

**Summary of
The Immersion Project
From Planning to Action
Towards having a good life**



22nd – 26th April 2013

**The Malton Hotel,
Killarney, Co. Kerry**

Purpose of the Immersion Project

From Planning to Action - Towards having a Good Life

Introduction



The National Federation of Voluntary Bodies provide a wide range of supports to service providing organisations to help them engage with the changes that are now in train. Central among these supports is the Immersion Transformation Project, which involved an intensive five-day orientation to individualised ways of working, followed by a year-long supported change programme.

The core aim of Immersion is to promote deep-seated reform in how people with intellectual disabilities are supported in order that they might live lives of their choosing and occupy socially valued roles in their communities. The programme addressed three critical questions: *why* is change needed?; *how* can quality individualised supports be developed?; and *what* specific steps must be taken?



It was led by international experts, John O'Brien, Michael Kendrick, Hope Leet Dittmeier, Pat Fratangelo, Janet Klees, David Pitonyak, and Patti Scott.

Important contributions were made by representatives of Irish organisations Western Care, CoAction, and Muiriosa sharing their experience of developing individualised supports.

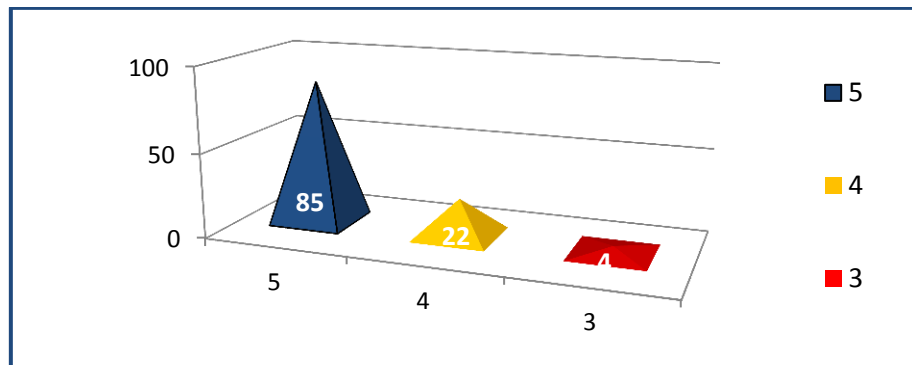
The Conference Delegates

Over 300 people attended the week long Immersion Event in Killarney made up of representatives from over 25 organisations. The programme's unique style placed the focus on creating an **internal dialogue in organisations between the key stakeholders** as a key change strategy



Evaluation Findings on the Immersion Event

Overall how useful was the Immersion event to you on a scale of 1-5 with 5 being high?



Comments included:

"It has given me greater understanding and valued information to enable me to go back and inspire my fellow colleagues and in turn influence and enhance the lives of our service users".

"Eureka moment for me. 30 years working with people with I.D – David Pitonyak made sense of it all for me"

"It has completely changed my thinking and I will hopefully change my approach to enhance lives".

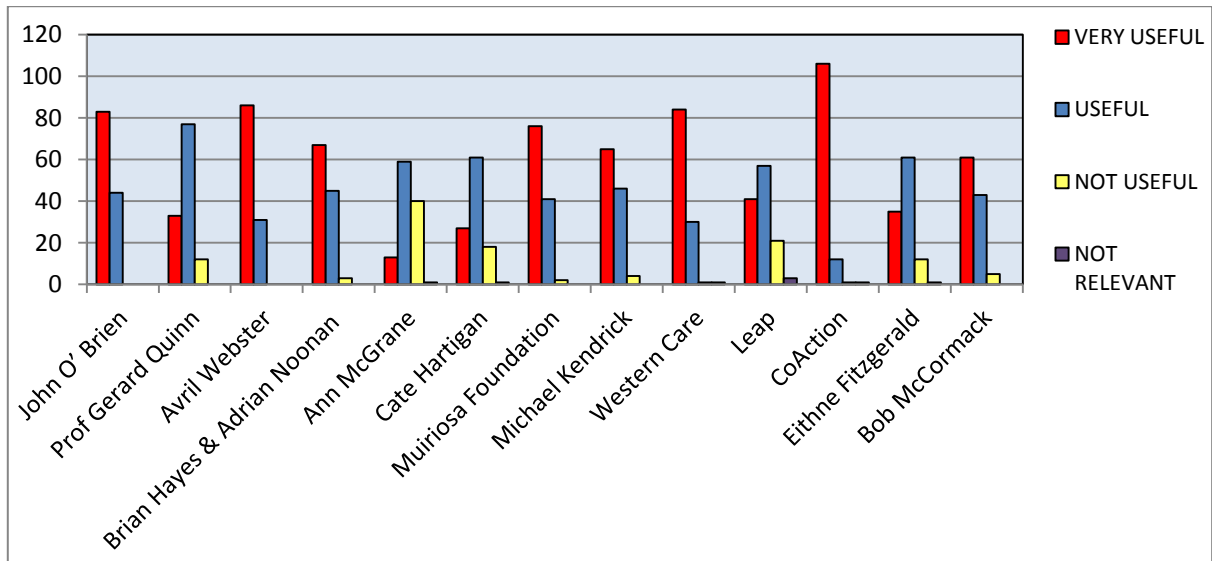
"I would give it 10. It was probably the most influential week I have had in my professional carrier. Amazing experience".

"It will have a huge impact on the work I do and the way I see people and listen to them. It also had an impact on a personal level".

"Fantastic learning and networking opportunity. Found answers to many, many questions and have come away inspired and motivated".

"It will change my perspective and the way in which I work and deliver a service to people".

Presentations Evaluation Findings



Overall the presentations were found to be very informative with perspectives heard from self-advocates, family members, Irish organisations, Government bodies and International experts setting the scene for change.

Delegates commented favourably on the examples shown by Muiriosa, Western Care, Seasamh and CoAction and the importance of seeing what can be achieved but also the necessity to hear the pit falls encountered.

Comments included:

- ◆ Interesting
- ◆ Excellent
- ◆ Really inspiring!
- ◆ We could learn a lot from Western Care.
- ◆ Great to hear of an Irish organisation making changes - more of this please!



The most popular presentation was made by Ann and Caroline from CoAction

Their honesty and openness in demonstrating their clear determination to live a life of their choosing proved very popular and was followed by an insightful letter written by Caroline's mother explaining her fears and worries resulted in comments such as:



Excellent! Both presentations were given from the heart.

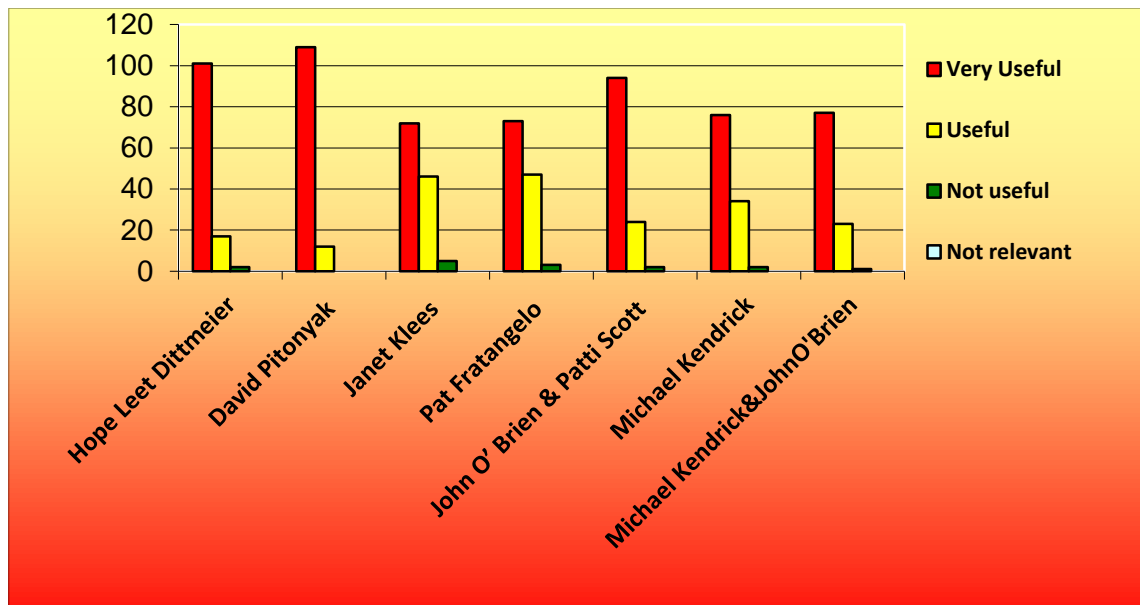
Two heart rendering presentations. Fabulous honest letter from mother (should be shared).

Inspirational stories about what is possible given support and taking risks to give people their own lives. Barriers have to be demolished to progress.

'Personal stories are always inspirational and motivational – both ladies are testament to their mere resolve and personal spirit and thankfully they received supports to live their lives as they wanted' Wonderful inspirational presentations from Ann & Caroline. Loved it!

Absolutely fantastic presentation. Inspiring mum's letter was brilliant

Workshop Evaluation Findings



Key messages from workshop 1

The Personal Journey to Citizenship

Hope Leet Dittmeier and David Pitonyak

- The importance of the 'Discovery' of the person
- Focusing on peoples abilities
- Understanding challenging behaviour
- How serious a problem loneliness is for people



Comments included:

"Eureka moment for me. 30 years working with people with I.D – David Pitonyak made sense of it all for me"

This allowed me to ask myself the questions about the service I work with. Although we have made community connection, have we made community relationships?

The "real" discovery – looking deeper is key – open mind, open heart, open ears, open questions

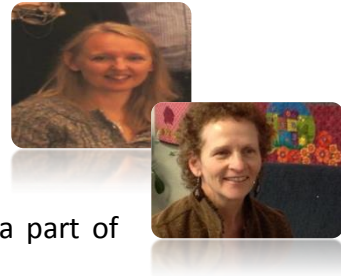
Excellent morning with Hope. Road to "Discovery" would be a very useful tool and would like getting training in this area at a future point. Very relevant to individualised supports for a service user.

Key messages from workshop 2

Supporting Relationships

Janet Klees and Pat Fratangelo

- Seeing each person as unique
- Building relationships is key to a life of meaning
- Developing roles to become part of community
- The change in staff roles
- The difference between living in a community and being a part of community



Comments included:

Excellent workshop – in particular the lived experience of people who are supported and have been listened to.

I loved how real Janet's presentation was and felt it was very applicable to the Irish situation.

Pat gave us a vision of what we should be aiming for.

Key messages from workshop 3

Exploring the Different Dimensions of the Transformation Challenge

John O'Brien, Patti Scott and Michael Kendrick

- Supporting people to develop a network of friends
- Supporting the person to 'create a home' by connecting to natural supports
- Brokerage
- Agency transformations from fixed models to personalised support arrangements



Comments included:

The session provoked a lot of questions and issues for further debate in organisations, service users, and families in Ireland to move forward.

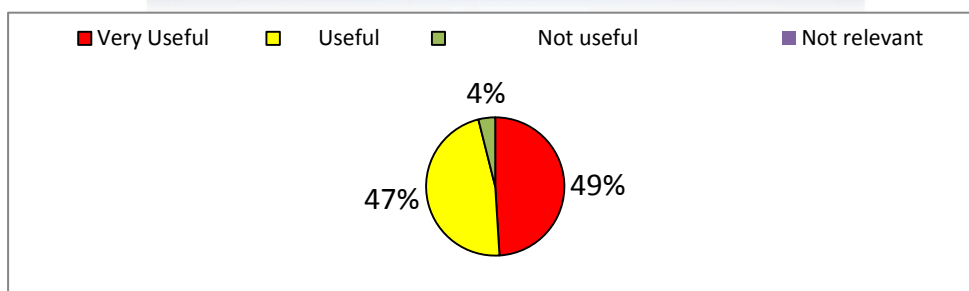
Mike gave us a clear 12 step programme to follow to allow us to begin our journey.

Excellent! Patti made it very real, tangible and practical.

Coming from an agency it's good to understand how to start the change and keep it going!!

Found round-up by john – amazing!

Panel Discussion Evaluation Findings



Panel Key Messages:

Despite the long intense week there was good attendance at the Closing panel which provided a forum to reflect on the learning from the week and to identify issues in planning ahead. Key messages included:

Mr Adrian Noonan & Mr. Brian Hayes, Seasamh – We have a right to a good life – make the person the focus and provide the right support, let the person lead and most importantly see people's ability. Listen to people about what they really want – we all have a voice – people stories help us to visualise the journey to happiness and independence. You work for us – we do not work for you.





Ms. Suzanne Maloney, HSE - The excuses and barriers have been slowly unpicked during the week. Being part of a team sharing different perspectives has been invaluable. The importance of relationships and discovery and the difference between activities compared to roles. We will follow up between the NDU and the National Federation of Voluntary Bodies.

Mr. John Hannigan, Sunbeam - Believe that we can change. Person directed is a lot more than person centred. Listening and discovery is critical. The centrality of the right to risk and the importance of the rights relationships. Learning that loneliness kills. Immersion has started the process of working together as cross stakeholders – we need to keep this going. Do not compromise on moving to support a good life.



Ms. Avril Webster, Parent - Education and information benefits everyone - both families and providers are all at different stages. **It has been a wonderful week of learning and for me is life transforming.** There has also been the gift of friendship. We will be looking at connecting and supporting each other and share this conversation. How do we get good information out to families?

Mr. Paul Doherty, Genio - There has been significant investment at all levels in the week. There has been unequivocal significant learning. People have said that they found the week illuminating on understanding beneficial individual supports and had revelatory moments. The cross stakeholder groups working together have been very important. Learning of the impact of past trauma triggered by present threat was very powerful. Also trauma for families and for organisations when they are unable to provide what is needed. The spirit of the conference is about seeing each other as human beings to work together to work things out – we need to keep this going.



Evaluation Form Findings on the Questions Posed

There was very substantial detailed feedback given to the questions provided on the Evaluation forms. Below are representations of the answers given.

What did you learn from this event?

- The importance of the 'Discovery' of the person
- The need to listen
- That family need support
- Changing mind sets



- For services to get out of the way so people can have a good life
- The difference between social access and social inclusion
- The importance of relationships

How will this learning impact on you?

People reported that Immersion will have a significant impact on the way they support people going forward. They felt reenergised and refocused. It has given them a changed outlook on the way they will work.

In response to – ‘What was most challenging?’ Answers included:

- ◆ To have the guts to close the book on what I thought I had learned the last 24 years and to be prepared to start a fresh new book to fill with new and fresh ideas to go forward with.
- ◆ Service Brokerage as I am afraid for families who will fear it rather than see the possibilities for their family member.
- ◆ Thinking of how much we need to change, how we do things and trying to figure out how we are going to start.
- ◆ The feeling that what we have been doing for the last number of years has no significance in empowering and stimulating change / make opportunities. Some of the stories have been tough to listen to. The need to question everything.
- ◆ Hearing that what we thought was us offering a person centred service was not really giving people a “Good life” just good care.

How can the National Federation of Voluntary Bodies through the Immersion Project support you in the year ahead to make the changes you have committed to?

- ◆ Provide More Training
- ◆ Mentoring & Support
- ◆ Facilitate connection Between Organisations
- ◆ Reports on Change in Organisations
- ◆ Follow-up Meetings

Comments:

"I think it would be positive if the Federation sets review dates over the next 12 months, for example every 3 months, where all the groups would have to send someone to make a presentation on what progress, no matter how small, has been made by their service".

"Mentoring – showing us what is happening in the disability world. Put us in touch with resources".

"Share this information on the website. Be a resource to us and link us in with other organisations".

"We need to link more organisations to establish how they have progressed and perhaps the Federation can facilitate additional learning for staff who couldn't attend Immersion".

"With contacts information. Training events".

"Knowledge of initiatives going on around the country that may be useful to other agencies trying to do the same things".

"Encourage services with backup and follow up supports. Encourage services to be creative in how they provide services to people. Provide training to providers on how they engage with people using their services and their family".

"Provide information, including accessible information that sets out people's choices in life and services".

"As with all Federation events the whole week was organised and managed to an incredibly high standard – from planning right through to implementation"

People reported that despite Immersion being extremely intensive and needing a lot of energy, people found it extremely informative and rejuvenating.

The Drama group had a mixed response but was strongly favoured by the self-advocates who were one of their key intended audiences.

While significant measures were taken to make information accessible, more work is needed in this area.

But overall a life changing week.

