts (Gash 1993; Gash *et al* 2000). It is possible that this also increases with age, although it has been suggested by Nowicki (2005) that girls and boys may differ in how they respond to attitude measures that relate to specific types of responses and that these differences may be more indicative of gender-based response biases rather than gender differences in their opinions. This may also explain, at least in part, the lack of differences between the younger males and females in the current study. However, the research findings in this respect are mixed and it is not clear at this stage if age and attitudes are related to any great extent (Gash and Coffey 1995; Diamond, Hestenes, Carpenter and Innes 1997; Tamm and Prellwitz 2001). Nowicki (2005) also asserts that within gender, age differences in attitudes may be greater than any attitudinal differences across gender.

One finding of particular interest in the current study was the absence of any differences between those children who had a friend or relative with Down Syndrome and those who did not. It was thought that those with such contact might hold more favourable attitudes, particularly in relation to sociability, but this was not the case. This finding contrasts with some other work including a study by Helmstetter *et al* (1994) who found that non-disabled children who had previous contact with a child with SEN had a more positive attitude towards those with SEN and viewed their inclusion as more favourable than those without such experience. By contrast, however, Scheepstra *et al.* (1999) reported that almost half of 23 students with Down Syndrome in an integrated mainstream school were rejected by their peers. Furthermore, contact alone between children with Down Syndrome (and other learning disabilities) and their non-disabled classmates may not automatically lead to enhanced social interaction, or to the development of positive attitudes (e.g. Lyons 1991).

A substantial body of evidence has suggested that children and early adolescents can provide reliable information regarding their personal relationships and their social and emotional functioning (Elliot, Huizinga and Ageton 1985; Jolliffe, Farrington, Hawkins, Catalano, Hill and Kosterman 2003; Lynch and Cicchetti 1997). Consequently, the above finding (and perhaps some additional findings also) may be due, in part, to the possibility that some of the items on the AQ may not accurately reflect the ways in which children relate to each other in social or school settings. Gash *et al* (2000) and Gash (1996) argue that the AQ reflects attitudes in observable ways and has good reliability, and validity, but further work is needed to establish the full range of psychometric properties of the AQ. Nonetheless, the AQ was chosen because it was brief and easy to complete (eg. containing 'yes' and 'no' answers only) and contained age-appropriate language. No other similar such measure could be identified from the literature.

It was also thought that the number of other children in the family or a child's place in the family might have a

*The data were gathered from a convenience sample of children attending schools in rural settings. Whilst the sample was of a reasonable size, it is possible that the attitudes of children in larger schools based in cities or towns may differ from those of children in typically smaller rural settings.*

bearing on overall levels of sociability, in particular, and perhaps also attitudes toward other children with Down Syndrome. For example, children in larger families may be generally more tolerant of differences. Again, however, no differences in sociability or inclusion were found with respect to this variable.

The current study was cross-sectional in nature and necessarily constrained by time and resources. The data were gathered from a convenience sample of children attending schools in rural settings. Whilst the sample was of a reasonable size, it is possible that the attitudes of children in larger schools based in cities or towns may differ from those of children in typically smaller rural settings. Again, future research should expand data collection beyond one geographical location (in this case rural areas) and across different settings, thereby enhancing the generalisability of the findings. For example, Nowicki (2005) argues that studies of attitudes similar to the present study might yield different results if conducted in other contexts, such as playgrounds or sports venues.

A larger, longitudinal study would also be more beneficial in assessing any changes in attitude over time (perhaps also using the AQ) across a number of different settings. Only these kinds of studies can add to the current uncertainties surrounding age and attitudes in the research literature. More specifically, as stated by Nowicki (2005), longitudinal designs provide an opportunity to examine the consistency of results across measures and potential interactions between factors that may not be uncovered when potential attitude-related variables are investigated in isolation.

Another limitation of the current study and one that was beyond the researcher's control (owing to time constraints and restricted access to schools) was the short time period between the video and the second AQ. Ideally, the second AQ should have been administered at a greater length of time after presentation of the video (e.g. two weeks later), but this was not possible in the current study. This may also have led to some degree of response bias in that some children (particularly the older group) may have become aware of the purpose of the video (because it was administered so soon after the first AQ) and perhaps adjusted, or declined to adjust, their responses accordingly. However, there were a number of measures put in place to try to control for this (insofar as possible). For example, the children were instructed to provide their own responses without consulting others or viewing the questionnaires of other participants. Both the class teacher and researcher were also present at all times.

It is also noteworthy that difficulties arise when attempting to compare results across studies because of

the variety of measures and designs available. For example, according to Gash (1996), there is considerable uncertainty surrounding whether an improvement in attitudes is due to a change in the *feelings* about a child with learning disability (LD) or if a child's view of LD changes depending on the nature of the disability (eg. mild or profound). The image of a profound LD may evoke fear in children with little experience of others with LD. Therefore, if a child's idea or image of LD changes from profound to mild, the attitude may be expected to improve.

Additional research is required to disentangle the potentially complex interplay of factors that impact on overall attitudes. There is considerable scope, in particular, for conducting qualitative research. For example, a study by Francis and Muthukrishna (2004) used unstructured interviews as a means of investigating and understanding the experiences of primary school children with disabilities in South Africa. This paper raised some interesting issues in relation to growing up with a disability including cultural attitudes toward disabilities and social relationships. Similar research conducted in Ireland could prove valuable.

Gilmore *et al* (2003) state that accurate knowledge and positive, but realistic, expectations are important for enhancing the acceptance of children with learning disabilities (including Down Syndrome) within their schools and in their communities. Reassuringly, Gash *et al* (2000) found that Irish children (and their Spanish counterparts) were found to be more favourably disposed toward inclusion than children from either France or Portugal. However, the findings of the current study and other work in this area illustrate, above all, that the attitudes of non-disabled children toward their peers with Down Syndrome and other learning disabilities are complex. Previous inconsistencies and methodological variations in research carried out in this area are common and a need for further research is highlighted.

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# Cautionary Tales

Inclusion Ireland's Annual Parents' Seminar was held at the Radisson SAS Hotel in Athlone on Saturday, 3 November 2007.

During the morning session speakers sought to unravel aspects of 'supported decision making'—from philosophical to legal. Guest speaker Michael Bach, who is Vice President of the Canadian Association for Community Living (and was formerly Director of Research of the esteemed Roeher Institute), argued that respecting their personhood, people with intellectual disabilities should be assisted/supported in making their life decisions, rather than being provided with substitute guardians (or even wardship of court committees).

Article 12 of the UN Convention on the Rights of Persons with Disabilities—adopted in 2006 by all EU countries, but not yet ratified into Irish law—states that:

- ◆ Persons with disabilities have the right to recognition everywhere as persons before the law.
- ◆ Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
- ◆ Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. (Further detail available in Article 12)

Michael Bach explained how such measures indeed can be introduced—instancing the Canadian province of British Columbia which now has laws which recognise and provide monitoring, funding and advisory mechanisms for such support groups (e.g. circles of friends).

Máirín McCartney's paper brought the question of legal capacity and decision making back to the Irish context. She pointed out the lack of legal protection for persons (families or care services) currently making decisions for adults with intellectual disability. She summarised the Law Reform Commission's 2006 Report on Vulnerable Adults and the Law, which recognises the philosophical shift in policy toward an emphasis on autonomy, capacity and empowerment, and the fact that individuals may have the capacity to make some decisions, but not others. The Commission also produced a draft Mental Capacity and Guardianship Bill 2007 (which fell with the dissolution of the last Dáil). Although acceptable in many respects, Máirín recommended that the proposed bill should be amended to reflect Article 12 of the UN Convention—and to include the provision for supported decision making.

In conclusion, Máirín said:

*'New legislation is long overdue, particularly in view of the fact that the Wardship Act dates back 130 years. Any new legislation should underpin and support the right to self-determination, the right to participate and the*

*right to make choices. In the light of ...UN Convention, the emphasis in new legislation should be on the presumption of legal capacity and supported decision-making. Substitute decision-making and guardianship should be the exception, but in my view it will still be necessary ... in very restricted cases and under very stringent guidelines. The answer to the question 'who decides and how' is clearer, but is still evolving.*

Whew, after the morning's very careful, thought-provoking and valuable presentations, we were ready for the excellent buffet lunch provided by the hotel, and the chance to unwind a bit—before returning to the daunting topic of long-stay (health) charges.

Walter Freyne, Director of the Daughters of Charity Services and representing the National Federation of Voluntary Bodies, opened the discussion by presenting the NFVB's view that new legislation is needed to clarify entitlements and charges for people with intellectual disabilities, who were unfairly included in the 'nursing homes' context of the 2005 legislation. He pointed out that service providers are experiencing loss of income and considerable confusion because of the inequities of the present regulations.

Kevin Doyle, Chairperson of the Inclusion Ireland Parents' Committee, spoke about how the charges are negatively affecting his family. Other parents told stories of the new charges regulations causing confusion and upset amongst people who use services and their families.

Pat Marron and Bernard Haddigan of the Health Services Executive bravely attempted to explain the Long-Stay charges regulations and the administration of the Repayment Scheme. I admire them for their efforts, even to providing a roadcaster information service. But to this listener, it all remains an unintelligible quagmire.

My summary, I'm afraid, inadequately reflects the excellent Parents' Seminar and the great work that Inclusion Ireland staff, and the Parents' Committee, put into organising it. I recommend that *Frontline* readers go to the Inclusion Ireland extensive website ([www.inclusionireland.ie](http://www.inclusionireland.ie)) where you can download the seminar papers and read them at your leisure. You will also find Inclusion Ireland's clear-as-possible explanation and position paper on the long-stay charges, as well as the text of the UN Convention on the Rights of Persons with Disabilities.

**Mary de Paor**



# *Team Ireland do us proud at Special Olympics World Summer Games*



The 2007 Special Olympics World Summer Games in Shanghai ran from 2-11 October. 7200 athletes from 165 nations and regions took part in the Games, which were held for the second time outside of the USA and for the first time in Asia. Of these, 141 athletes, 55 coaches, 200 volunteers and over 400 family members travelled from Ireland, making us one of the largest delegations at the Games.

Preparations for the Games had been ongoing for almost a year and as the time drew closer the excitement and anticipation were palpable. The Law Enforcement Torch Run marked the countdown to TEAM Ireland's departure to Shanghai. For three days hundreds of members

of An Garda Síochana and the Police Service of Northern Ireland carried the flame of hope through towns and villages across the island. The torch run culminated in a gala event at the Westmanstown Garda Sports and Leisure Centre in Dublin, where TEAM Ireland were honoured by the attendance of President Mary McAleese, who came to wish them all the best prior to their departure to Shanghai.

**Above:** Pauline Crompton, PSNI and Garda Pat Merrick carrying the Flame of Hope

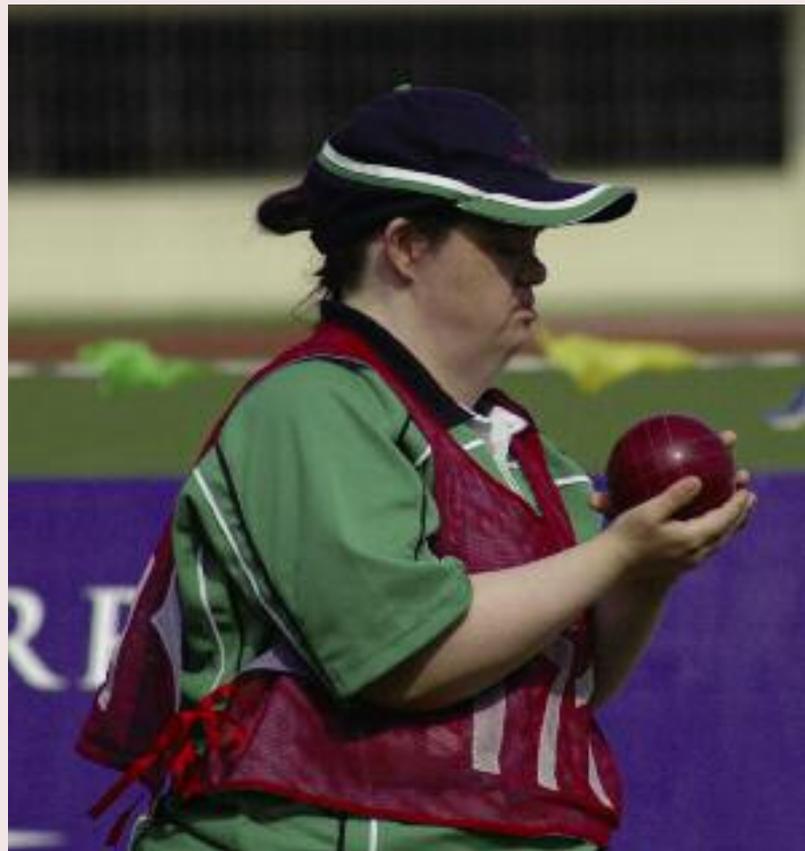
Speaking at the ceremony, the President expressed her pride in all that they had already achieved: 'Our athletes have had to work and train very hard to earn their right to be on the road to Shanghai. We admire them for their talent, their determination and their spirit. We know that Shanghai is going to love Team Ireland.'

And so it was....from the moment TEAM Ireland set down in Shanghai they experienced the very best in Chinese hospitality and culture. TEAM Ireland's Chinese experience began in the Luwan District of Shanghai—which was their host town for five days. They stayed at the Pearl Hotel where they were treated to an array of Chinese culture, hospitality and entertainment including martial arts displays, tai chi and sword dancing. Just before they left the Pearl Hotel they received a surprise visit from Colin Farrell, who is a Global Ambassador for Special Olympics.

After a breathtaking Opening Ceremony the Games got under way on 3 October. TEAM Ireland got off to a flying start, putting the many months of hard work and training into action. This form continued for the duration of the competitions with each and every one of our 141 athletes doing their very best and giving their all. The final result was an amazing 119 medals and 69 ribbons. This is a phenomenal achievement and huge credit is due to the athletes, coaches and their families for their commitment.

Over 400 family members and supporters travelled to Shanghai to cheer on the athletes. They came from all over the world with several families reuniting for the first time in many years, having travelled from Ireland, the UK, Australia, New Zealand and the United States to cheer on their athletes. Family members of all ages attended—the oldest was 80, and the youngest just a year old.

Everywhere they went, the Irish contingent created an impact, forming a sea of green in their Toyota/Special Olympics polo shirts, waving flags and banners and making plenty of noise. There was even a giant teddy bear, wearing a family polo shirt, who required his very own seat at the sports venues!



The families were fantastic, not only supporting their own athlete, but supporting all of the Team Ireland athletes and ensuring that those athletes whose families were unable to travel to China always had plenty of Irish support to cheer them on.

TEAM Ireland returned home on 12 October, to a heroes' welcome in Dublin Airport where they were cheered and congratulated by hundreds of family members and supporters. Speaking at the airport where he officially welcomed home the Team, Minister for Arts, Sport and Tourism Séamus Brennan said: 'I am delighted to welcome home our returning Special Olympians, and on behalf of the Irish people, to congratulate and thank all the athletes, coaches, families, supporters and volunteers for what has been a memorable and joyous few weeks. Our athletes have done the country proud with their courage, skill, and superb sportsmanship.'

**Above:** Linda Mooney of the Bocce Team

Naturally we want to say a special well done to all those returning home with medals and ribbons, but the Special Olympics has a beauty and a resonance that cannot be measured by a medal and ribbon tally. Each and every one of our athletes have given of their best and in doing so have held firmly to that most important and inspiring core principal of the Special Olympics movement: "Let me win, but if I cannot win, let me be brave in the attempt".'

Special Olympics Ireland received huge support from thousands of people in the months leading up to and during the Games. A group of 200 volunteers travelled to the 2007 Special Olympics World Summer Games in Shanghai. Ireland was the only delegation at the Games to send their own volunteers, which is something we are very proud of! They all worked incredibly hard during the two weeks in Shanghai to ensure that everything ran smoothly for all the Irish Delegation. In addition, credit is also due to

the thousands of people who supported their local athletes through the Support An Athlete Campaign. Special thanks should also be extended to Eircom, who for the past 22 years have been huge supporters of Special Olympics Ireland.

The 141 athletes who travelled to the Special Olympics World Summer Games were a very small representation of the 11,000 Special Olympics athletes who are involved in Special Olympics programmes in Ireland. Special Olympics Ireland hopes that the success and excitement generated through these Games will encourage even greater participation in Special Olympics programmes in Ireland—both in terms of athletes and volunteers. After all, at Special Olympics Ireland there is a place for everyone! For further information visit the Special Olympics website: [www.specialolympics.ie](http://www.specialolympics.ie).

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Special Olympics Ireland provides year-round sports training and athletic competition in a variety of Olympic-type sports, for children and adults with a learning disability, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendships with their families, other Special Olympics athletes and the community.

Special Olympics Ireland aims to invite every person with a learning disability to take part in its sports training programme. The organisation is focusing on recruiting new athletes in targeted areas around the country in the coming months.

Participation in Special Olympics Ireland is open to any person with a learning disability aged six years or over. Regular competition starts from the age of eight. Special Olympics is unique because it allows athletes the opportunity to compete at their own level, regardless of their abilities.

You can help us identify potential athletes (i.e., those who are six years or over and have been assessed by a psychologist, psychiatrist or other care professional as having a learning disability) by encouraging them or their parents/carers to get in touch with us.



To support this athlete recruitment drive, please contact:  
Fiona O'Loughlin,  
Special Olympics Ireland,  
4th floor, Park House,  
North Circular Road, Dublin 7.  
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[fiona.oloughlin@specialolympics.ie](mailto:fiona.oloughlin@specialolympics.ie)

# The challenges of authentically getting what people actually need on a person-by-person basis

**M**uch attention and energy has been given in recent years to developing new options for people with disabilities that would be more desirable alternatives to group-based services. Naturally, a wide range of terms has arisen to describe these, such as 'person-centred', 'individualised', 'personalised', 'tailor-made', 'self-determined' and whatnot. In many locations, the rapid adoption of such terms by so many people may create the impression that a virtual outbreak of person-centredness is underway. Yet, common sense indicates that this could not possibly be the case. After all, surely some situations are not at all 'personalised'. Nonetheless, if we are unable to be more precise about what is, or is not 'person-centred', then it risks being whatever anyone says it is, or wishes it to be.

In addition, without some way to sort out what is authentic from an impostor, it will mean lesser versions are going to be equated with outstanding ones. It also means that things that are the opposite of 'person-centred' or 'properly individualised' will now be claimed to be the same. This may have quite sad results, as all of the advances possible in the lives of people that have been achieved with such difficulty in recent decades, will be nullified to the extent that regressive practices become allowed to camouflage themselves as beneficial, simply through re-labeling themselves with contemporary slogans.

For instance, in a traditional residential institution, it recently emerged from an independent review that the staff had virtually never recommended that the residents obtain any options for their habilitation program that were not already available in the institution's program offerings. This included the option of permanently leaving the institution and pursuing a life within the community. Yet, each of these persons had a 'person-centred plan' that was signed off by all of the professionals in this facility without any record of officially registered dissent from any of them. This occurred at a time when, throughout the world, people with disabilities by the near millions were taking up new lives within the community, and governments and agencies everywhere were reducing institutional options, including in the state where this occurred.

On one level, they did have a degree of personally targeted activity opportunities *within* the institution, but even these were only modestly relevant to the person's needs, given that much better options in the community would have had comparatively more beneficial developmental results. For instance, people with the same degree of disability had already acquired 'homes of their own', that they actually owned, while the people in the institution were still living on custodial wards. In matters of formal supports, almost their whole lives were lived out in group contexts and group programs.

To be fair, many of these group programs were largely similar to those offered in the community and, in some instances, the institution residents and community clients shared the same day programs. So, the question is not resolvable in terms of 'community' and 'institutions', since personalised options may be equally unavailable in each. It is also true that both communities and institutions may equally be susceptible to simply adopting the language of 'person centredness', while largely still failing to

really address people's needs and potential to the degree they deserve and that is feasible.

To complicate matters somewhat more, to say that games done in a group, such as chequers, bingo or cards are 'individualised' may be accurate insofar as the person enjoys bingo more than cards, and can sometimes have this preference respected. Yet, that may be one of the only features of a formal service program that grows out of, and is meaningfully linked to addressing the potential and needs of that person. Yet, when we claim that a whole program is 'person centred', it suggests that more than one feature is individualised. In this regard we might be expecting something more approaching comprehensive individualisation.

Obviously, when we consider what precisely is 'person-centred', we need to be open to a continuum from minor individualisation to perhaps profound and dramatic life changing individualisation. They both qualify as valid, but differ in degree and existential importance, assuming that each advances the person's address of their needs and potential. Yet, while most of us can sense these qualitative differences at an intuitive level, in terms of the degree to which some conditions are exceptionally beneficial to a person's life and fulfillment, the words 'individualised' or 'person-centred' cannot, in themselves, capture it.

For instance, there is a young man in Europe who has spent many of his recent years in a group living residence in the community. He was living there, not because he or his family wanted him to move from the family home and the small community he was from, to a group home facility in a major regional city an hour away. This option was simply the only one the agency could offer at that time from within its portfolio of existing options. The choice of creating something 'from scratch' had either not occurred to anyone, including the family, or was judged to be impractical or inexpedient.

The young man had, in fact, a person-centred plan that presumed that he would continue to live in the group home. This was because the agency planned on the basis of what was presently available, not always what was actually needed or ideal for the man. The people involved were not indifferent to the man's needs at all, nor were they unconcerned with his potential, but the possibility of him having a home and lifestyle that was uniquely his own had not arisen in their minds as a practical possibility. This was due to the fact that their imagination had been so completely bracketed by the channeling of their imagination of 'better' into an evaluation of existing and familiar agency options, that they had foregone their ability to design an entirely unique option around the man.

When this young man and his family gave themselves permission to ignore what was on offer from the agency at that moment, they were then better able to begin to picture a more ideal life and lifestyle. He was freed to the possibility that he could develop dreams for his life that were uniquely his. In a sense, they were able to return to seeing the young man as a person with potential, as opposed to a being a man with autism that needed a 'service'. As it has turned out, this young man will soon have a

home of his own quite near to his family, and any detail of his new life can be changed by him as it may be needed, given that the support arrangement is his to guide and steer with the help of his friends, family and support staff. It is also noteworthy that the involved agency is now fully supportive of this new chapter in his life, despite the fact that they had previously not encouraged it.

When there is such a potentially profound engagement of a life defining need, such as getting a real life or home of one's own, then it reveals that there is a remarkable difference between a person being able to make some minor choices of their own in a group home, and redesigning one's life in an overall sense. This distinction is further accentuated when there is also the deliberate intent to do this in the context of asking about and seeking ideal or optimal answers to what is precisely needed by a given person, rather than attempting to secure minor personalised adjustments within existing service models.

While being able to eat one's favourite foods, have a preferred choice in clothing and setting one's own bedtime may be, on one level, a genuine expression of one's personhood, these may also simply be indicators of deeper and more fundamental needs in the person that possibly may not be addressed solely through a minor expansion of ability to make some selected choices within an existing service situation. If this distinction is real, then it raises a dilemma, because it asks us to look at 'person-centredness' as possibly ranging from minor examples of it to something more significant.

This recognition would call for us to be better able to qualitatively distinguish between greater and lesser versions of 'person-centredness'. This would also require that we more frequently put adjectives in front of the word, such that the varying degrees of achievement of person centredness become more apparent. For instance, we might describe 'trivial' individualisation from 'profound', or 'significant' versus 'insignificant' individualisation, or perhaps 'superficial' versus 'deep', or 'partial' or 'selective' individualisation versus 'pervasive' or 'thoroughly comprehensive' versions. The words themselves ought not to be the focus, but rather what is or is not happening with and within people's lives.

All of these distinctions can help point out that a continuum may exist in the quality and relevance of the type of individualisation being experienced by the person at a given moment. It can also help illuminate that a given response to a person's needs may conceivably be inhibiting and preempting a deeper and more relevant address of a person's needs, because the existing form of individualisation is relatively minor, but is mistakenly judged to be profound, optimal or near ideal.

If for some reason the people involved, including the person, cannot properly appreciate and understand the person's more profound existential needs, and true long-term potential, then they may simply settle for much less than might well be possible. Given the pervasively low expectations that have historically shaped the lives of people with disabilities in our culture, it should not surprise us that a few crumbs might well be taken to be an elegant meal, if the bar is set too low.

We might all be aware of instances where rather shallow and largely minor changes in people's lives are heralded, by those involved, as evidence of considerable person-centred success. This is actually quite understandable, as most of us would like to believe that we are doing the right thing, and making a useful difference in people's lives. Also, many of these minor achievements are both valid and relevant in themselves, and ought to be savoured for whatever benefits they may bring.

Nonetheless, what makes these claims of significant person-centred success problematic, is that they may serve to block or delay the recognition that much of what is, or could be, better for the person will not be explored. This, in turn, will mean that the person's true potential will neither be recognised nor pursued.

Nonetheless, if we are not more willing to be critical of superficial individualised responses to people's needs, we may then be functioning as agents of keeping people's real potential hidden and ignored, while we address needs and wants that may be comparatively easy and convenient to address.

In this regard, we will be colluding in a possibly unconscious process of dampening expectations for people's lives through a tacit unwillingness to vigorously explore what might be optimal or ideal in relation to a person's potential.

If we imagined that a contest existed within society as to whether a person's scope for extensively having and enjoying a good life if being amply supported and upheld, then a choice exists between expansive visions for people's lives and truncated ones. If there is too little vision, then the person will do without, whereas with more generous levels of vision, we could well anticipate a greater prospect of enriched lives.

An example of this can be seen in the premise that many people may have encountered, where it is believed that obtaining an individualised support arrangement is simply a matter of assisting people to leave group support arrangements. This can often be seen in services that are no longer center based, or congregate, and in which each person supported apparently is ensconced in some manner of individualised support arrangement. Yet, one can often see that, despite the obvious physical distinctness of 'one person at a time programming', there may well be people whose personal needs are not at all well met by the precise individual option they have obtained. It is conceivable that some people's actual needs may even be ignored, neglected and even worsened by arrangements that are admittedly organised on an individual basis. In a sense, one could have organisational or programmatic individualisation, yet fail in delivering relevant existential results, given what the person actually needs.

Though it seems rarely done as yet, one could say with some legitimacy, that these new individual options might actually be a novel kind of 'rip-off', insofar as the largely irrelevant, or even harmful individualised option, is serving to keep people entrapped in a lifestyle that is now holding them back, but perhaps in different ways than had been the case in the (prior) congregate era. This conclusion is obviously predicated on the assumption that 'good' or 'preferred' individualisation involves helping people meet their needs and life purposes and achieve their inherent potential, and 'poor' individualisation would be where the person is held back or deprived in regards to these. In a shorthand way, good quality is 'life giving', and poor quality is 'life denying'.

It should also be recognised that this is not in any way an argument against celebrating the genuinely beneficial outcomes of individualisation, as even small gains are still gains to be thankful for. It also does not mean that modest benefits should be forsaken for profound ones, as that would set them up as being opposed when, in reality, both can be achieved in a person's life simultaneously. Rather, it is simply a call both for greater clarity as to what constitutes actual progress in people's lives, and a decided preference that people not be cheated out of the long term potential in their lives through our lack of proper consideration of it.

Naturally, we are all tempted by the tendency to equate symbols of individualisation with its actual achievement. Yet, we

must be careful in doing this. It would be unwise to equate service system practices that are labeled as 'person-centred' with actual enriched lives, as we would be succumbing to treating the presence of 'means' as being equivalent to the achievement of 'ends'. Genuine results and outcomes are revealed in people's lives, not in the bureaucratic or rhetorical artifacts of either formal systems or informal ones.

Yet, we will all be constantly confronted by claims that something is 'person-centred' because of the presence of suitably 'person-centred' symbols that are taken to be a sure sign that actual personalised achievements are taking place. This can be seen already in the widespread adoption of the language and vocabulary of 'person-centredness'. For instance, in the example of the 'person-centred' institution already mentioned, that had insisted it was a champion of a person-centred approach, it was most certainly true that they had experienced a considerable shift in their routine service-related vocabulary towards person-centred buzzwords. The institutional staff in this example are no different from most of us, in that they equated a genuine intention around expanding person-centred options as being equivalent to actually achieving them.

We can see similarities in another example of the use of symbols to convey the impression of substantive results if we consider the tendency to equate the presence of person-centred plans, or individual planning processes, as being the same as actual results in people's lives. After all, the plans may not be implemented, or they may be intrinsically inconsistent with people's actual potential. Yet, their presence is apparently widely believed to be evidence of a person-centred outlook and outcomes.

These symbols are many, and may include various seemingly beneficial things like individual 'success stories', the decline of group models, the existence of individual funding, the growth in personal control over aspects of services, the existence of support circles, the existence of 'dreaming', the presence of individual home ownership, the person having notable peak experiences, the person or agency having been cited as a leading example and so on. These sorts of suggestive symbols are commonly taken as signs of success and progress, and may actually contain many positive elements. However, this may not be the same as certain proof of progress, as they are simply indicators that are being relied upon to serve as proxies for success. Even if these serve as a catalyst, true results can only be determined by a close examination of what has really transpired, or not, in a given person's life.

Given that success may be a continuum, by settling for too little we may risk strengthening the lesser or shallow end of this continuum at the expense of the better end. However, if we take the undoubtedly harder road of struggling to define and pursue 'better', as being what ultimately substantively benefits a person, then it is quite foreseeable that what we will come to witness is seemingly miraculous breakthrough after breakthrough. Naturally, as the artificial constraints imposed by too low or pessimistic expectations gradually yield to the actual truth of people's potential, then a breakthrough is both logical and predictable.

It is also likely that the harder this task may get, of trying to deepen our grasp of what is authentic person-centred results, the less interest will be shown by people who really want what might be called 'easy' or 'easier' person-centredness. Equally, the more that many people will be tempted by shortcuts, cutting corners and the passing off of 'fakes' or deceptions as if they were the real thing. After all, it is not unheard of for people to cheat if the going gets tough enough, and the rewards are substantial.

It could also be the case that the needs and preferences of other

involved parties might be gradually substituted for those of the person, but be misrepresented as being only those of the person. Instances where that which is done is undertaken to principally benefit people other than the person, can easily be portrayed as being entirely 'person-centred', yet it may actually involve a sabotage of the persons interests if the benefit that is gained for other parties comes at the price of the person not getting what they really need.

There may be no harm *per se* in other parties benefiting from a person-centred initiative. Still, it is important to be able to evaluate what is really behind person-centred success claims in order to be as sure as one might that a new kind of exploitation is not underway. After all, quite unseemly things could be done in the name of person-centredness, or any other legitimating slogan for that matter. This would not be the first time in history that something questionable was concealed and disguised by creating the appearance of moral or virtuous conduct. It could make some of us wonder whether things are not what they appear despite all of the right notes being hit.

So, for advocates, change agents, progress minded leaders, innovative service providers and many others who seek a better world, the challenge of authenticity in person-centredness is ultimately a question of truth and discernment, coupled with an increased willingness to become a great deal more demanding and principled as to what we will settle for. The dangers in unduly trusting in appearances and symbols can only be offset by paying much closer attention to the realities of people's lives, and less to claims of success that are not upheld in practice.

We most likely will need to be more on guard, more sceptical, more doubting, more challenging, more testing of our cherished illusions and wishfulness, and more questioning of the new orthodoxies and vested interests that are gradually appearing and entrenching in the 'person-centred' universe. Paradoxically, at the same time, we will also need to be more willing to dream bigger dreams, to hope with yet more vigour and courage, and to persevere in raising the bar a little higher whenever an opportunity appears.

We will not likely enable matters to get better because we avoid painful realities and difficulties, but rather because we solve the problems we encounter properly, and with the solidity they deserve, and with the integrity that comes with trying to be faithful to demanding but worthy principles. We must be wary of those who claim to have easily surmounted the many perplexities that are involved in assuring that people's lives are fulfilled, as that which is authentic and good is not likely to have been achieved quite so effortlessly, and at such little cost.

We most certainly have the assurance of knowing that it is quite feasible, and hardly beyond the pale, to have real hope that the lives of people could become better, as the evidence that this is so can be seen in the genuine accomplishments already made by thousands of people with disabilities in their lives, despite the fact that they and their allies had faced and overcome unrelenting pessimistic prognoses. Countless lives most certainly hang in the balance, and it is important that we seek and support all that brings and enriches life. Authenticity in person-centredness need not be forsaken as an illusion, as life can and should be good, particularly when it has been earned and gained through sound efforts.

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# Working all the live-long day: Parenting and employment

In recent decades, more and more mothers are entering the work force. This societal change has given rise to a surge of research aimed at measuring how working outside the home affects women's lives. In this column, we will share some research findings on the complex relationship between employment and parenting. Whether you work outside the home or not, we aim to present some strategies you can use for reducing stress while parenting. (Note to fathers: We recognize that many of you work and provide parenting as well, but since the research literature focuses on mothers—who traditionally had the monopoly on parenting—we will feature them here.)

For most mothers, working outside the home or staying home to raise one's family is a constant balancing act, and involves consideration of the money to be earned, child-care needs, values and desires. You may be surprised to learn that many mothers raising children with developmental disabilities are employed at sometime during their childrearing years: About half of these mothers are at work when their child is three years old, and about two-thirds of these mothers by the time their child is a teenager or young adult.

## How does employment affect mothers' mental and physical health?

Being employed is just one of the many roles that women might occupy, in addition to mother, wife, community volunteer, relative, friend, and neighbor. Research on women's roles has centered around two competing ideas. One is referred to as the *role enhancement theory*, which argues that employment provides psychological and social benefits to women, through increased contact and social interaction with other adults, and increased sense of self-esteem and mastery of a job or skill. On the other hand, the *role overload theory* suggests that the pressures and demands of juggling multiple roles, such as work and parenting, may exhaust women's personal resources and be damaging to women's physical and mental health.

Overall, most research suggests that mothers who work outside the home, volunteer, belong to social organizations, or are otherwise highly engaged in their community, have better physical health and report less stress and more life satisfaction. Research on mothers of children and young adults with exceptionalities also suggests that mothers who are employed are physically and psychologically healthier, and, in particular, are less prone to depression than mothers who do not work outside the home. Indeed, many mothers of children with exceptionalities report that their work outside the home provides them with a needed respite from their child-care duties.

On the other hand, for some mothers, the stress and childrearing duties associated with raising an exceptional child may mean that holding a job overloads women's resources and leads to more stress. The child's needs—such as behavior and psychiatric problems, specialized treatments, and frequent

doctor visits—may require mothers of exceptional children to miss work more often than other mothers. Too, mothers of children with exceptionalities may confront more difficulties finding reliable and competent childcare.

Overall, the benefits or drawbacks of being employed may depend on the nature of the job, the needs of the child, the support from friends and family, and the way women cope with stress.

## Can mothers' employment have negative effects on parenting?

Drs Jay Belsky and David Eggebeen from Penn State University looked at the effects of early maternal employment on children's development. These researchers found that in a sample of mothers who returned to work full-time when their child was one- or two-years-old, the children were less compliant to parental demands. However, these results should be viewed in light of the fact that children naturally become slightly more difficult as they get older—hence, the "terrible two's." One might also consider the children of working mothers as more spunky or independent than children whose mothers stay home. The quality of non-parental childcare that the children of working mothers experience will also impact child behavior.

## How can maternal employment improve parenting?

Researchers Dr Ellen Greenberger, Dr Robin O'Neil, and Dr Stacy K. Nagel studied how the nature of parents' jobs relates to their parenting behavior. The researchers examined this relationship in a group of 188 parents with children between the ages of 5 and 7. Among the benefits of employment, they found that positive features of parents' work, like challenges, stimulation, and complex interactions with other people, were shown to be associated with more effective parenting, including less harsh discipline, more warmth, and greater responsiveness. They also found evidence that some aspects of work can enhance parenting practices and child expectations. For example, parents who have to reason with others on the job may bring this skill home with them, leading to more firm but flexible control in parenting. Other research indicates that mothers whose jobs include more positive features will be more satisfied with their work, which will enhance their mood. These mothers will then bring this positive mood home with them, helping them to be more sensitive and warm with their children.

Dr Elizabeth Cooksey and her colleagues at Ohio State University have also found that mothers whose jobs involved more complex interactions with people had children with lower levels of behavior problems. The authors speculated that the financial benefits of mothers' employment, together with the skills they learn on the job and bring to their parenting, outweigh possible disadvantages like the decreased time working mothers may have to spend with their children.

## How can I protect my health and well-being, whether I work or not?

### 1) *If you work, make clear boundaries between work and family time.*

Dr Ellen Kossek and colleagues at Michigan State University have been studying how employed parents balance work and family. In a 2005 study, Dr Kossek and colleagues found that workers who try to integrate family and work life, rather than keeping the two spheres separate, are the most stressed. If you work outside the home, you can help reduce your own stress by establishing clear boundaries between work and family. If you need to work at home, try doing so at scheduled times, in a separate room with the door closed. Alternately, consider arranging a few extra hours of child-care help each week and try to get your work done during this time, rather than letting it spill over into family time. Separating the two spheres of your life means that the time you spend with your family will be higher quality and less stressful.

### 2) *If you do not work outside the home, give yourself a break.*

Having adequate help with child-care may be especially crucial to mothers who do not work outside the home. In a study of 252 mothers raising a young adult son or daughter with intellectual disability, we (Jan Blacher and Abbey Eisenhower) have found child-care support to be crucial to women's well-being. Mothers who had at least four people they could count on for help with child-care reported good health and well-being regardless of whether they worked outside the home. However, mothers who reported having zero to three people they could depend on for child-care support faced poorer physical and mental health, especially if they did not work outside the home.

This finding suggests that getting a few hours of respite from child-care duties each week can be especially important for mothers who do not work outside the home, as this may be your only "break" from child-care in the week. Consider asking qualified friends, neighbors, or relatives to assist you with a little extra time each week. Alternately, contact your local disability service agency in order to obtain respite care, a service which many agencies provide for free on a limited basis.

### 3) *Take an active approach to coping with stress.*

In the same study of mothers raising young adults with intellectual disability, we also found that certain ways of coping with stress seem to enable unemployed mothers to fare just as well as employed mothers. We found that, in times of stress, it was especially adaptive for mothers of children with intellectual disability to seek out social support and help from friends; those that did so reported good physical and mental health regardless of whether or not they worked outside the home. But this support-seeking strategy appears to be especially useful for mothers who do not work outside the home; unemployed mothers who cope with stress by seeking social support are as healthy and happy as employed mothers, who may have "built-in" social support through their work.

On the other hand, mothers who feel that stressful situations are out of their control or who choose to wait for the problem to go away report poorer health and well-being, regardless of whether they work outside the home.

### 4) *Find ways to make your work interesting and stimulating.*

The benefits of being employed may hinge on the nature of one's work. In 2001, Dr Marji Warfield at the University of Massachusetts interviewed 122 mothers of 5-year-old children with developmental disabilities about their jobs, parenting, and stress. Dr Warfield found that the working mothers as a whole were no more or less stressed than non-working mothers. However, working mothers who rated their jobs as interesting reported less parenting stress than working mothers who did not find their jobs interesting. In other words, having a stimulating, interesting job may help alleviate the stress of raising an exceptional child, whereas having a boring, unstimulating job does not provide a respite from childrearing stress. Although you're probably not in a position to give up your job for a more interesting one, consider looking for ways to take on assignments or interact with people that you find interesting and stimulating during the course of your workday.

### 5) *Get involved in your community!*

It's not too late to improve your ability to cope with the stress of raising an exceptional child. In a study of over 400 older mothers raising a young adult or grown son or daughter with intellectual disability—some of whom had been raising their child for as long as 5 decades—Drs Jinkuk Hong and Marsha Mailick Seltzer at the University of Wisconsin studied mothers' social involvement and feelings of depression over a three-year period. These researchers found that joining a support group, maintaining regular contact with a friend, relative, or neighbor, or holding a job, all led mothers to report less depression, even resulting in significant improvements in their feelings of depression over time.

In a similar study, Phyllis Moen and colleagues at Cornell University followed over three hundred married mothers from 1950 to 1986. These mothers generally had typically-developing sons or daughters. The researchers found that women who participated in their community—through work, volunteer work, or by participating in a club or organization—during their early years as a wife and mother had better physical health in their sixties, seventies, and eighties and even lived longer than other women. In fact, even intermittent, occasional participation in volunteer work or clubs led to better health and longevity down the line. Overall, it seems that getting involved in your community or establishing social relationships can be valuable for your long-term psychological and physical health.

One thing is for certain, though: Mothers of children with exceptionalities all "work," whether or not they get paid for it. As a group, they have much to blow their horn about!

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#### Editor's note:

This article is reprinted from the March 2005 issue of *Exceptional Parent Magazine*, a US publication for parents of children or young adults with disabilities. In the US, the term 'exceptional children' is often used for children with intellectual disability, autism and other conditions that challenge. Complete references to works cited in this 'Research Reflections' article may be obtained by emailing: [epedit@aol.com](mailto:epedit@aol.com). See also the website [www.eparent.com](http://www.eparent.com).

# Changing places—changing lives

**C**hanging Places, a new national campaign in the UK, was launched in 2006 by a consortium of disability organisations including charities Mencap and PAMIS. Thousands of people with profound and multiple learning disabilities need 'Changing Places' toilets—rooms properly equipped to allow people to use the toilet with assistance or have their continence pads changed. They include an adult-sized, height-adjustable changing bench, a hoist, a toilet with space either side for a carer, and plenty of space.

Without these facilities, carers are often forced to change family members on a dirty toilet floor with little or no privacy. This is unhygienic and is also extremely dangerous, as carers must physically lift the person they care for on and off the floor. However, the alternative is to limit outings to a couple of hours or not to go out at all. Health-and-safety considerations mean that carers employed for adults are not even allowed to attempt these procedures, meaning that many people with profound and multiple learning disabilities are unable to take part in activities enjoyed by others at their day centre, school or college.

While many buildings now include an accessible toilet as standard, this facility does not meet everyone's needs—including people with profound and multiple learning disabilities, some people who have had a severe stroke, some people with acquired head injuries and some frail and elderly people. There are almost no public Changing Places toilets in the UK. The campaign is calling for their installation in all large public places, including city centres, shopping malls, arts venues, hospitals, motorway service stations, leisure complexes, large railway stations and airports. Changing Places toilets should be provided in addition to standard accessible toilets.

Disabled artist and author Alison Lapper, who is supporting the campaign, explains: 'From my own experience I know how frustrating and humiliating it can be to come across toilets which just don't meet your needs. For someone with profound and multiple learning disabilities this is a common occurrence, resulting in people having to be changed on a dirty toilet floor or being forced to return home. The Changing Places campaign is so important because it is about more than just toilets; it's about people's quality of life.'

The following selection of real-life stories show how beneficial this campaign can be for people in the UK, and what similar facilities would mean in Ireland

## **Toby (8) and his mum Julie**

*Toby is 8 years old and has severe and multiple learning disabilities. Toby needs to use a Changing Places toilet when he is away from home, but there are virtually no Changing Places toilets in the UK. This places a huge restriction on where the family can go and what they can do. They find it is virtually impossible to do things on*



*impulse. When they are away from home, Julie carries an aerobics mat so that she can change Toby on a toilet floor if there is no alternative. This involves Julie lifting Toby from his chair to the floor and back again—a hazardous action for both her and Toby. 'I slipped a disc 20 years ago—my back just seized up and I couldn't move,' Julie explains. 'I'm terrified that it will happen again. Getting on the floor to change Toby is the worst position for me to be in. What would I do if it happened while I was changing him and I couldn't get up? If more Changing Places toilets were installed it would make such a difference to our lives—we could do normal everyday activities. Things that other people take for granted.'*

## **Matthew (16)**

*Matthew, who lives in Wrexham, North Wales, enjoys doing lots of activities, like going to concerts or on day trips. But Matthew faces great difficulty when he wants to go out—because he can never find a toilet that meets his needs. 'I have cerebral palsy and am quadriplegic', Matthew explains. 'I need a lot of support when I go to the toilet as I cannot stand or transfer out of my wheelchair on my own. I need enough room in the toilet for me and two carers, a hoist system and a height-adjustable changing bench. If there is no toilet that meets my needs, unfortunately we cannot go to that place. It is very difficult and very restricting.' Matthew desperately needs Changing Places toilets to be installed in public places. As he explains, this would open up a whole world of possibility to him. 'If there were Changing Places toilets in public places it would make such a difference to me, in fact I would say it could be life changing. For some disabled people like myself it can mean the difference between getting out and living your life, or staying in.'*

## **Craig (19) and his mum Jenny**

*Craig, from Angus in Scotland, loves visits to the cinema, tenpin bowling and animal parks. Like any teenager, he loves to go shopping for clothes, DVDs and music. He is an*

outdoor person, and loves going out and about for the day. Craig has profound and multiple learning disabilities, needing total care and support for all his day-to-day needs. The lack of Changing Places toilets in public places means that Craig's life is restricted. Craig and his family have tried to find their own solution, but this is far from ideal, as his mum Jenny explains. 'We take Craig out in his minibus which has darkened windows so he can be changed inside. Craig is now fully-grown and taller than I am, and it is extremely difficult to change him in this way. I have to manually lift him out of his wheelchair and then kneel with him in my arms as I manoeuvre him through the door onto the floor of the van—it is absolutely backbreaking! If Changing Places toilets were provided in public places it would make a huge difference to both Craig's life and mine. How I would love to take Craig to the theatre, shows, and exhibitions! Visits that I can only rarely make with him now.'

### Sara (36) and her sister Linda



Sara, from Nottingham, is severely disabled with cerebral palsy and needs 24-hour care. She lives in her own bungalow and receives many hours of support from her sister Linda, who is determined to give Sara the chance to enjoy many of the things in life that other people do. That's why she takes her out somewhere every day—to the shops, the pub, drama classes, or the local Church Fellowship. 'But every time we go out,' Linda explains, 'it's like the clock is ticking—we can't really stay out for longer than three hours at a time. That's because there simply aren't any toilets anywhere that Sara can use, ones with a hoist and a changing bench. Instead we have to come all the way back to Sara's bungalow, so she can go to the toilet in her own bathroom, where there's a hoist. This means that we're pretty much restricted to local journeys. Changing Places toilets would make a huge difference to our lives, giving us freedom and choice, and stopping us from worrying every time we go out.'

The Changing Places campaign has invited groups and individuals across the UK to get involved. The Changing Places Consortium includes Mencap, PAMIS, Nottingham City Council, Dumfries and Galloway Council, the Department of Health Valuing People Team and the Scottish Executive Same as You Team. Some of the campaign's achievement to-date are:

- ◆ The number of public Changing Places toilets on the UK map has increased from eight to 32.
- ◆ 30 venues have committed to install a Changing Places toilet in the near future.
- ◆ Plans to install Changing Places toilets in Asda supermarkets and other key venues are being developed.
- ◆ Eight venues with Changing Places toilets won a 'Loo of the Year' award, and Nottingham City Council also won a national Community Care Award.
- ◆ Significant progress has been made to secure a change to British Standard 8300 (which gives recommendations for the design of new buildings to meet the needs of disabled people) to include Changing Places toilets.
- ◆ A factsheet on the legal issues associated with Changing Places toilets has been produced by the Changing Places consortium, together with experts in law and disability and moving and handling policies.

The incredible support and hard work of campaigners up and down the UK country has greatly contributed to this success. Many campaign groups have been formed and are making significant progress locally. In particular, local efforts in Bradford have led to the opening of seven Changing Places toilets with plans for even more, and mums Julie and Alison have been successful in getting Changing Places toilets installed in their local shopping centres. All this means real changes to the lives of families who had previously struggled to leave the confines of their house. As one family explains, 'We can now enjoy a day out just like anyone else.'

### Can Changing Places toilets also become a reality in Ireland?

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#### For more information:

Visit [www.changing-places.org](http://www.changing-places.org)

Get a local campaign pack from website: [www.changing-places.org/get\\_involved.asp](http://www.changing-places.org/get_involved.asp)

Join our web group to keep up-to-date with the campaign:

[www.changing-places.org/get\\_involved\\_emailgroup.asp](http://www.changing-places.org/get_involved_emailgroup.asp)

#### Editor's note:

For further background on the early stages of the 'Changing Places' campaign, see an earlier article by PAMIS member Anne Browne, on pages 14-16 in *Frontline* 60 (2004).



# Creative arts therapies service

An exciting new pilot project has recently been established by the Mountmellick Development Association in collaboration with a wide range of partners. Áthas is a creative arts therapies service delivered in the Laois and Offaly region to persons with a physical, intellectual, emotional, mental health and/or sensory disability. Funded until 2008, under the Enhancing Disability Services Program, the Áthas project is committed to providing a vibrant, client-driven service and creating meaningful change in community life.

Creative arts therapies (CATs) are the use of creative arts to achieve clinical goals with a range of clients who have needs in social, educational, psychological, intellectual and/or physical domains. Creative arts therapists are experts in using gentle, non-intrusive, non-verbal qualities of arts in conjunction with their insight and training in therapeutic relationships to develop programmes that help identify and address clients' needs. Creative Arts Therapies sessions do not take the form of art-teaching exercises. They focus on the process of creation and the triangular relationship between therapist, client and invoked image, rather than the end result or the acquiring of skills.

The service is provided on an outreach basis and is available to groups and individuals accordingly. Using the comprehensive network of facilities available through the participating partners and other community outlets, Áthas will develop a model of excellence that can be easily replicated throughout the country. The service has commenced by researching the range of people who can potentially benefit from creative arts therapies and a panel of qualified art, music, dance and drama therapists has been identified. Following the consultation and assessment, therapists will set up programmes with set targets for each participant to be reviewed on a regular basis and revised according to individual needs. It is envisaged that CAT therapists will complement the existing services of multidisciplinary teams and work in conjunction with other health and care professionals.

*Creative Arts Therapies sessions do not take the form of art-teaching exercises. They focus on the process of creation and the triangular relationship between therapist, client and invoked image, rather than the end result or the acquiring of skills.*

Project coordinator Annemarie Ní Churreáin, Research and Development Officer Eibhlín Clifford, and Administrator Kathleen Moore have been appointed to put the service in place and devise an action plan for the implementation of the programme. Their functions includes formative and summative evaluation which will inform the mainstreaming of the project once the pilot is completed.

A wide range of partners have been engaged in the development of this proposal and are committed to remaining as partners in the implementation of the service. These include the Health Services Executive, Laois County Council, the Disability Federation of Ireland, Laois Sports Partnership, Midland Arts (c/o Westmeath VEC), Mountmellick Development Association Social Inclusion, Midland Employment Support Agency, Laois VEC, Gandon Logistics (Rehab Group), Sisters of Charity of Jesus and Mary (Moore Abbey), the Irish Wheelchair Association and the National Council for the Blind of Ireland. This broad representation sets the foundation for a collaborative and inclusive approach, enhancing and adding value to existing disability services.

The Áthas project confronts the challenge of bringing together people with varying disabilities, who often previously worked in isolation within their cohort group, to harness the benefits of working together and learning from each other. A unique aspect of this programme is the long-term aim of the project to foster social inclusion and integration for clients by creating paths to social networking post-therapy. It is hoped that the development and expansion of these social networks will remain long after the project is finished, thus reducing future isolation.

Further information regarding the project and services can be obtained by contacting Annemarie Ní Churreáin (tel: 057-8624525, email: Annemariec@mdasiltd.ie). Current news and developments are available on our email Monthly Project Diary, available at the same email address.

# Frequently Asked Questions

## ***What exactly are Creative Arts Therapies (CATs)?***

Creative Arts Therapies use the creative arts to achieve clinical goals. Therapists are trained in one of the following disciplines: Art, Music, Dance or Drama. In the Creative Arts Therapy session the client may use art tools or art activities to realise their clinical goals. CATs are often referred to as 'expressive therapies' as the client is encouraged to express his/herself in a non-verbal way.

## ***What skills do I need?***

No skills are needed to participate in a creative arts therapies session. Therapists do not teach skills and will not assess images produced during the session. The focus is on the creation process rather than the resulting art product.

## ***What is the difference between arts activities like drawing and creative art therapies?***

Arts activities may have a therapeutic side effect or a general positive impact on well-being. A creative arts therapist manages a referral by consulting with the client, assessing the need and developing a therapy programme that will allow the client to realise clinical goals.

## ***Can Áthas assist someone who wants to engage in arts activities and not in therapy?***

Our service is a creative arts therapies service. We do not deliver arts activities or organise arts events. However, we have compiled a useful database of contact details for tutors, teachers, individuals and groups working in the area of arts and we are happy, where possible, to point questioners in the right direction!

## ***Who will deliver therapy programmes?***

Only professional therapists can deliver therapy. All our Creative Arts Therapists are qualified to clinician level, are in professional supervision and will receive ongoing in-house Áthas training.

## ***Where will therapy sessions take place?***

Áthas services are offered on an outreach basis and normally take place in facilities belonging to the referring organisation. In the instance where no facilities are available to facilitate sessions, Áthas may (subject to availability) be able to offer an appropriate space at the Mountmellick Development Association.

## ***Who can make a referral?***

A health or care professional, someone with a knowledge of the medical history of the client can complete a referral form (with the authorisation of the client). Self-referrals can be made, but referrals forms must be accompanied by a GPs letter.

## ***Once a referral is received by Áthas, what happens next?***

Once a referral has been received, the applicant will receive a letter of acknowledgment from the project. During the next ten days, subject to the availability of a therapist and project resources, a therapist will visit (the client) to carry out a consultation.

## ***What happens during a consultation?***

During a consultation, the therapist will identify the clinical 'need' and may ask for information regarding social and medical circumstances. The therapist will answer any questions or concerns, explain more about the project, services and the various types of creative arts therapies.

## ***How long does a therapy programme last?***

The needs of each client will vary. As a general guideline, Áthas therapists may spend up to six-weeks assessing the client. The length of the actual therapy programmes will also vary.

## ***Does Áthas offer any post-therapy support?***

A unique part of the Áthas project is that, where appropriate, we hope to connect clients to social groups and organisations in their area following the completion of their therapy programme. Our mission is to impact positively on lives by promoting *social inclusion* and well-being for adult persons with a disability.

# Looking after your breasts



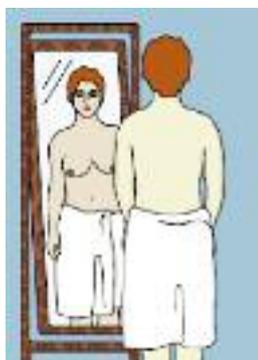
**B**reast cancer is considered to be one of the most common cancers to affect females. According to Davies and Duff (2001), women who have never given birth have a statistically higher risk of developing breast cancer. Women with an intellectual disability are living longer and in the main do not have children and are therefore considered more at risk of developing breast cancer. Davies and Duff (2001) propose that more information should be provided for women with an intellectual disability and their carers on how to access existing services and what to expect when they do. In this issue I will look at what you and your carers can do to support yourself in looking after your breasts. I will highlight some examples of literature and training material designed specifically in easy-to-read format for people with an intellectual disability.

It is very important that we look after ourselves and keep healthy. We need to look after all parts of our body—head, heart, arms, legs, tummy and breast. We can do this by eating well, resting, exercising and keeping a regular check on our bodies.

A good time to check your body could be when you are having your shower or bath. You should check your breasts regularly and become familiar with their shape and size. This way you will become aware of any changes that might occur. It is very important that you let your carer or family member know about changes so that you will be looked after immediately. If you notice something different about your body—such as a rash, a lump or soreness that was not there before—you should

let your carer or a family member know. Your breasts may feel full and tender just prior to your monthly periods, in which case it is better to check yourself during or after your period.

Breast awareness should be part of your overall body awareness. If you are familiar with your breast now, then you will be more aware of any changes that may occur and this will be your prompt to seek help without delay. There may be many reasons for changes to occur and these may be



Checking for breast changes in the mirror

harmless, but they need to be checked in case there is a small chance that they could be the first sign of cancer. Remember the sooner this is reported the sooner treatment can begin.

Attending a BreastCheck clinic is very important when you reach 50 years of age. This free service is funded by the government. Breast screening is an important way of checking for breast cancer.

Health screening programmes are an important way to detect unmet needs (Cooper *et al.* 2006). However it is suggested that accessing these services for people with an intellectual disability entails overcoming quite a few barriers, and the need for tailor-made clinics should be considered. For whatever reason you need to have your breasts screened, here is some information that you may want to know about having a mammogram breast screening.

You can decide if you want to go for breast screening by

looking at the information in a booklet explaining more about screening. Booklets are available online at [www.breastcheck.ie](http://www.breastcheck.ie).

Consider who you want to come along with you (family / carer) and check that the appointment date suits you. Arrange with the clinic if you need any additional help—climbing stairs, waiting in a queue or reassurance. You will need to take your top and bra off for the examination, so wear something comfortable and easy to remove. When you go to the clinic you may have to wait a while, so be prepared for this. When it is



Taking a Mammogram picture of your breast

your turn you will be asked to get changed in a dressing room. This will mean taking off your top and bra and then having your mammogram. Your carer / family will not be able to go with you, but the staff at the clinic will be able to look after you.

A mammogram is the name for an x-ray (film photo) of your breasts. This is done to look for signs of disease in your breasts. An x-ray plate will be placed on top of your breast to take the picture. This may feel cold or a little uncomfortable, but it should not hurt. The radiographer will take two pictures of each breast, you have to try to stay very still so that the pictures will be very clear.

When the x-rays are taken, usually two of each breast, you will be asked to wait in the changing room until they are checked, to be sure the pictures are clear. You will then be told to get dressed and you can go home with your carer/family. You will not be given results that day, as the x-rays will need to be very carefully examined. You will be sent a letter with your results a couple of weeks after your appointment. Most women are found to be healthy, but if you need further tests you will receive a letter telling you about it.

BreastCheck is a national screening service in Ireland that provides free breast cancer screening services for women aged between 50 and 64 on an area-by-area basis. BreastCheck has developed a detailed information booklet aimed at women with an intellectual disability and/or carers entitled *A Guide to Breast Screening*. found at [www.breastcheck.ie](http://www.breastcheck.ie)

**Liz Mc Keon,**  
Nursing Lecturer,  
Dublin City University

## Suggested reading

BreastCheck 2008 [www.breastcheck.ie](http://www.breastcheck.ie)

Cooper, S., Morrison, J., Melville, C., Finlayson, J., Allan, L., Martin, G. and Robinson, N. 2006 Improving the health of people with intellectual disabilities: Outcomes of a health screening programme after one year, *Journal of Intellectual Disability Research* **50** (9), 667-77.

Davies, N. and Duff, M. 2001 Breast cancer screening for older women with intellectual disability living in community group homes, *Journal of Intellectual Disability Research*. **45** (3), 253-7.

NHS Cancer Screening Programme 2008  
<http://www.cancerscreening.nhs.uk>

# How do we support people with disabilities to have meaningful lives?

**D**arcy Elks, from Pennsylvania, came to the Sisters of Charity Services in the Midlands—St Mary's, Delvin and Moore Abbey, Monasterevin—to meet with stakeholders, parents, service users, staff and managers with a message about inclusive lifestyles in a mainstream society. Darcy has lifelong experience in the process of de-institutionalisation; indeed, she worked as a volunteer in Willowbrook on Staten Island—which, during the 1970s, housed 5000 people with developmental disabilities. She knew from that formative experience that 'one person can make a difference' and that 'our mindset powerfully impacts on what we offer people and how our assumptions can have a positive or negative impact on those we support.'

Darcy continues to work as an advocate for people with disabilities in Pennsylvania, now with more vigour than ever. Her daughter Mary, who is a vibrant 16-year-old with Down Syndrome, prompts her to think outside the box in terms of how we craft the individual supports that people need to have a customised service. Darcy refers to philosophical assumptions about beliefs and she holds that 'having a vision flows from beliefs'. She fights against the reduced identity that is circumscribed by the 'I can't, versus I can, perspective.' She refers to a passage in the Old Testament: 'Where there is no vision, the people perish.'

Darcy is an exponent of socially valued roles—suggesting that we ask ourselves the question: for people of this age and gender, what does Irish society have to offer? Then 'go for it!' Quite simply, she reflects on a person's identity in terms of personality, interests, gifts, calling, talents, competencies, dreams, roles, relationships, life experiences—and a clear understanding that if one is living with impairment, 'what and how does it impact on lifestyle and identity?' Darcy is convinced the society is a better place if everyone is present and she regrets the 'life-wasting experience of negative roles that people with disabilities can experience in terms of rejection by broader society, i.e. the eternal child which becomes self-fulfilling, the lifelong client, the person who lacks control of their own life, the object of pity, and the burden of charity—versus positive roles that we experience, such as that of colleague, partner, sibling, home owner, voter, employee, car owner, professional, sports fan, consumer, etc.'

From social role valorisation (SRV), which derives from Wolfensberger's teachings, the enablement, establishment, maintenance and/or defence of valued social roles for people with intellectual disabilities are paramount. From Talcott and Parsons, a social role may be defined as socially expected patterns of behaviour, responsibility, expectation and privileges. Darcy imagines that people were thinking about roles for you before you were born. She refers to model coherency and conceptualises roles as pathways that bring richness that impact on what we could call 'a good Irish life'. Roles have a powerful impact on the image that one has in the eyes of others, including status and reputation. Further to this, the image that one has in their own eyes—self-mage

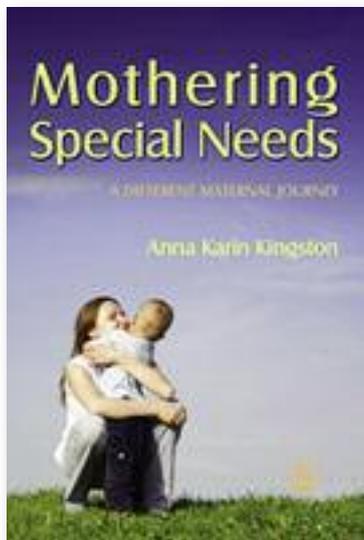
including an image of acceptance, belonging, association, relationships, autonomy, freedom, personal growth, opportunities, the material side of life, and lifestyle. This can negatively impact if people live in 'staff-land', with only paid people in their life. Darcy suggests that model coherency (i.e., 'is it a good fit?') can be achieved by 'walking with people in their life's journey'.

While a lot of Darcy's message is deeply philosophical and challenging, it also points to a dramatic change in the way that we consider service delivery to people with intellectual disabilities. She gives the example of her own daughter Mary, who at sixteen has a vision of a life built on her identity as a young woman, rather than somebody who, after leaving school, will be fast-tracked to a sheltered work environment. This also holds true for many young Irish people who require optimal individualised service planning, not just being offered off-the-shelf services.

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l-r: Karina Wallis, Sr Ann Devine, Darcy Elks, Sr Kathleen O'Connor



**MOTHERING SPECIAL NEEDS: A different maternal journey**, by Anna Karin Kingston. (2007), Jessica Kingsley Publishers, London. ISBN 798 1 84319 543 5.

This book is like a gust of wind through the literature involving parents of children with special needs. As Christopher Gillberg, Professor of Child and Adolescent Psychiatry,

says in his introduction to the book: 'it should be required reading for all involved in supporting families who struggle with a lifelong disability.' In her research between 2001 and 2004, Anna Karin Kingston interviewed 18 mothers about their experience of parenting children with autism, ADHD or Down Syndrome. The mothers' voices are powerfully exposed in the book, speaking with an openness which was no doubt facilitated by Kingston herself, who is the mother of a teenager with complex needs.

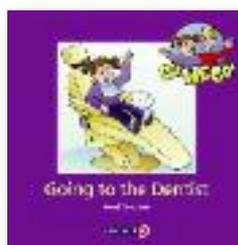
Chapter One provides an introduction to the text. Chapter Two: 'The challenge of maternal voices', discusses the existing literature on mothers and summarises the policies and legislation on disability in Ireland. The mothers' constant fighting for services, their relationships with professionals and service providers and the themes of grief, stress and coping are discussed in Chapter Three (Maternal Coping). 'Maternal work and employment' considers the work involved in mothering a child with special needs and how this impacts on the mothers' personal and work-related choices and opportunities. The point is made that while fathers can take the maternal role in the family, it is mainly mothers who carry out maternal work. Mothers' relationships with fathers, extended families, the public and Catholicism are explored in Chapter Five. Of particular interest is Kingston's analysis of what society tells us is a 'good mother', versus the idea of a 'bad mother'. The final chapter draws together the various themes, exploring different ways how mothers of children with learning disabilities may be supported and empowered.

*Mothering special needs* will strike a chord with many parents and advocates. Ultimately it argues that mothers should be supported to voice their own needs, as well as those of their family, as opposed to silencing these needs in their maternal work for the child with learning disability. For service providers and professionals the book will prove an uncomfortable read. The unsatisfactory nature of service provision is a recurrent theme in the mothers' stories. Their

sense of struggle and battle to have their children's needs met is enough to burst any bubble of professional confidence or pride. Accounts of both good and bad professional practice are given and the lack of a coordinated efficient service is apparent. As a Swedish journalist living in Ireland since 1989, Kingston provides an interesting perspective on the cultural context, history and evolution of Irish service provision. The qualitative research approach allows her passionate and political voice to come through strongly in this feminist work which can be read at many levels. Some readers will find the mothers' stories enlightening in themselves; others interested in a substantial academic discussion will go into more depth. The book is both an emotive and enlightening book and, indeed, it should be required reading for those interesting in improving service quality.

Anna Karin Kingston has a PhD in Social Sciences and is currently a member of the MA in Women's Studies teaching board at University College Cork. She is one of the founder members of the Association for Research on Mothering – Ireland (ARMI), Department of Applied Social Studies, UCC. The book is available via the Jessica Kingsley Publishers website at [www.jkp.com](http://www.jkp.com).

**Ciara Maye,**  
**Child Behaviour Therapist,**  
**Brothers of Charity Roscommon Services**



**ONCE UPON A TIME—Off we go!** by Avril Webster. (2007). Speechmark Publishing.

RRP £6.99 each

Each book is 16pp, 210 x 210mm



The series of books is available in all good bookshops.

*Going to the supermarket*  
ISBN: 978 0 86388 630

*Going to the dentist*  
ISBN: 978 0 86388 631 7

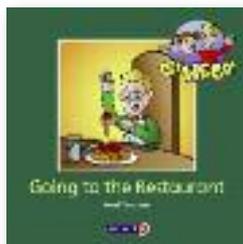
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To be published in 2008:

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*Going to a birthday party*

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*Going to the optician*

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*Going to buy shoes*

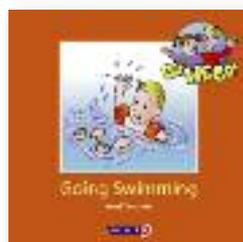
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*Going to buy clothes*

ISBN: 978 0 86388 660 7

*Going on a plane*

ISBN: 978 0 86388 661 4



Little did Limerick-based Avril Webster know when she created books at her kitchen table to help her disabled son Stephen cope with everyday activities, that they would lead her to a publishing contract for a series of six books. In just over a year, from those homemade versions, her first series is now published, with another six to follow in 2008.

Seeing the benefit Stephen was getting from the homemade books, Avril set about adapting them for Stephen's classmates. With the help of illustrator David Ryley (whose close family friend Christia attends the St Vincent's Special School, Lisnagry, with Stephen) Avril created the *Going swimming* book. Things took off from there. The sample spreads were shown to Sarah Miles, Managing Director of Speechmark Publishing, at the Children's Book Fair in Bologna, Italy. Sarah saw the potential for the books and contracted Avril to produce the first series of six books for publication in 2007.

With invaluable input from Avril's two other children, Michael (6) and Rachel (4), and from other parents, teachers and speech and language therapists, the books are now published. The *Off we go!* books explain 'what comes next' on an everyday outing, such as going to the dentist, thus reassuring the child and encouraging cooperation in each situation. By reading the book together at home and preparing for a new task or event, a child can manage the stages more

easily, ultimately reducing stress for themselves and those around them. The books can also be taken along to the actual event. The first series includes *Going to the dentist*, *Going to the doctor*, *Going to the hairdresser*, *Going to the restaurant*, *Going to the supermarket*, and *Going swimming*.

The *Off We Go!* books proved to be extremely helpful in preparing Stephen for the activities covered in these stories. Stephen loves books with pictures and the author found these an effective way of communicating with him. Stephen and his friend Christia appear in the books, as well as in the Off We Go! logo.

Each book contains colourful illustrations, with 12 pages of text, a length recommended by speech and language therapists. Multi-ethnic characters appear in all six books, so readers can 'get to know them'. Each picture is clear and uncluttered, and a clock has been used in all the stories to represent a period of waiting or the time for an activity to finish. The simple text uses basic vocabulary which can easily be made more complex if needed, but together with the pictures will help to give structure and routine to children of different ages and abilities.

The *Off We Go!* series provides an invaluable resource for professionals, parents and carers of children aged 3-7 of all abilities, and particularly children with intellectual disabilities or autism. The books have also proved very helpful for children where English is a second language. Due to the success of the first six titles in the series, six more are planned for publication in 2008. Each book is a simple, clear uncluttered analysis of a task; it can be used to prepare for an upcoming event and to support the child during the event. Each book has the same look and feel, and uses the same multi-ethnic 'family' of characters, some of whom have a disability, which promotes familiarity and learning. The books can be used as part of a child's Individual Education Plan to help them to experience new activities and to achieve developmental milestones.

Avril Webster lives in Limerick. She and her husband Robert have three children; their eldest son Stephen has a moderate to severe intellectual disability. Avril has been a full-time carer for Stephen since 1998. Supporting her son involves working with his teachers and therapy team to achieve developmental milestones, fundraising, and attending events on issues related to disabilities. Avril is a volunteer on the Lisnagry Association, Limerick, and also does voluntary work for Enable Ireland.



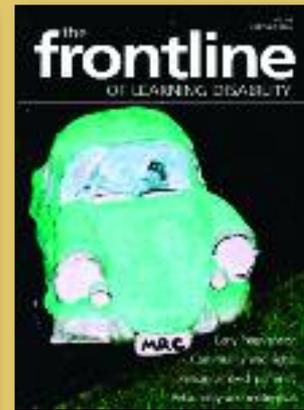
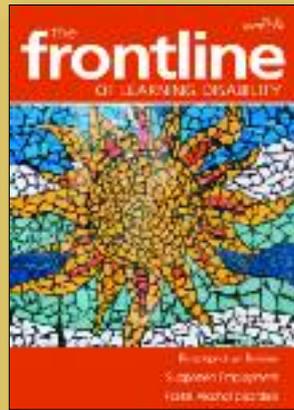
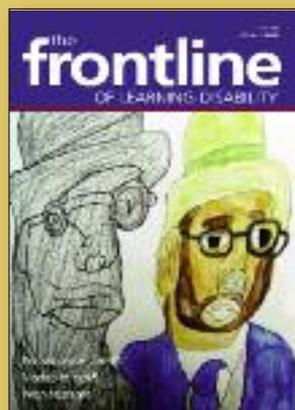
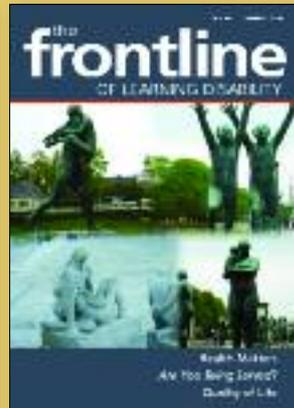
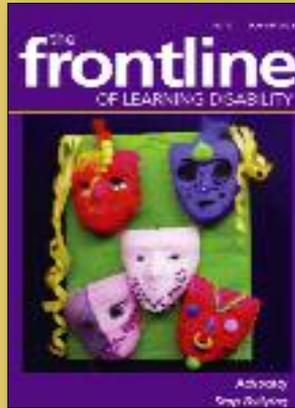
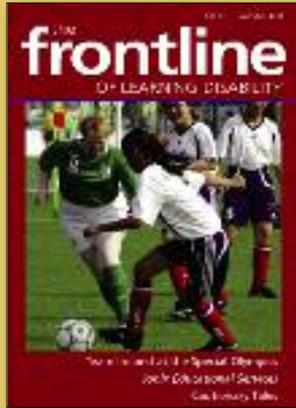
The dentist uses a special mirror and  
a shiny tool to check my teeth.



The dentist looks into my mouth and  
counts my teeth - one, two, three...

# the frontline

OF LEARNING DISABILITY



Wordwell Books Ltd. have published and supported Frontline magazine for 71 issues, from its foundation in 1989. Now, because of changing circumstances, Wordwell has withdrawn, and the Editorial Board is engaged in securing a new structure for the magazine.

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