

MAKING HEADWAY

Bringing **positive change** in the lives of those affected by Acquired Brain Injury

Spring 2009 Issue



New Website Goes Live!

Inside

Making Headway is published by

HEADWAY

Bringing **positive change** in the lives of those affected by Acquired Brain Injury

Limerick Ball	2
Are you in need of hope and inspiration?	3
My Story, by Jim Hegarty	4
A Day in the Life of Information & Support	7
Research Round Up	10
Support and Empowerment for people	11

Making Headway is published by:
Headway, the National Association for Acquired
Brain Injury.

1-3 Manor Street Business Park,
Manor Street,
Dublin 7, Ireland
Chy No: 7417 Tel: (01) 810 2066
Fax: (01) 810 2070
Helpline: 1890 200 278
Web: www.headway.ie

The views expressed in this publication are those
of the contributors and may not reflect the views
and/or policies of Headway.

About Us:

Headway provides support and services to people
affected by brain injury. Founded in 1985, we also
work to heighten public and political awareness
of acquired brain injury and the impact it has on
individuals, families and carers.

Our Mission:

To bring about positive change in the lives of
those affected by an acquired brain injury.



Marathons

The Bupa Great Run is taking place on Sunday
5th April at 1pm in the Phoenix park. To run
for Headway contact Teresa (details as above)
Headway can provide sponsorship card and
t-shirt. Entry fee is €28. Entry forms and further
details from www.greatrun.org

Women's mini marathon

Takes place 1st June. Entry is available online from
today 26th Feb [www.florawomensminimarathon.
ie](http://www.florawomensminimarathon.ie) and also through the Evening Herald.

Participants must be 14 years or older. Entries must
be received prior to 21st April 2009. As above
T-shirt & sponsor card available from Headway

Lucan Disability Action Group

(LDAG) is calling on all 'drivers' to take part in their
6th Annual Charity Golf Classic in the picturesque
surroundings of the prestigious Hermitage Golf
Club, Lucan, Co. Dublin on Friday 17th April 2009.

For a team fee of €460 (4 players), participating
golfers can expect a leisurely day of golf followed
by a four course meal in the clubhouse and an
awards presentation later that evening.

Further information is available from Lucan
Disability Action Group, Unit 24 Hills Industrial
Estate, Lucan, Co. Dublin

Tel: 01-6100475

Email: info@ldag.ie

Website: www.ldag.ie

Calling All Golfers

Headway are looking for golfers to participate in
and also run golf classics nationwide. Headway
wants to enter the JP McManus PRO AM. For your
further information www.jpmanusproam.com

*Limerick Ball Photo – Caitriona Tierney of Q102/Limerick 95
FM with Headway's Aisling Burke (middle).*

Are you in need of hope and inspiration?

With the ever worsening economic environment, the threat of industrial unrest and the doom and gloom that is pervading society at the moment we could all do with a little inspiration in our lives.

Why not make an appointment to visit a Headway service in Dublin, Cork or Limerick and meet people who will inspire you and make you appreciate what you have, despite the demands for more taxes or levies or reductions in living standards?

There is a two way stand off argument continuing on the airwaves: *"the levy is unfair and targeting one particular sector"* from the unions and *"people are in secure jobs with good pensions"* from the Government.

What about the people who have been robbed of everything as a result of fall, assault, car accident or brain haemorrhage?

Brain injury is commonly known as a "hidden disability" and some people with brain injury and carers suffer in silence due to the effects of brain injury. They may have been robbed of the capacity to earn a living, to go to university or partake in society as full an equal members.

They may have been robbed of memory or insight into their situation and the consequences may have robbed them of the ability or confidence to communicate effectively.

Our job is to facilitate and enable the people we

serve to participate in society and community in meaningful ways. Despite funding cuts and knock backs our wonderful staff are motivated and inspired by the efforts of our clients to adapt to and accept new realities.

So if you are feeling bad, demotivated or financially poor why not get inspired and make arrangements to visit a Headway centre?

We have recently launched our new website which we hope all people with an interest in brain injury will find informative and refreshing.

There is a forum for people to share information and stories and offer mutual support.

We would also like to create a forum where professional people can exchange views and seek opinions and advice on clinical matters.

Despite the current economic environment we can not let down the people we serve. Statistics will show that in economic downturns volunteering increases and Headway needs volunteers at this time. Services are patchy and inadequate, a fact acknowledged by the HSE.

We need people to assist in our centres (after induction training), we need people to assist with our fundraisers such as our Annual Ball and we need a particular volunteer, with a knowledge of and passion for golf, to assist with Headway's attempted entry into the JP McManus Pro-Am in 2010.

Significant consequences of stock market collapse

The public at large are very concerned about the collapse of share prices, dividends, and investment returns. There is one group of particularly vulnerable people for whom this situation could be catastrophic and they are Wards of Court.

The Court invests settlements on behalf of Wards of Court – these investments, more than likely, have been affected by recent economic events. Parents and or nominated Committee Members

of Wards of Court need to be acquainted with the current situation of each investment as awards were calculated on the basis of a person's need for the whole of life.

Where does the burden of responsibility lie if the settlement is decimated?

If this is a concern to you please advise Kieran Loughran, CEO of Headway, in confidence, and he will attempt to link you with other interested parties, and appropriate advice.



Telling Tales

MY STORY by **JIM HEGARTY**

My name is Jim Hegarty and I'm married to Sheila and we have four children, three boys and one girl. Last year we had a welcome addition to the family, my first grandchild, Sean. I worked for 37½ years as a supervisor in Ballinahina dairies, this was then known as Dawn dairies and retired in April 2005 just before my brain injury.

On the 1st of September 2005 I went to bed early. I had a pain in my head for about two days and when I tried to get up in the middle of the night I fell back on to the bed. I next remember seeing two ambulance men and I don't remember anymore until I woke up in the hospital. I went for a CT scan, which I remember having and this showed a haemorrhage. I spent 8 weeks in the South Infirmery and have very little memory of it. I do remember one incident when I was feeling confused and thought I was being held against my will. A doctor came around and lent over my bed and I hit out at him.

This was very out of character behaviour for me and I was totally confused at the time. My balance and particularly my right side were also affected. After 6 weeks in hospital my memory slowly started to come back. My eyes began to open and I started to recognise my doctor and his entourage on his daily rounds. I then gradually started to recognise my family when they visited me.

When I left the South Infirmery I went home to my wife and children. I went for regular speech and language therapy and physiotherapy. I suffered with headaches and found that I got tired quite easily. I had difficulties with my memory and often had a problem recognising people when they would come to visit me. I found that I was quite low in myself and was spending most of my time at home, which was very different to my life before my brain injury.

A few months later I started in Headway's Day Service programme. We do a combination of group and individual work and I enjoy meeting with the other people in Day Services. I attend

on Tuesdays and Wednesdays and I really enjoy it. On Tuesdays we do "movement to music", "reeling in the years" and FETAC award art and design. I particularly enjoy "reeling in the years" as we discuss and reminisce on specific years in the past, which is good for jogging my memory.

We are now up to 1993. On a Wednesday we go out and about on the Headway bus and do different activities in the community such as visiting museums, art galleries, coffee shops and garden centres and are given specific tasks to complete with support. At the moment as part of our Art sessions on the programme we are doing a project for Brain Awareness week and the theme is "hidden key".

We are each doing an individual piece and they will all be exhibited in the Wilton library in Cork from the 9th of March for two weeks. We are all working towards our FETAC level 3 in art. My art work is a country scene and I'm enjoying this project. However I do face additional difficulties due to my eye sight deficits but it is not stopping me from completing my work for the exhibition.

I have also participated in the Community Access programme, which aims to encourage and support people to participate in social leisure and recreational activities in their local communities. I attended my local gym in 2007 with Julie, the Community Access Officer for a few months and I used the bike and the treadmill. I enjoyed attending the gym and my confidence and independence was increasing but unfortunately I developed a problem with my leg and I was advised to stay off it so I can't attend any longer.

Last year I was unwell and couldn't attend the Headway centre for about eight months. I met with Julie in my local shopping centre every Tuesday during the time I couldn't attend Day Services. I missed attending Day Services but found that participating in Community Access gave me an opportunity to get out in my local community, interact with other members of the public, it gave my wife a break and also made me feel that I was still linked to Headway and what was happening in the centre in Ballincollig.

There is no doubt but that my life is different now to before my brain injury and unfortunately my eye sight is deteriorating. I am now more reliant on my wife and can no longer drive. I miss the independence of just jumping in the car and heading off myself but I am very grateful for the support my wife and family have given me. I was always on the go and I particularly loved fishing but I unfortunately had to sell my boat after my ABI as I no longer had a use for it because I couldn't head out on my own. I also still suffer from headaches and tiredness. There is no doubt but that I have faced some huge challenges in the last few years but I have also had some particularly memorable days.

On June 19th of last year I got the opportunity to attend the Áras an Uachtaráin to attend a Forum on Disability: Access and Attitude. I met Paul and Julie, the Community Access Officers, in the train station in Cork at 7.00am and we got the 7.30am train to Dublin. We arrived in Dublin at 10.15am and the sun was shining. We got a taxi to the Aras and it was the first time any of us had asked a taxi driver to take us to the President's house!

We got on a bus at the front gate that took us through the gardens to the house and we went into a big meeting room. The president was the first to speak and welcomed everyone to the Aras. We then listened to various people speak about different abilities and disabilities and about the importance of supporting all people to reach their potential. We then went for a stroll around

the grounds and went into the main building for fingerfood and coffee. We took some photographs around the Áras as evidence that we were there! It was then time to head back to the train and we got back into Cork at 6.00pm after a very enjoyable day.

In September of last year I travelled to Spain for a very important event: my only daughter's wedding. Due to the difficulties with my leg I was worried that the doctors might try to stop me travelling but I knew that no matter what they said nothing would keep me from giving her away. Thankfully I was fit and well to travel in September and we had a great week in Spain and daughter's wedding went very well. We all had a fantastic day and I managed to stay awake until about 10pm when I was found fast asleep on a couch!

I still also have some great friends and we often meet up. I still love to go fishing and even though I sold my own boat and cannot go out alone, my friend has a boat and when the weather is good we head out together. We go to Roches point and then we generally head east. I love the peace and quiet of being out on the sea. I am following a healthy eating diet and catching and cooking fresh fish makes sticking to the healthy eating plan much easier and tastier!

Like everybody else I have hopes and dreams for the future. I hope to increase my days in Headway from two to three days a week. My youngest son has recently left for the blue skies of Australia and I hope that my wife and I will visit him for a month some time this year. I have always loved to travel and I have visited America and many countries in Europe and I have a long list of places I still want to visit. Mostly I want to live a long life and watch my grandson as he grows.

I am following a healthy eating diet and catching and cooking fresh fish makes sticking to the healthy eating plan much easier and tastier!

A Day in the Life of Inf

By Richard Stables

Information and Support Manager

[The scene is the Headway Information and Support Office in Manor Street, a haven of peace and calm. The Information and Support Line telephone sits silent on its cradle].

Ok, let's get going, I'll start with checking the emails, we get some interesting queries. Here's a family hoping to relocate to Ireland from abroad and wondering what benefits and services they're likely to get. A couple of public health nurses and a speech and language therapist have each requested some information packs to be sent out, and a few people have signed up to our regular e-Newsletter. A typical morning haul.

[phone rings]

A call from public health nurse asking about services available in Kildare.

Ok, need to check the website, make sure it's still there (it was attacked twice last year by hackers), need to update the news section to announce the launch of Brain Awareness Week. Mental note to speak to the man from Wexford who offered to write a blog piece for us.

[phone rings]

It's a call from person who is a little distressed and worried that she might have Alzheimer's disease as well as a brain injury. I emphasise that we can't give any medical advice but we discuss the ways that she can clarify her diagnosis.

Now, check out the new forum on the website. Who's registered, has anyone posted a comment? Do I need to respond? Seems to be a good solid core of people offering each other mutual support. Hope more family members get to sign up, they may not know about it yet, must get the word out.

Can I attend a meeting of the Family Carer Research group scheduled for later in the week? Possibly, if time allows. They produced some very good research recently on the health of carers which definitely deserves a wide audience.

[phone rings]

It's my colleague in Kilkenny who's had a query from the family of someone who's being discharged from a residential home and wondering what rights they have under the circumstances. We discuss various avenues of support and advocacy and suggest a conversation with the specialist advocate for people with brain injury based in BRÍ.

[phone rings]

Another Information and Support call, this time a social worker in Tallaght Hospital looking for placement possibilities and day care for someone with a brain injury. Discuss possibilities and waiting lists, send out the forms.

Print more fact sheets – these have proved very popular over the last 12 months. Must remember to upload the revised fact sheet on services to the website, where they're all downloadable.

Another email response arrives from our Information Needs Survey advertised on the website. Don't have time to analyse it now but it's all going help the design of a new leaflet we're doing with BRÍ and the Peter Bradley Foundation (funds permitting, of course).

Ok, have a bit of time now to edit a piece of video for the website. It was taken by our Rehabilitative Training service in Finglas and there are a couple of people telling their story that really come across well, positive stories of recovery. I'm really excited about the prospect of getting some video content available for people. A picture is worth a thousand words.

Ok, time for lunch

[back in the office]

[phone rings]

A call arrives. Are we familiar with difficulties following burst aneurysm? Reassure the caller that many of our current service users have similar

Information and Support

cause of injury. Listen to the caller's story, they are still coming to terms with the huge upheaval that is taking place in their lives. Sobering. Take some time to reflect on this call before carrying on.

My colleague is off to give a talk to Occupational Therapy students at Trinity College school of OT. I'm off to a meeting of the BRÍ brain injury advocacy project, need to check the Information and Support line is covered, we can redirect it to another centre if necessary. Isn't technology amazing? That reminds me, must check out the possibility of using Skype.

[3:45pm, back in the office]

[phone rings]

A call arrives. Someone interested in volunteering. Pass them to Fiona our Human Resources Manager. Hope we can make use of their time and energy.

Have conversation with my colleagues on Ideas – Should we explore social networking, Twitter, live chat, mobile text support, video support? How would we do these?, What level of resources might be needed? How do we know what works? That reminds me of an upcoming meeting of the Telephone Helplines Network, our next discussion will be on the subject of evaluation and evidence.

Suddenly realise we are half way through the month and we have to get more posters, flyers out. Keeping the profile of the service up is a constant challenge. How do we get brain injury on the radar? This is a constant question.

Check helpline emails, nothing new just now, gives me a little time to follow up on some outstanding queries. I'm trying to identify resources for someone with alcohol related difficulties and brain injury in West Cork.

Talk to our web developer about how we could improve the website. We are all delighted with the flexibility of the new site and the way it makes it so easy for us to update and put new information up. Talk to our referrals co-ordinator Ciarán who does a brilliant job handling all our new referrals. How long are our waiting lists? Am I giving out the

right information? Looks like Headway will need to expand its services to cope with mounting pressures.

Wonder how come there isn't more funding for brain injury services? Reflect on the ongoing process for developing a National Strategy for Rehabilitation Services. We put in a submission to the Department of Health and Children and HSE about this (did I upload that to our website? Yes, I did, relax!). Such a huge need, where do you start? I just wish someone would grasp the nettle and commit some resources and energy to creating a truly joined up approach.

Ok, an email has just come in from one of the trainers in our Cork service. The clients there have produced some great digital photographs, I need to get these up on the website. It shows the type of thing that people in our service can get involved with and hopefully will give the trainees a sense of achievement to have their work displayed.

Check out our online feedback system where callers and emailers can comment on our service. Come across this comment:

"Headway staff didn't just give me information – I was also given follow up help. Now I feel ready to take the next step."

I remember what our work is all about.



Research Round Up

Doreen Hoerold

Living with neurological conditions: the impact on carers.

The focus of this year's Brain Awareness Week is on the impact of acquired brain injury on carers and family members. The following selected articles describe different approaches to this topic. The results from these and other studies highlight the many ways in which relatives and other caregivers are affected by acquired brain injury, and the requirement to identify and meet the potential needs of these individuals.

Jumisko, E., Lexell, J. & S`derberg, S. (2007)

Living With Moderate or Severe Traumatic Brain Injury: The Meaning of Family Members' Experiences.

Journal of Family Nursing, 13 (3), 353-369.

In many cases, family relatives are the primary caregivers of individuals with chronic brain injury. Jumisko and colleagues describe a study which aimed to achieve an in-depth understanding of the meaning of a family member's experience when an individual sustains a traumatic brain injury. The research team note that such detailed investigations, although they should be the starting point for all efforts to understand carers' well-being and psychological health, are in fact very rarely conducted. In this study, the researchers conducted detailed semi-structured interviews with eight close relatives of individuals with traumatic brain injury. These interviews were recorded and transcribed, and interpreted in terms of common themes that emerged from all participants. This analysis showed that relatives experienced a great degree of anxiety and sorrow during medically critical periods of illness, and that they felt forced to rapidly take on an entirely new role in life. This new role involved great responsibility, for which carers felt unprepared. This sense of increased responsibility never ended, and relatives struggled to balance the taking of power from the ill person and the support of independence. Carers reported that relationships within families deepened, and that this gave some strength and alleviated suffering. Relatives also revealed a great sense of despair, mixed with a "willingness to fight on" regardless – a

Carers reported that relationships within families deepened, and that this gave some strength and alleviated suffering.

process which the researchers interpret as a sign of courage. A deep compassion for the ill person, and a willingness to put their own health second emerged, as well as a struggle to be strong enough to support the ill person. Carers' experience included not being taken seriously in their suffering (especially by health care professionals) and at times being treated with a lack of dignity. Finally, relatives in this study reported never losing hope for a better future. Overall, carers were keen to narrate their stories, and expressed a sense of relief at being able to reflect on and share their experiences with a wider audience by participating in the research.

Ergh, T.C., Hanks, R.A., Rapport, L.J. & Coleman, R.D. (2003)

Social Support Moderates Caregiver Life Satisfaction Following Traumatic Brain Injury.

Journal of Clinical and Experimental Neuropsychology, 25 (8), 1090-1101.

This study set out to measure the specific factors that determine life satisfaction among caregivers of individuals with traumatic brain injury, which has not been investigated in many previous studies. By life satisfaction, the researchers here mean the extent to which a carer's satisfaction with his/her current life status matches the standard of the life they would like to live. This includes a long-term perspective, as well as short-term concepts such as emotional reactions to more immediate, situational factors. Sixty pairs of participants took part in this study, each pair consisted of an individual with traumatic brain injury and his/her active caregiver. Data collected from

these participants included both characteristics of the individuals with TBI (such as injury severity, time since injury, neurobehavioural and affective functioning) and those of the caregivers, such as age, and perceived social support. A number of interesting findings emerged: Firstly, the severity of the traumatic brain injury itself was not related to caregivers' life satisfaction. Additionally, the results suggested that older caregivers reported more life satisfaction than younger caregivers. The analyses also showed that the amount of social support caregivers perceived to have available to them, along with neurobehavioural and affective functioning of the TBI individuals, can be used to predict the level of life satisfaction for a caregiver. In a final analysis, the authors show that among those caregivers with the lowest level of social support available, life satisfaction depended significantly on the patients' cognitive functioning, and also on their degree of symptom unawareness. What these findings suggest is that adequate levels of social support for family members and other carers for patients with traumatic brain injury can play an important role in determining how well carers cope with the many adverse effects of brain injury. This level of support available to carers may in some cases be more relevant than injury severity or specific symptoms themselves. At Headway, we facilitate support groups for family members and caregivers throughout the year. Additionally, we provide individual counselling and other psychological services.

Rivera, P.A., Elliot, T.R., Berry, J.D. & Grant, J.S. (2008). **Problem-solving training for family caregivers of persons with traumatic brain injury: A randomized control trial.**

Archives of Physical Medical Rehabilitation, 89 (5), 931-941.

In this article, the authors describe and evaluate a specific psychological training programme for caregivers of individuals with traumatic brain injury, designed to decrease depressive symptoms, health complaints, and improve psychological well-being. Previous research with caregivers of individuals with acquired disability has suggested that those with excellent problem-solving skills are less likely to develop symptoms of depression, anxiety and poor health, compared to those

...the severity of the traumatic brain injury itself was not related to caregivers' life satisfaction.

carers with poor problem-solving skills. Thus, the researchers set out to investigate whether it is possible to train family caregivers in the use of effective problem-solving skills, and whether this training would lead to improved psychological well-being among caregivers. Thirty-five family caregivers completed the problem-solving training programme, which continued over the course of one year. Training consisted of four training sessions every four months in the caregiver's home, and additional telephone sessions once per month. During the home sessions, the researcher guided caregivers' approach to problem-solving, using five basic principles: identify the problem, brainstorm solutions, critique the solutions, choose and implement a solution, and evaluate the outcome. Additionally, the researcher guided a discussion of the feelings experienced by the caregiver when encountering problems. A control group also took part in the study, which

consisted of a group of caregivers who only received monthly phone calls from the researchers, where education materials were reviewed for 10-15 minutes. This control group of caregivers had spent the same amount of time caring for an individual with traumatic brain injury as the group receiving problem-solving training, and was also similar to the treatment group in many other relevant ways, such as age, level of depression, sense of burden, etc. The data analyses revealed that the caregivers who received problem-solving training showed significantly decreased depressive symptoms, health complaints, and degree of dysfunctional problem-solving style. Importantly, the 'education only' control group showed no such improvement over time, which suggests that the problem-solving training had quite a specific effect, over and above the effect of receiving education alone. These results are important for increasing our awareness of the range of services that have been developed for carers. Problem-solving training may be a beneficial alternative or addition to other support services that can be provided to caregivers of individuals with traumatic brain injury. A useful expansion of this study would be to directly compare the efficacy of problem-solving training with that of other forms of psychological support for carers, especially with regard to long-term well-being of carers.

Support and Empowerment for people with ABI Through Independent Advocacy

Sarah Campbell, Advocate, BRÍ

BRÍ Advocacy Service for people with Acquired Brain Injury

“Advocacy is a means of empowering people, supporting them to assert their views and claim their entitlements and where necessary representing them and negotiating on their behalf. Delivering a professional advocacy service means providing a trained person, who on the basis of an understanding of a client’s needs and wishes, will advise and support the client to make a decision or claim an entitlement and who will, if appropriate, go on to negotiate or make a case for him/her.”

(Comhairle Advocacy Guidelines, Comhairle 2005)

We all need support and guidance from time to time in our lives, but who to ask and where to seek that help is not always that obvious. The prospect is even more overwhelming and intimidating for those with an acquired brain injury. Last year, Brí launched its Advocacy service to bridge this information gap and assist ABI sufferers and their families as they negotiate the services ‘minefield’.

The BRÍ Advocacy Service is an independent, confidential and free advocacy service which works to support and empower people with acquired brain injury, to promote justice and create equality of opportunity and participation. At the moment, it is the only advocacy service in Ireland that works exclusively for people with an ABI. The Dublin-based service advocates in the areas of Health, Rehabilitation, Housing, Social Welfare, Education and Employment, but this is not an exhaustive list.

Advocacy is concerned with taking action to strive for one’s rights and entitlements and making sure one’s opinions are heard, interests are respected and needs acknowledged. Advocacy takes many different forms, from a parent acting to get what their child needs, to the health or social care teams working for their client within the system. And of course, there is self-advocacy, standing up for your own rights and entitlements. As a professional Independent Advocacy Service, BRÍ can add extra support and empowerment to the individual and/or their family.

The Service works in three ways:

- **Personal Representative Advocacy:** one-to-one, individual and personal;
- **Group Peer Advocacy:** meet to talk about experiences, share advice and information;
- **Lobbying Advocacy:** Bringing forward issues at policy level.

Personal Representative Advocacy

The BRÍ Advocate is trained to listen to a client’s needs and requirements and offer guidance in deciding the best way to achieve the desired goals. The Advocate works in partnership with the client and can represent and negotiate on their behalf.

Group Peer Advocacy

There are a number of Support groups that meet around Ireland to provide group peer advocacy, in a supportive environment.

The Dublin Support Group is facilitated by the BRÍ Advocacy Service and meets on the 4th Wednesday of every month in the Friends Meeting House, 4-5 Eustace St, Temple Bar, Dublin 2.

An effort is made to create an environment which is not only supportive but also an enjoyable social space, where the group share experiences offer the support of each other, combat isolation and decrease stress levels. The group is open to all with ABI, families and carers.

Lobbying

The BRÍ Advocacy service is active in highlighting service inadequacies to the various policy making organisations and vigorously challenges for better services in the areas of rehabilitation and support. The Advocacy service is also energetically campaigning to increase the number of Neurologists, Neurosurgeons and indeed Advocates around the country.

Contact Info

To get in touch with the Brí Advocacy Service for more information, call:

Sarah Campbell; (01) 235 5125 or
Gillian Quigley; (01) 235 5463

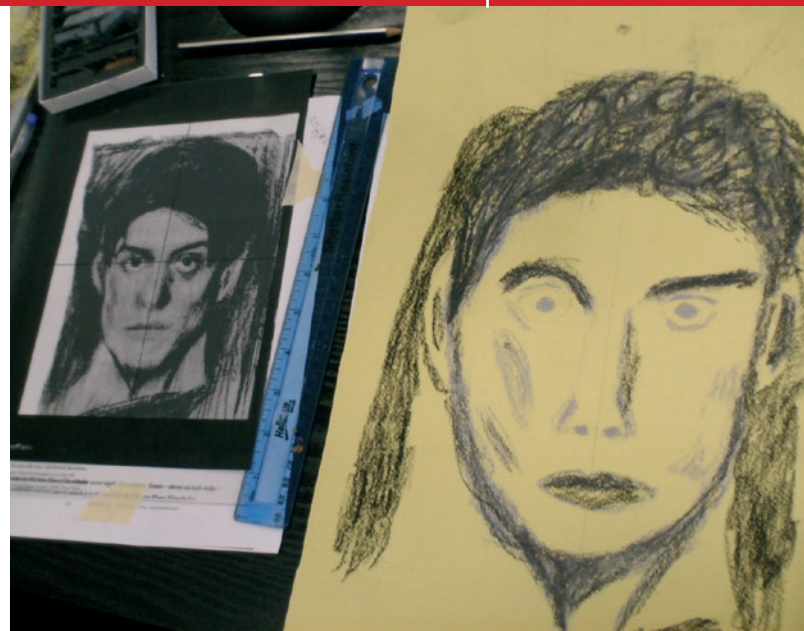
Research into Practice:

Exploring the experience of participating in an Art Based Cognitive Rehabilitation Programme

Aisling Burke, one of our rehabilitative training officers in Limerick, was part of a research team that looked at Limerick clients' experience of participating in a Cognitive Art Programme, which is part of their rehabilitative training programme. For this edition's "Research into Practice" section, she writes about the research project and what Cognitive Art means for clients.

Although, art therapy is widely used with people with disabilities, the use of art in cognitive rehabilitation has generally not been seriously considered (McGraw, 1989 as cited by Garner). In the past, cognitive rehabilitative programmes have generally taken a compensatory approach to brain injury rehabilitation, for example, by using external aids such as diaries. Compensatory approaches were the main forms of neuropsychological rehabilitation because, until relatively recently, it was believed that restoration of brain function after damage was impossible. However, recent research suggests that it is possible to re-train cognitive functions.

It could be argued that art plays a central role in neuropsychological assessment. For example, tests such as the Rey Complex Figure Test assess visual memory through the use of drawing tasks. There are also constructional and drawing tasks in the Wechsler Adult Intelligence Scale (WAIS), which assess an individual's cognitive and intellectual functioning. However, as highlighted by Garner (1996), although these art based tests are used to highlight the nature and location of brain damage, they are not employed again as part of a



client's rehabilitation programme. Consequently, it is suggested that an art programme designed to specifically target cognitive areas may support retraining of cognitive functions after brain injury.

Clients in our Limerick centre have the choice of taking part in three modules as part of their rehabilitative training: cognitive art, vocational art, and art and craft. The cognitive art module differs from the others in that it is structured to concentrate on (re-developing particular cognitive skills whereas the others are more concerned with developing skills in arts and crafts. Examples Clients participate in art-related modules for up to six hours a week. The vocational art and art and craft modules have been running at the service since 2004, and the cognitive art module has been running since 2006.

We decided to evaluate the programmes late in 2007, to better understand what our clients gained from using art specifically for cognitive rehabilitation. The study consisted of two unstructured focus groups with clients who had taken part in any of the modules. The ethical guidelines according to the British Psychological Society and the Psychological Society of Ireland were used in guiding all ethical decisions about this project. Headway granted permission for the study to be conducted. Ten people took part in the study. The research looked at clients' experiences of art in the training centre.

There were a number of considerations that we

needed to make for the focus groups to give data that reflected everyone's experience. For example:

- When working with people affected by acquired brain injury distractions must be limited (including background noises) due to possible attention problems;
- Participants were encouraged to use their diaries and make notes during the session so that ideas that clients may have and the contributions they would like to make are not forgotten if another person is speaking - strategies used to deal with the cognitive consequences of by acquired brain injury.
- A flipchart was used during the focus group as a memory strategy to help participants to focus on their "experience of cognitive art".
- A physical and cognitive consequence of Acquired Brain Injury is impaired communication and strategies such as allowing participants the opportunity to speak were put in place to ensure that all persons participating had an opportunity to contribute to the group if they wished to do so.
- Visual prompts were used as a memory aid during the focus group research and the group looked at their art work during the focus groups.
- At the start of each of the focus groups researchers explained the aim of the art research and the rights of a participant and what is expected of a participant in during the focus group as a memory aid.

Two main themes emerged from initial analysis of the research:

Cognitive (Planning): Participants reported experiencing the need to plan during an art session in a variety of different ways. One participant reported that "a lot more planning" goes into Cognitive Art. Another participant explained why he preferred Cognitive Art by stating that "I am not able to draw things from my brain that much now so I look at a picture and it's easier for me". In contrast, another participant reported difficulties he experienced about the Cognitive Art stating that "I much prefer to do my own thing with it and get on with it in my own way that the step by step would be too much for me". Finally, a different participant reported that with Cognitive Art there is "no real planning to go on". The fact that participants spoke about their experience of planning a piece

of art may indicate that they were encouraged to reflect on their ability to plan in the art modules. However, it is also possible that participants' level of planning ability may have had an impact on how they experienced the class and whether they appraised the experience as positive or negative.

Social/emotional (Self-expression): Again this was a theme that became apparent after hearing participants talk about their different experiences of art and how it impacted on their sense of self. One participant reported that unstructured art is "a way of expressing myself - I get a great kick out of it - it's something that I make that makes me feel good after it - it's a good feeling a way of creating something". Another participant agreed with this statement. Finally, another participant reported that "you're trying to do something that you never did before trying to make yourself a bit better in a small way". For the participants that reported on the experience of self-expression and creativity through art, they portrayed it as something very positive and worthwhile.

The study would suggest clients were encouraged to reflect on their ability to plan in the art modules. Additionally they feel that they are benefiting from the well-documented outlet for expression that creative activities give.

With further analysis of the study data and research, we are tailoring our modules to improve the rehabilitative value of art in our programmes.

People involved in this research:

Aisling Burke Training Officer, Headway, Limerick
Denis Mangan Centre Manager, Headway, Limerick

Olivia Henchy formerly Training Officer, Headway, Limerick

Dr Mairead Ni Eidhin Senior Clinical Psychologist, Headway, Cork

Kim Keating formerly Training Officer, Headway, Limerick and Assistant Psychologist, Headway, Cork

Sandra Power Assistant Psychologist, Headway, Cork

Marie Claire formerly Assistant Psychologist, Headway, Cork

Special Thanks:

To the clients in the Limerick Headway Training Centre who participated in this research.