
NATIONAL FEDERATION OF VOLUNTARY BODIES

Providing Services to People with Intellectual Disability

New Ideas – New Approaches Supporting Innovation

in Services & Supports to People with Intellectual Disability

**Tuesday 23rd & Wednesday 24th October 2007
Hotel Kilkenny, Kilkenny, Ireland**



Easy Read Version

Acknowledgements

The Board of the National Federation of Voluntary Bodies would like to thank the excellent work of our conference organising group:

- Brendan Broderick, Sisters of Charity of Jesus & Mary
- Breda Crehan Roche, Ability West
- Brendan Sutton, Cheeverstown House
- Brian O'Donnell, National Federation of Voluntary Bodies
- Brigid Butler, St John of God Hospitaller Services
- Caroline Looney, National Federation of Voluntary Bodies
- David Dunne, St. Michaels House
- Edel Tierney, National Federation of Voluntary Bodies
- Francis Coughlan, SOS Kilkenny
- John O'Dea, Western Care
- Mary Barrett, National Federation of Voluntary Bodies
- Richard Collins, Brothers of Charity, Clare

Thanks also to our plenary speakers and to our Session Directors. We would also like to thank our conference participants and in particular those who use our services for sharing with us their personal views and opinions.

The conference was organised and supported by the National Federation of Voluntary Bodies Secretariat.

National Federation Secretariat Staff:

Brian O'Donnell, Chief Executive

Edel Tierney, Director of Research & Policy Development

Maria McMahon, Office Manager

Caroline Looney, Administrative Officer

Mary Barrett, Administrative Officer

Brendan Dolan, Administrative Officer

Brian Donohoe, Clerical Officer

Breda Casey, Policy Development Co-ordinator

Jillian Sexton, Human Resource Training & Development Co-ordinator

Alison Harnett, Informing Families Project Co-ordinator

This document was written and produced by Brian Donohoe, National Federation of Voluntary Bodies.

Day 1

Morning Session



Mr. Brian O'Donnell, Chief Executive of the National Federation of Voluntary Bodies, welcomed everyone to the conference & introduced Mr. Jimmy Devins, TD, Minister of State, Department of Health & Children who opened the conference

Minister Jimmy Devins

"I would like to say that I am pleased to have been invited here today by the National Federation of Voluntary Bodies to open this conference. As the new Minister for State at the Department of Health and Children., I always take opportunities like this to learn about all areas which involve Disability.



I would like to stress the Government's continued commitment to the on-going development of services for people with disabilities. Conferences like this can give us all possibilities for new approaches for future service development. By working together we can bring about a disability service worthy of the Ireland of the 21st century.

All that's left for me to do is thank all involved in this conference. Personally, I would like to thank you for giving me the opportunity to open the conference and wish the event every success.

*-Opening Address Dr. Jimmy Devins, TD,
Minister of State,
Department of Health & Children*

Mr. Brendan Broderick

Can I start by thanking you for supporting this event? The Organising Group have been working very hard over the past six months setting it up looking at several versions of what it might look like. I hope it works for you.

Too often we speak on behalf of those who use our services. What this event is about is working out how we can provide services in a new & better way. This can only be done by everybody working together. When I say everybody I mean people with disabilities, their families, service providers, staff in the services, funding organisations etc.



As a national organisation of service providers we believe in providing a person-centred service and we know there is a difference between the service we actually provide and the person-centred service that we should be providing. A person-centred service is the standard we must always achieve.

The objectives of this conference are:

- To show those taking part new ways of working
- To show good examples of work both in Ireland & in other countries
- To start looking at new ideas to help us deal with the challenges we will face.
- To get people to work together and come up with ideas in a new way.

This event will be as good as its participants.

*Mr. Brendan Broderick
Chairperson
National Federation of Voluntary Bodies*

How to get more value from this conference

For his opening talk of the conference, Mr. Ed Bernacki spoke about how everybody at the conference would have ideas but that there was no point in having ideas & not acting on them or making notes & never looking at them again

In closing, Mr. Bernacki asked people to think about why they were here, and about the challenges they faced, both personal challenges and organisational challenges.

He explained that the main problem to be faced was to bridge the gap between thinking & doing

After Ed Bernacki, a break was taken to absorb all the information that the participants had received. Once the break was over Dr. John O'Brien gave his keynote address to the conference.

Dr. O'Brien talked about the UN convention and what it said about the rights of people with disabilities to live and work in places of their choice the same as everyone else but went on to say that this still doesn't happen in reality

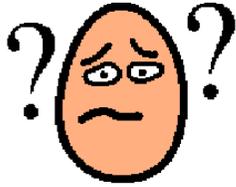
What is the reality?

We know that people with disabilities have the right to work in places that they choose yet the reality is that hundreds of people spend most of their day in created work places i.e. sheltered workshops



We know that people with disabilities should choose where they live in their community. The reality is that hundreds of people are still living in institutions. Why is this?

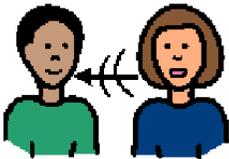
Dr. O'Brien also spoke about how service providers think for those who use their services by not asking them where they want to live or work or by thinking they know the answers for example: someone is better off in a sheltered workshop all day or safer and happy at home with their family or in a service with other people with disabilities



'If you're not part of the problem, then you can't be part of the solution'

If we decide to make real changes that will help us to support people to be really included in society we will meet challenges because what we are trying to do now goes against what we have always been paid to do which is the following.

- We provide places for people to live and spend the day
- We provide professional care and treatment
 - We keep people safe and make them happy
 - If someone needs on-going paid help as part of their life they should be able to decide how the money that pays for that help is used.
 - If someone needs help to make decisions the decision-making should happen as close to the person as possible, & should reflect a persons own interests.



- The system of rules within which people have to work must be clear and open in order to make it easy for the person to take control of their own support.
- When someone is using their personal money they should be free to spend their funds in the way that makes best sense to them, without restrictions.
- People should explain their decisions and to share what they have learnt.
-

*Dr. John O'Brien
Inclusion Associates, USA*

Afternoon Sessions

The afternoon parallel workshops were 75 minute sessions divided between presentations & 30 minute solutions session where the people taking part had to answer two questions what does different look like? & how do we get there?.

Parallel Workshop 1 – How can we work together creatively?

This session explored how managing change can be achieved by working together. The Thought Provocateur (person who suggested ideas) was Mr. Larry Walsh, Director of the Health Services National Partnership Forum. Mr. Walsh spoke about how we can have world class health and social services by working together. This could only happen with a lot of change but if changes were made by everyone it was possible

There was only one presentation in this workshop and it was given by three speakers with a lot of experience in managing change and working in partnership; The three speakers included a service provider & HSE director in Mayo. They were joined by service users who spoke about how advocacy works in partnership with Management. They also spoke about advocacy and working together in a number of areas – advocacy groups, partnership in action.

This joint presentation, called ***'Partnerships deliver quality results for people'***, talked about how important social networks & quality of life are in trying to achieve equal citizenship for people with disabilities

Participants of this session suggested solutions to working creatively in a spirit of partnership:

What does different look like?

- Develop vision of partnership between staff, service user & family
- Staff need more support in how to be better listeners.
- Involve service users in recruitment of staff who will be supporting them.
- Involve service users in management – decisions that affect service users directly.
- Find a better way of communicating if we are really going to take service users seriously.

- Have more meetings between service managers & service users.
- Support a national network of self advocacy groups

Parallel Workshop 2 – How can we help people have their say?

Parallel Workshop 2 looked at ways of consulting the people who use services and their families. Two people from inclusion Ireland spoke about how people with disabilities have the right to speak for themselves or be supported by someone to do that. They asked everyone at the workshop to think about **‘How can people have their say?’**



The first presentation was called **‘People Connecting – A New approach to community participation and inclusion’**, and



was given by two members of the Community Participation & Inclusion Committee. They talked about how a workshop was held in order to ask people with disabilities what stopped them from being included in their community. At the workshop, everyone was given time to give their opinions, **giving people their say**. The speakers said that people with disabilities wanted:

- To work and live in the place of their choice,
- Information to be easy to read and understand.
- Extra money to be provided to people with disabilities.

These issues were brought to the Board of the National Federation. The workshop findings and recommendations have been published in an easy-to-read document, *“People Connecting”* and a copy was given to everyone. The presentation finished with the speakers asking two questions

- What can **you** do to bring about change?
- What can **you** do to support people with intellectual disability to be really included in the life of their local community

The second presentation, ***'Bridging the Gaps - Empowering the person at the centre'***, was presented by two people from Brothers of Charity Services, South East. This presentation talked about how person-centred planning can be very positive for the person who uses a service and his/her family.

The final presentation of the session, Called ***'Seasamh- A home grown model of advocacy'***, was a group presentation by members of the Seasamh Parliament. This presentation explained how the Seasamh Parliament was formed & how it helps people have their say by giving them the chance to speak out about issues that affect their lives.

Participants of this session suggested solutions to help people have their say:

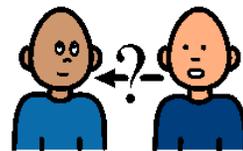
What does different look like?

- Having control over of my life
- Decision making based on rights for people.
- Cultural change based on the true value of inclusion
- We need to change our language
- We need to really listen
- Support should be invisible
- Power needs to be balanced
- Decision making should be inclusive

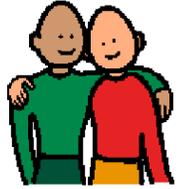


How do we get there?

- “people supports“ rather than “services“
- Create opportunities for cultural change leading to inclusive decision making
- Rebalancing of the power situation.
- Being more accountable
- Changing of service provision outside of 9-5
- The real change will come when the money goes to the person
 - The person using the service should be at the centre of the decision making

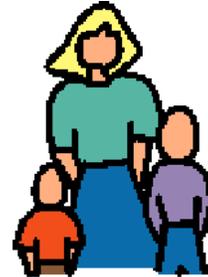


Parallel Workshop 3 – How can we respond creatively to what we hear?



This session explored new ways of providing real choices for people. The (**Person suggesting ideas**) for this workshop was from the National Institute for Intellectual Disability Trinity College. She said that responding creatively meant really listening to people in services & having real & positive relationships based on trust.

The first presentation '**A Good Life**' - **The central role of the family as leaders in Canada**, the speaker presented a simple introduction to the story of PLAN – a family leadership programme which leads to a service based on choice for the person. He also said that what is really needed is an ordinary Good life for the person who is using the service.



The next presentation was from three speakers from Trinity college Dublin. In their presentation each of the three speakers gave different points of view on the development of the **Certificate in Contemporary Living** which is a two year Certificate Course for people with intellectual disability. It is run by the National Institute for Intellectual Disability at Trinity College Dublin. Students are given the choice of course they want to study. This course offers 'real' choice & 'real' education



The next presentation was by a speaker from KARE **From sheltered work to supported employment - An innovative approach** This was about best practice in the area of employment for people with disabilities. He said that a lot of people with disabilities still spend their day in special centres or sheltered workshops and don't get the chance to do real work in the community.



Participants of this session suggested solutions suggested from this session

What does different look like?

- People get the service they want instead of the service that's there
- People decide how money is spent.
- Staff free / able to respond creatively
- Every person has a support Network
- People supported to take opportunities in their communities

How do we get there?

- Moving the balance of power from services to people, families
- By supporting people to have control over their own money
- By providing relevant training
- By changing culture in services
- By building meaningful relationships
- By building strong community links / partnerships



Parallel Workshop 4 – How do we promote best value?

The aim of this workshop was to look at how services are funded and to see if services can be funded in a way that makes it easy for services to be person-centred & also makes the service use funding better. In suggesting ideas a speaker from HSE West talked about how decisions were made about funding services for people with disabilities & how this process could be made better.

The first speaker was a Senior Lecturer at the University of Kent, In her presentation called ***'From Institutional to Community Settings - Successful strategies in Europe'***, The speaker talked about the move from closed institutions to community living in over 20 countries in Europe & talked about how people with disabilities lived in these countries & how their services are funded.

The next speaker was a social worker from a service in the North East. In his presentation '**Are Value for Money and Common Sense Enough?**' the speaker talked about two different types of service he had worked in & looked at both types of service to see if they provided value for money both for the service & for the people who used the service. He also said that flexible types of services found it hard to compete against more traditional services

The final speaker of this session was from St. Anne's Services, Roscrea. This presentation called, - **A flexible approach to service provision in the community**', the speaker talked about the service she worked in and said it was 'a flexible needs led service'. She said it was a very good example of a person-centre support service which was funded by the HSE and that the funding was used according to best practice.

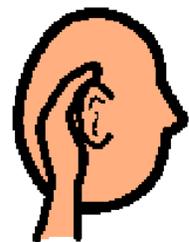
Participants at this session suggested some solutions to promoting best value

What does different look like?

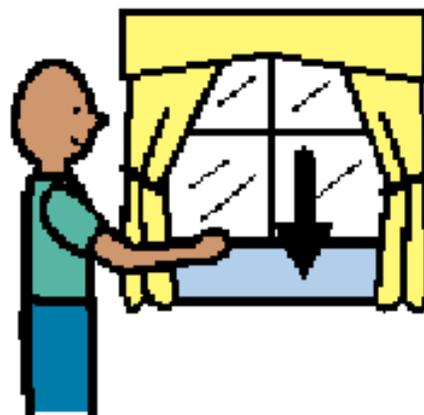
- Special supports would only be funded in cases where the mainstream can't provide...
- No new buildings.
- People would write their own service plans with independent support.
- Service funding would be controlled by person using the service
- Only services that support real inclusion would exist.

How do we get there?

1. We would change our mind set
 - Recruitment would have service user involvement.
 - Changing the route of money to be nearer the service user.
 - Change the government department that funds disability services.
 - Training staff to listen – "There is listening and then there is listening".
 - Direct Payments to Service users
 - Legislate for direct payments
 - Address duty of care issues arising from direct payments.



- There needs to be safeguards to prevent abuse of funds e.g. enhance the role of MABS.



Day 2

Morning Session

The Day 2 Morning Session was chaired by Mr. Dermot Ryan of the Department of Health and Children. The session opened with a presentation from Mr. Ed Bernacki entitled '**How to stop killing ideas**'. In this presentation, Mr. Bernacki asked the question: while it is easy to work with people who think like you?, how good are you when working with people who do not think like you? The speaker explained how some organizations are better able to kill ideas than to capture them and put them into action.



The second speaker of this morning session was Mr. Peter Cassells, He is a former General Secretary of Congress of Trade Unions and has negotiated five National Partnership Programmes. In his presentation, entitled '**Building Ability for Change**', Mr. Cassells talked about the changing shape of the disability sector, driven by the National Disability Strategy, He said that the biggest challenge for Disability services will be to manage change but that relationships between Disability Services & government departments, state agencies & local service providers needed to be good. He said it was also important to have good relationships between management & staff in services.

After Mr. Cassells' presentation the participants once again split into the parallel workshop of their choice to address one of four more questions:

- How can we promote health & wellbeing?
- How can technology assist?
- How can managing risks create opportunities?
- How can people get their money?

Parallel Workshop 5 – How can we promote health & well-being?

This session was about making the health of people with disabilities better. Two speakers were a parent & person from services were speaking about how people with disabilities were more likely to have health problems & that health checks should be done as much as possible.

The first presentation was called ***'I'm Ok, are you Ok? - a nurse-led health check to meet the health needs of people with intellectual disability'***, and was presented by a Clinical Nurse Specialist with St. John of God Services. She explained how the service ran a nurse led health-check project which met the health needs of people using the service.



The second presentation called ***'How can we improve health and well-being in persons with Down Syndrome who are deeply forgetful?'*** was given by a speaker from the Daughters of Charity service who spoke about what is being done by that service for people with Down syndrome who are forgetful. The speaker said that the service was trying to see how many people were at risk in the future & how staff can be trained to meet their needs.

The last speaker of the session, with his presentation ***'A Way to Grow-working with adults with intellectual disability.'***

The speaker spoke about his project A Way to Grow which involved working with adults with intellectual disability to improve health & well being. The speaker said how this project had been up in running in many residential & day services within his organisation & was showing good results.



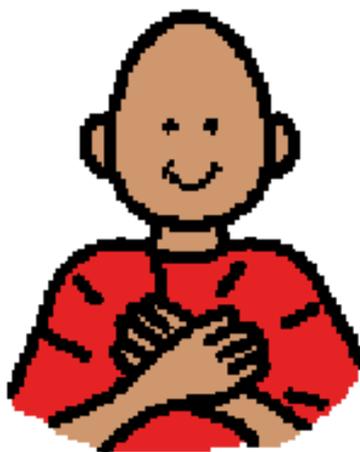
Participants of this session suggested solutions to improve health & well-being

What does different look like?

- Services would be based on need instead of age.
- Proactive Health Promotion.
- GPs & Consultants would be trained in disability specific areas.
- Accessible information for everyone.
- Different would look different but not stand out.
- Include me don't provide the answers for me

How do we get there?

- Work together to provide information & education
- Develop Information packs for Stakeholders
- Linking with National Initiatives
- Communication through multi-media
- Education in how to convey diagnosis and prognosis in all areas
- Link health and well being



Parallel Workshop 6 - How can technology assist?

This session was about discovering how technology can help people to live more fulfilling lives.

a joint presentation was given by ***the Speech and Language Therapy Accessible Information Working Group*** The speakers were from different services and spoke about how symbols & picture were often needed to help people with disabilities understand & give their opinions.

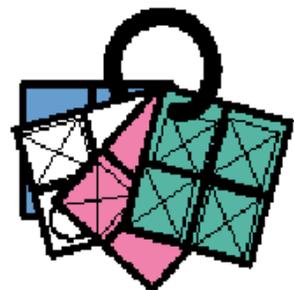
TATE(Through Assistive Technology to Employment) ***'Assistive Technology - New Frontier*** The speaker told how the TATE project helped people with disabilities to become more independent & employable which helps them live more fulfilling lives.

The last speaker was a speech & language Therapist with COPE Foundation. The speaker spoke about how COPE Foundation were going to run a pilot project which will involve the development of Information & Communication Technology which supports video conferencing. This link will provide a support service from a distance.

Participants of this session suggested solutions to how technology can assist

What does different look like?

- Better communication
- Set up a central database
- Person centred technology
- Cost of person centred technology factored in to any new developments



How do we get there?

- A National policy on communication.
- Set up National Working Group linked to Government Agencies.
- Set up a National Disability Forum on (person centred) technology
- Find new & better types of technology

Parallel Workshop 7 – How can managing risks create opportunities?

This session was about allowing & supporting people to take risks without blame. Two parents spoke about their experience of being parents of children with disabilities & the fears & worries they had for their children. They said that risk cannot be completely taken away so parents need help to overcome the fear of risk so that their children can have full active lives.

The first presentation, called ***‘Covering Our Buts’***, the speaker said that risk management was a problem solving process that involved everyone including the person, the family & the service. He said it was about negotiating. He said this meant getting to “yes” by getting past “No-But”. He said that families could help by sharing responsibility which would mean the service giving up some of it’s power to the family & the person using their service.



‘One by One: A new approach to supporting people with challenging behaviour’ was given by a speaker from Brothers of Charity who talked about positive support for people with challenging behaviour which involved working with one person at a time instead of groups of people together which the speaker said just did not work.

‘Sexuality and Relationships - Walking the tightrope’

The speaker spoke about the right of each person to a sexual relationship & this includes people with disabilities. The speaker also talked about the fears of family & service providers and that this was a barrier to people with disabilities expressing their sexuality



What does different look like?

- Well managed risk Strategy.
- Person Centred approach.
- Balance between risk & safety.

How do we get there?

- Change culture
- No blame environment

Parallel Workshop 8 – How can people get their money?

This workshop explored how people can have control over their money. The speaker was a service provider who spoke about the need to involve people who use services in the getting & spending of the money which has been given to the service provider for them.

The first presentation ***‘Planning, Designing and Delivering your Own Services – The Microboards Approach’*** The speaker explained how the microboard project would help both people with disabilities & their families plan & design their own service to meet their personal needs & to give them control over their own money.

The second presentation ***‘Direct Payments – The UK experience’*** The speaker explained the In Control project which is a pilot project in the UK which gave people with disabilities easy access to their money to spend in a flexible way which gives them more freedom & independence.

Participants of this session suggested solutions to people getting their Money



What does different look like?

For the Individual

- People have their own bank accounts with free access
- Choice of services

For the system

- Shift of power from service to service user
- New methods of payment such as Microboards, direct payments.
- Better communication between services & funding authorities.

How do we get there?

- Banks will be more accessible to people with disabilities
- Advocacy/self advocacy
- Right to direct payments
- Services to be more accountable
- Expand microboards & other such arrangements

Final Session

Ed Bernacki gave his wrap up by asking everyone at the conference to think about ways to change & improve the services in which they work.

After Ed Bernacki, A group from Brothers of Charity Clare gave a 30 minute presentation called '***From Institution to Own Home-Transforming a Service***' In this presentation the group talked about how they changed their service from large centres in Ennis & Limerick to the communities where the people using their service were from and wanted to be. They also showed a DVD telling the story of a man who returned to his home town after spending years in an institution.

Dr. John O'Brien gave his closing speech in which he talked about the on-going struggle for equality for people with disabilities. He said the task ahead was all about crossing boundaries so we can get better quality of life in services

After Dr. O'Brien, Mr. Brendan Broderick, Chairperson of the National Federation of Voluntary Bodies gave the final speech of the conference.

"I'd like to share one final thought about the work we have just heard about from the people in Clare. Over the past two days, we have spent a lot of time thinking about new ways of working. About person centred services which will lead to inclusion. We are always complaining about not having enough funding but over the past two days we have learnt how to use what we have better.

I would like to thank all who took part in the parallel sessions. I would also like to thank today's presenters from Brothers of Charity Clare for telling us about their on-going work in Clare. I would like to say a special thank you to our international presenters: Ed Bernacki, for taking us where we needed to go & to John O'Brien for sharing his wisdom & his years of experience in disability services.

I would like to thank Francis Coughlan for all his help. I would also like to thank the Federation staff & the organising group especially Brian O'Donnell & Edel Tierney who made this event possible."

Entertainment

Members of the Dreamtime Studio performing group gave a performance of their show 'Out of the shadow into the light' for the people attending the conference during dinner

After this show a film called "The Goldfish Bowl" was shown. The film was produced by "Glasseye Productions and funded by the Department of Arts Sport & Tourism. The most important thing to say is that the script was written by the actors themselves.



The Goldfish Bowl told the story of Steve & Ellen And their search for true love which faces opposition from the management of the service they both go to.

All of the entertainment was greatly enjoyed and appreciated by all who attended the Conference.

Presentation to Children's Sunshine Home

During dinner a special award was given to Ms. Phil Dunne from the Children's Sunshine Home for their achievement in 2007 for being the winner of the Health Services Innovation award. This is given for innovative work done in the health services.



Conclusion

This conference was about finding new ways of working in services & better ways to support people with disabilities. This was done by getting the people who attended the conference to take part in it through parallel workshops which included the finding of solutions.

In the Generating Solutions workshops those taking part came up with answers to the two questions that were put to them. What does different look like? & how do we get there? The answers were all written down by the Rappateur (person taking notes).

From these answers came common themes/important points from each of the 8 workshops. The common themes from all 8 workshops were put together and can be summarised below.

For the future we need to:

- Develop Partnerships
- Change Culture
- Shift Power
- Develop listening skills
- Share decision making
- Look at how to achieve person-centred services
- Support people with disabilities to have control over their money