



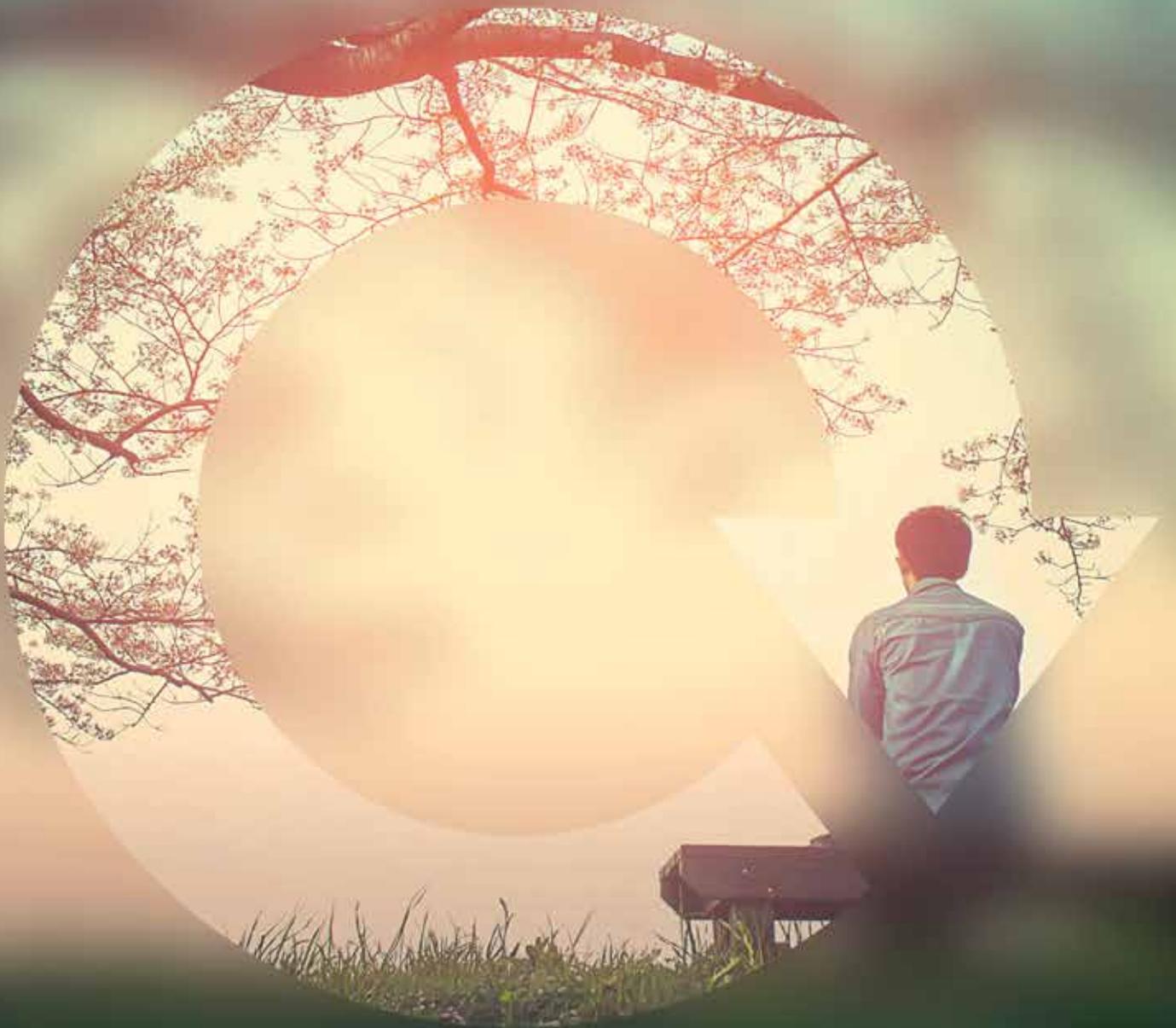
ACQUIRED  
BRAIN INJURY  
IRELAND

# Getting my life reset

Living with an acquired brain injury:  
The Irish experience

JUNE 2017

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UNIVERSITY of LIMERICK  
OILESCOIL LUIMNIGH



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## Dedication

ABI Ireland dedicates this research to the  
memory of Patrick Pierce.



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# Foreword



Brain injury is a hidden phenomenon in our society. Rarely, if ever, do we get to hear the voice of the person living with ABI. This report, using a research framework, lifts the lid and lets us gain an insight into what life is like for people with a brain injury. It provides a valuable insight into the lived experience, illustrates the challenges people face with life altering, traumatic change and how they strive to live a meaningful life of their own choosing in the aftermath. It illuminates, in very clear terms, the barriers faced, the lack of services that people contend with and difficulties experienced in trying to get access to services.

While the report captures the lived experience of people with brain injury, it also clearly demonstrates the massive contribution that families make, both in the short and long term. It tells stories of families who never gave up on their loved one and the extraordinary determination on their part to make life better. There is also a strong message of hope from the research that people living with brain injury display the ability to adapt and be resilient even when faced with such adversity.

This is essential reading for all of us involved in the brain injury world. It is essential reading for health policy makers who are framing policy on neuro-rehabilitation. It is essential reading for our elected representatives who need to hear these stories and understand what people with ABI and their families deserve in their decisions regarding the allocation of resources.

Thank you to Professor Orla Muldoon and the team of researchers who conducted the research. It is a really valuable contribution to brain injury discourse in Ireland.

A handwritten signature in black ink that reads "Barbara O'Connell".

**Barbara O'Connell**  
Chief Executive, ABI Ireland  
June 2017

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# Executive Summary

In early 2016, Acquired Brain Injury Ireland commissioned the University of Limerick team to complete a report that would allow wider understanding of the impact of acquired brain injury (ABI). The condition is marked by a range of physical, cognitive and behavioural changes that can affect individuals' lives profoundly subsequent to their injury and as a result many of those affected by ABI cannot return to their pre-injury jobs and roles and face a very different life-course. The following report is the outcome of this effort. It reports on a series of interviews that aimed to capture the impact and experience of brain injury. In order to achieve this, 15 participants were interviewed over the summer and autumn of 2016. All interviews were semi-structured. An interview guide provided a loose structure within which to explore the topics of interest, and participants were prompted to expand on relevant and interesting responses. This qualitative data was recorded and transcribed for later analysis. Here it is reported subsequent to a systematic analysis.

Five themes are exposed in the data. These relate to 1) the role of families in supporting those affected by ABI, particularly as a consequence of their often reduced social worlds; 2) the difficulties encountered by those affected by ABI in navigating and securing support services; 3) evidence of the particularly complex needs of those affected by ABI; 4) the role of group activity as a means of social engagement and meaningful doing and 5) adaptation and resilience of those living with brain injury. In the proceeding report we use participants own words to illustrate these issues.

The analysis seeks to present a parsimonious overview of the main issues that arise for those living with ABI. Throughout the report, exemplar quotations from the interviews evidence the point being made. In synthesising the shared experiences of participants, this report shines a light on the difficulties experienced by those living with this chronically challenging condition. The report, and its associated recommendations, contributes to a greater understanding of this condition among service providers, policy makers and wider society.

# Introduction and Background

# 01

ABI is a significant public health issue with estimated prevalence in Ireland similar to other European countries. ABI is an injury to the brain that has occurred after birth. The brain is responsible for producing all forms of human behaviour. Unfortunately it is a very fragile organ and injury can result in significant problems.

Typical causes include external forces (such as a blow to the head with or without a skull fracture), disruption of blood flow to the brain (for example during stroke or cardiac arrest) or as a consequence of injury during an infection, seizures or intracranial surgery. ABI results from a change in the activity of the brain as a consequence of changes to the physical integrity and metabolic activity of the brain. Each injury is unique, and the experience of ABI can vary widely accordingly. After a brain injury, there are several common long lasting changes that can occur. These changes are in three categories: physical, cognitive and behavioural domains. While physical changes such as reduced mobility, speech or sight are easily recognisable, the cognitive and behavioural changes associated with ABI can be more difficult to recognise. Typical cognitive changes include new difficulties for example with memory, judgment, concentration and speech and language. Typical behaviour changes centre on reduced self-awareness and understanding of social situations together with increased impulsivity and moodiness. Because these changes in the areas of thinking and behaviour often result in unrecognised long term problems, ABI has been referred to as a hidden disability.

Recent figures for ABI in Ireland suggest that in the case of cerebrovascular accident, some 10,000 people experience a stroke annually and there are an estimated 30,000 people in the community with residual disability from stroke (Peoples & Fortune, 2011). Stroke also accounts for up to 4% of total health expenditure in Ireland (Smith et al, 2010). Economic and Social Research Institute figures (quoted by Neurological Alliance of Ireland, (2010))

suggest that some 11,000 people admitted to Irish hospitals each year with TBI. Of those affected by both conditions, many require ongoing care and rehabilitation, and experience considerable disability.

In the first year following ABI, it is common for those with communication difficulties in particular to lose their pre-morbid circle of friends (Walsh, Fortune, Gallagher, Muldoon, 2014). Moreover, inability to communicate effectively means access to health and other community supports may be problematic (Cruice, 2007). For instance, Nicolson et al (2012) in a systematic review of the literature found that one of the two greatest facilitators of rehabilitative exercise post-stroke was social support. Effective support is attuned and perceived to be available to meet the needs of the individual at that time. And while post-acute multidisciplinary rehabilitation often has clear goals in terms of community integration for people with ABI as an outcome, recent systematic reviews demonstrate that the available methods tend not to yield significant improvement in the social/community integration arena (e.g., Brasure et al, 2012).

It is perhaps therefore not surprising that there is a decline in social contact over time evident in those who have experienced a brain injury. Even among those that retain their social contacts after their injury, they are more likely to receive, rather than initiate visits. Furthermore, the neurological damage sustained by the injury, together with the impaired learning associated with actions and efforts in bringing about desired outcomes, may compromise feelings of autonomy. This is particularly important, as engagement with a socially enriched environment has

been shown to protect brain structures from further atrophy post injury (Miller et al., 2013). All these factors — poor social relations, lack of agency and less ability to learn new and agentic social contingencies — have been linked to poorer well-being. Health research led by the needs of the end user is critical, yet the physical and psychological challenges associated can impact on the person's ability to actively participate in research. The lived experiences of ABI have been neglected by research and most of the existing studies that have included them have tended to focus on only one aspect of the experience, such as memory loss or post traumatic growth. One study focused specifically on the lived experience of brain injury rehabilitation for inpatients and their family caregivers (Fleming, Sampson, Cornwell, Turner, & Griffin, 2012). Their findings highlighted the need for a therapeutic environment, meaningful occupation and a family-centred approach to ABI rehabilitation in acute care. Building on those findings, the present research focuses on the lived experience of individuals who are out of the acute care phase and living with their injury in post-acute settings.

This study then explores participant defined meanings and lived experiences of ABI. The main aim is to synthesise and provide an overview of the perspectives of individuals living with ABI. This research aims to facilitate good practice in provision of services. Good practice attends to the views of users when providing services and as such the research responds to national policies on service provision for people in need of rehabilitation. Furthermore, it is hoped that this study offers people with ABI the opportunity to express their story in their own words and provide an opportunity for them to feel that their perspectives are a valid source of knowledge (Hollway and Jefferson, 2012; Murray et al., 2009).

### Background to the research

One of the many gaps in research knowledge is the lack of any evidence of the reality of the lived experience for people with ABI. There is very little research that explores the experience and views of people with ABI and their families. There is limited knowledge, from a research perspective, about how people have travelled from their diagnosis to the reality of their lives now, in particular their

interface with services and supports in order to lead a meaningful life after their injury.

In order to address this gap in knowledge and to generate evidence, ABI Ireland commissioned the University of Limerick to carry out a qualitative research project with the following aims and objectives:

### Aim and objectives of the research

The aim of the research was to explore the authentic voice of people with ABI in relation to their lived experience post injury and the issues that they face in their lives. The objectives were as follows:

- To describe peoples' lives post injury (from diagnosis to where they're at now)
- To explore experiences of services and supports with a particular focus on the post hospital experience
- To determine the issues that are facing people in order to live well in their communities over the longer term
- To ascertain what people want in relation to services and supports.

### Interview process

Participants were primarily recruited through ABI Ireland as well as through social media. In this way participants that had engagement with support services as well as those that not engagement were recruited. In the case of participants that were recruited through ABI Ireland, information about the study and consent to participate was completed prior to any contact with the research team. For those that responded to public recruitment efforts, consent was secured verbally by phone and subsequently on the day of interview in writing. Participants were interviewed in their own home or in a place of their choosing on a prearranged mutually agreed day. Most participants chose to be interviewed in their own home. A small number came to the University of Limerick to be interviewed and another small number were interviewed in their service provider premises. All interviews occurred during May-October of 2016 by one of three researchers (OM, SW, MC).

Interviews were semi-structured and an interview

guide provided a loose structure within which to explore the topics of interest and participants were prompted to expand on relevant and interesting responses. The interview guide included: (1) an outline of a participants day, (2) what life was like prior to their injury, (3) how life had changed since injury, (4) experiences of rehabilitation and support services since injury, (5) any ongoing challenges participants face. Because of the language and comprehension issues sometimes associated with ABI, interviews were at times difficult and establishing what a participant meant was, on occasion, slow and disjointed. Interviews ranged in length from 45 to 90 minutes. Some participants did not have problems with language and as a consequence were significantly more articulate than others in expressing their experience of adjusting to ABI. In the proceeding account of our findings therefore, the researchers try and ensure that the voices and views of all participants are represented. In some cases, understanding of the point being made can only be made with due reference to the interviewer's contribution to the conversation or by referring

to earlier or later stages of the interview. Where this is the case, longer sequences of conversation are presented and gaps in the sequence of the conversation are marked.

## Participants

In total 15 people were interviewed as part of the research. All of these individuals had been affected by ABI. The nature of their injury and the variability in the severity of their injuries was diverse. Some participants could be considered fully recovered and were living without support independently in the community. Others had sustained life changing injuries that transformed their ability to live and work as they had prior to their injury. Participants brain injuries had arisen as a consequence of traumatic injuries sustained during road traffic accidents, occupational accidents, assault as well as injuries sustained as a consequence of stroke, haemorrhage, epilepsy and tumours. Participants ranged from age 26 to 63 years old, with the majority being in their 30s or 40s and many had lived with brain injury for many years. Ten participants were male and five female.

	Gender	Age	Marital status	Living	Area of residence	Mobility status
1.	Male	39	Single	Supported community care	Urban	Wheelchair user
2.	Female	52	Separated	Supported community care	Urban	Good mobility
3.	Male	28	Single	Living at home	Urban	Mobile
4.	Male	26	Single	Living independently	Urban	Mobile
5.	Male	52	Married	Living at home	Rural	Fully mobile
6.	Male	50	Married	Living at home	Rural	Fully mobile
7.	Male	38	Unmarried	Supported community living	Rural	Fully mobile
8.	Male	35	Unmarried	Living at home	Rural	Fully mobile
9.	Male	40	Unmarried	Supported community living	Urban	Wheelchair user
10.	Male	38	Married	Living at home	Urban	Mobile
11.	Male	63	Married	Living at home	Rural	Mobile
12.	Female	51	Widowed	Living at home	Rural	Mobile
13.	Female	50	Separated	Living at home	Rural	Mobile
14.	Female	53	Married	Living at home	Rural	Good mobility
15.	Female	47	Married	Living at home	Urban	Limited mobility

### Data analysis

Qualitative data was transcribed and analysed using thematic analysis (Braun & Clarke, 2006). Thematic analysis involves a number of stages of coding data in order to identify potential themes. The first stage coding remains very close to the data and involves paraphrasing utterances and identifying initial codes.

The second level involves reviewing the first level codes and seeing how they can be amalgamated into overarching elements and the third stage involves identifying broader themes under which the original codes can be combined.

In the final stage detailed outlines of the final themes are created. It should be noted that themes should not be compared to each other directly. Having five themes in any given area does not reflect the strength of the theme but the spread of the opinions. It simply reflects the nature of the views that can be captured by the themes presented.

### Ethical protocol

The study received full ethical approval from University of Limerick Ethics Committee and ABI Ireland's Research Ethics Committee. Participants were recruited from within ABI Ireland for those engaged with services and through social media for those who were not currently availing of any support services. All participants gave written and verbal informed consent prior to interview and again on the day of the interview itself. All interviews were recorded with the permission of participants and they were later anonymised and transcribed. Access to the digital recordings is password protected. Anonymised interviews were stored on a password protected computer for later analysis. Participants were advised at the start of each interview that they were free to withdraw from the interview or indeed to turn off the tape recorder should they wish to at any stage.

Five themes were identified subsequent to the analysis of all interviews. These themes outlined below were 1) the important role of families in supporting those affected by acquired brain injury; 2) the challenges participants had navigating the support services (finding their way through services); 3) the role of group activity as a means of social engagement and meaningful doing; 4) the complexity and diversity of needs in those affected by ABI; 5) adaptation and resilience of those living with brain injury.

## 01 The role of family in supporting people affected by brain injury

The first theme related to *the role of family in supporting people affected by brain injury* during both the acute and chronic stages of their adjustment to the condition. In their accounts of their injuries, participants emphasised how family members may not have been first to their aid in the aftermath of the injury, however, it was their family that were in for the long haul and that stayed the course with them through the long and often arduous recovery journey. This importance was amplified by the fact that participants felt that ABI often had a negative consequence in terms of access to their pre-injury social and occupational friendship networks. Families often supported in the acute, medium and long term management of participants' social and health care needs. For the most part, participants told stories of incredible family loyalty, generosity and industry in supporting their needs. For instance (in extract 1) one participant in recalling the period in the aftermath of his injury which he sustained in the UK where he received acute care stated:

*'It was a massive change; my parents had just retired when the attack happened. I mean it was massive upheaval for the whole family. So they travelled every week or they would travel every week during the week to the UK to be able to visit me and my sisters when they were off work, my brothers at the weekends... they all rotated as well, I was never on my own. I was never on my own. And you know it was that sense of*

*support I mean they really did help bolster me up.'*

These stories included examples of both practical support as well as emotional support which were greatly appreciated and valued by those affected participants. Another participant who sustained a severe injury during a road traffic accident whilst in Australia told of local fund raising his family drove to support him in the aftermath of his accident which allowed both family visits and his early return to the rehabilitative training unit (RTU) in Ireland. He recalled (in extract 2):

*'well in the six months that I was in hospital there, between my family, I have what, two brothers and two sisters and my parents and there is actually two aunts and an uncle that visited me. There were 15 different trips to Australia'.*

The importance of family support was particularly important for those affected by brain injury as often participants reported that their social circle was depleted by their injury. In explaining this reduction in their social networks, participants often alluded to the loss of contact associated with losing their occupational roles as well as the perceived impact of the stigmatised representation of brain injury. One participant in recounting the changes in life since injury stated (in extract 3):

**P:** *Well obviously as soon as I had the blood clot and it left me epileptic that ruled me out of any work as does the shunt.*

I: **Ok, yes.**

P: A physical job like inner city policing is not the place for someone with major problems.

I: **Yes, yes.**

P: And that was the first thing. A lot of friends, I found that as soon as the words brain damage are mentioned, people run away.

I: **Yes.**

P: They are scared you are going to sit in a corner and dribble at them.

I: **Yes.**

Another participant, a young man injured when hit by a car who no longer could live independently in his old neighbourhood spoke about the shrinking of his social circle as a consequence of having to move from his original community in Dublin to supported housing in a different area of the city. As well as being disconnected from the locality and those he grew up with, this disconnected him from a football club that was previously very important activity in his everyday life. Indeed later we point to the importance of meaningful activity for those affected by ABI and how these activities are often offered as rehabilitation supports (theme 4). It is worth mentioning at this juncture that meaningful activities are spontaneously undertaken by us all in everyday life, we are all busy with occupational, social and sporting activities which add value and meaning to lives. Here our participant talks about the loss of social contacts associated with the loss of access to sports clubs as a consequence of his relocation to supported housing after his injury (in extract 4):

P: I went to technical school in Clondalkin, that's where I met most of my friends. I've yet to meet any of them as it turns out, since the accident. I have met friends in the ABI since then but none since the time I was going to school, in school.

I: **You lost touch with those people?**

P: I've lost touch with them completely.

I: **Ok, that leads me onto what's changed since your injury?**

I: Well one of the things that's changed is I used to play in a soccer team, there was a soccer team where you were able to play the first second or third team. I played in the third team but I also played in the first and second. Now not many games for the first and second, but my father, Lord have mercy on him, was the chairman of the club at the time. Since I came here unfortunately there's no club to play for...

Importantly this reduction in the size and scale of this participant's social circle was linked to the consequences of their acquired brain injury. Below is a transcription (extract 5) of a conversation where the participant is talking about their cognitive difficulties as a result of his injury which he links to his reduced ability to interact with others.

P: And then, like, when your memory is not that good, like well just say like texting is a very simple thing, I used to have sore thumbs from it when I'd be at work. You know, I could text without looking at the phone. But you know you're thick when the phone won't let you spell a word and you have to change a whole sentence to say what you want to say because you can't spell the fucking thing you want to spell. Do you know what I mean? That kind of thing.

I: **Yeah. And is that more kind of like a word finding difficulty?**

P: No, it's just... I know what the word is I want to say, I'm very good with words. I've a very good vocabulary as such but I just can't spell the fucking thing. Like, well just say like knife is k.n.i.f.e but there's no reason to have a k there really, is there? Do you know. And if you put n.i.f.e it could say, like, 100 other words before it would come up with knife, necessarily. I mean predicative text is very good but if predictive doesn't know what you're saying because you haven't spelled it right. Do

you put an 'e' or an 'a' where there should be 'o'? It just doesn't work. So then you have to delete that sentence and try and say the same thing a different way and it just makes everything difficult. There's no spontaneity in anything.

I: **OK, yeah. That could be a bit difficult.**

P: Yeah. Which is, I suppose, a first world problem really isn't it. But I mean that works on other levels with other things as well but it's not necessarily just texting, do you know what I mean? To keep a thing flowing. Do you know? A conversation going and stuff is kind of an art really, knowing when to step in and when to let someone else say something Do you know?

I: **And do you find it a bit easier with people that you'd know?**

P: Like I just say, like sometimes people get annoyed when you're trying to think of a word. It's like a stutter but you don't have a stutter. Do you know what I mean? And then it's the same thing. Like I was just saying there about spelling, sometimes it's because I do miss words or just don't know... when I'm saying something I mightn't know the name of a thing. I'd forget the name of a thing. And then you have to kind of go a long way trying to explain what it is. And people don't want that nowadays especially, they want to know what you're talking about.

In this conversation a number of issues are apparent. First, the participant believes he has slowed down as a consequence of his injury and he uses the pejorative term 'thick' to describe himself. This negative self-appraisal can be seen as a form of self-stigma associated with brain injury and is undoubtedly linked to the complex needs of the group discussed in the proceeding section (theme 2). As well as this it is apparent that the particular difficulties experienced in relation to speech and language are perceived by the participant as having an impact on his interactions with others. He believes that the flow of conversation and spontaneity is impacted by his expressive difficulties. His depiction of the difficulties he experiences when text messaging gives a sense of the

effort involved for him in communicating effectively, something that he perceives as very changed from his preinjury life. It is of course paradoxical and poignant that his account of these difficulties is so articulate that we can here use it as an exemplar.

Evidence of the contribution of family to support of affected participants was also clear through deviant case analysis (Mays & Pope, 2000). The deviant case is a method that uses the exceptional case to prove the rule as it were. The example here emphasises the view that families are crucial resources facilitating care and support services for those affected by ABI because in this example their absence is so keenly felt. For example in describing her injury, this participant outlined a sequence of events where her marriage had broken down not long prior to her accident and she was in her early recovery relying on the kindness of strangers. She recalled (in extract 6):

**'I had fallen down two flights of stairs. And when I was released from the hospital they released me with a wheelchair and I had one for a little while. But I am a real church goer and I go to mass every morning. And it would mean I would have to get someone to push me across. And I didn't want to be dependent on anybody. And I managed thank God. I managed across the road with the help of pedestrians... And I got through it alright. Still haven't seen my children or my husband. I don't really care about him... the fact that he didn't care enough to come down to see me then or even let the children come and see me.'**

In the absence of family support meant that this participant left acute care to live in supported housing. At her most dependent, she relied on the help of unknown pedestrians. And though this participant 'got through it alright', her case was in stark contrast to others where families provided comprehensive emotional, practical and loving support.

Interestingly this value of wider community embeddedness for those affected by ABI was echoed in other participants. Though as stated previously social relationships were very disrupted by acquired brain injury, support from those affected by ABI from the wider community was also acknowledged. One participant stated that €20,000 had been fund raised

in the wake of his injury saying (in extract 7):

‘They actually had a little collection around the town for me. They had a few: there were big bottles and my name on them and a picture on them or whatever in supermarkets there and raising some money... People are great. That’s true people are very good’.

This orientation to and appreciation of the kindness of others was a key element of theme five which highlights the growth and learning many participants reported as a consequence of their injury.

## 02 The challenges participants perceived in navigating the support services

The second theme related to *the challenges participants perceived in navigating the support services* subsequent to their injury. There were a number of subthemes evident across the data. Whilst many respondents talked about excellent care they received within the hospital system, the rehabilitation services and from organisations such as ABI Ireland and Headway, many participants also reported that they had difficulty navigating the system. Particular points of difficulty related to the move from acute care and rehabilitation to longer term care. Participants also stated that they had difficulties finding and accessing appropriate services, and difficulties evidencing their need for services. These difficulties in accessing services sometimes resulted in extremely long gaps in support and rehabilitation after the acute phase of the injury. For instance one participant reported that she had lived through a period of 18 years where she had no contact with rehabilitation services. During this period the participant was in a wheelchair as a consequence of a stroke. After moving house, the participant moved to the care of another GP, access to rehabilitation was arranged. This participant then goes on to describe the value of the belated support received from OT and physio services 18 years after the initial stroke (in extract 8):

‘And the girls there, particularly the OT, they helped me to get things like my notepad, I’m rarely without my notepad and pencil. And there’s a while it would a shopping list down one side of the page and down the other side of a page, someone’s measurements for a

jumper or a phone number or all the day to day things or a TV programme I want to watch, written down so that I can, I don’t forget it....so when the physio I met and I said to her right “I warn you, you tell me to do and exercise twice four times a day you’ll be amazed”. And because I would quite happily do and you know tell me to do something like that you know ‘do that twice, four times a day’. Ha more like four times an hour. I do it ten times so I work hard at physio. And it is just being pointed in the right direction and helped to do little things like the first goal was to get to the end of the drive unaided. And that’s only 50 yards but it’s quite an achievement and when I was able to make it to the drive and I remember the key to open the post-box, that was a major milestone’.

Other participants reported that once they recovered from the acute injury they often went home without any support not realising the longer term consequences of their injury. Respondents reported changes to their behaviour, memory and concentration that had very meaningful impact on their ability to reintegrate into family and work lives which they did not realise were present and were unaware of (in the following example this is attributed to the brain injury itself) when they first were discharged from acute care. For instance one participant stated (extract 9):

‘I think definitely it’s a pity they didn’t know it two years before that. Because life at home for my family, my kids, everything, was horrible I’d say.’

Due to this gap in his care and the difficulties he had during this period he suggests that:

‘if there was some way they could I don’t know that they could kind of put a person in kind of limbo as such until they’re definite that there’s nothing busted you know. I think an awful lot of people get let out the system and it could change their whole life so you know. Something bad could happen or they could slip through, do you know what I mean. And it could set them on a completely different course. Like I still have my two kids and I have my wife and have my house but if something had happened in those two years then the whole lot could have changed. And no one would know... yeah I think when it comes to people heads they should kind... of... that they should be automatic,

there should be an automatic kind of set up where they have to have a test or if not a test they, they have to get to see someone a psychiatrist or something maybe two months after... just to see how they're doing. Just to see or talk. And there should be a thing where they talk to the relatives as much as the person themselves. Because I mean you might know.'

This approach was seen as something that would allow medium and longer term consequence of brain injury to be monitored and managed without people falling through service gaps or causing themselves and their families' further harm. In this way there would appear to be a gap between acute care and rehabilitation and longer term support services.

Another respondent who had had a tumour removed said that he had difficulty accessing services and that 'it took months to organise'. He stated he had very invasive surgery that had left him with residual brain damage and 'wasn't given any advice about aftercare and that it took months to get that (aftercare) organised. Eventually he was put in touch with an NGO service provider via a social worker that was working with a family member unrelated to his case: a happy accident as it were. However this NGO stated that because his tumour 'was pituitary, it wasn't brain damage so I didn't fit that category' Again emphasising the importance of family he attributes his success in locating the services to his 'eldest daughter, she had done most of the groundwork.' (Extract 10).

The difficulties surrounding brain injury and accessing services in support of rehabilitation was only one element of the problems encountered by those with ABI. Often the profoundly altered nature of participants' lives meant that they needed supports over and above rehabilitation after their injury. In the below extract, this participant who was confined to a wheelchair as a consequence of stroke aged 25 outlines the difficulties she has had securing appropriate wheelchair friendly housing (extract 11):

**P:** After I had been in hospital for three months and then I was in a rehabilitation centre for three months, coming home at weekends, that was it. You know I can honestly say I wasn't offered any day services or anything like that, you just kind of

'off you go now and sit at home and do whatever you are doing' and you know that was it.

**I:** So, say in terms of what you are at now, could you tell me a little bit about your typical day now?

**P:** Well now, I don't do a hell of a lot really because my house is in such a shambles, I have had a big battle with the council trying to, I have got a big problem with the council because they don't, now I have just heard this place is owned by the council.

**I:** This place here in (names village).

**P:** They have redeemed themselves this morning because I am always saying to the council 'Well 10% of the population are disabled, 10% of the housing isn't disabled friendly, why aren't you purposely building you know places for people that have families, disabled people have families, you know they do have places I suppose like this is where people can come but I couldn't bring my children here you know if this was here years ago, I couldn't have brought my kids here, even though I was widowed very young and everything so I have been fighting to kind of get housed and stuff and bungalows, they don't build bungalows very often and you know. I have had a lot of promises and then they don't come through on the promises and that's caused the biggest stress in my life since I have had my brain injury, that has been my biggest problem, housing, moving around you know because then the Government decided that they'd bring the rents down because people were charging extortionate rents so then I'd have to go to the landlord and say 'Well look I can only give you 700 I can't give you 800 and then he'd say 'Ah sure OK, maybe' or he might say 'You have to move out' and then the next year you would have to go again and say 'I have got to give you 600 this year because that's what the Government says'. And then they say 'Well no, I am not going to accept that,' so I have to move around, I think I moved around twelve times, I think we moved house twelve times in about, well my husband said fifteen years, yes about fifteen years, which is a lot.

Clearly there are wider issues around housing and housing provision nationally and this also speaks to this wider issue. However it is important to remember that these other statutory services are working to support people who are often extremely vulnerable due to disability. Any shortcomings in these services are likely to present additional challenges for those with additional and complex needs like those experienced by people living with ABI.

Despite the clear value in family terms of practical and emotional support when participants were adjusting to their injury, paradoxically the over-reliance on families to close the gaps in available care was also evidenced as problematic. One participant for example who described his wife as his carer stated (in extract 12) that:

*'my wife is my carer, still she doesn't really let me go anywhere on my own you know. Now I done a tests with the Wheelchair Association about, I didn't drive for ten years after my accident and I done a driving test with the Wheelchair crowd, it was six years ago...'*

In this example we can see how the concern of family members can be disabling rather than enabling, here working against the participants increased independence. This participant had described a close and warm relationship with his wife, yet relying on family relationships in this way can be seen to have a cost in terms of self-determination post injury for those affected by brain injury.

Equally this reliance on family meant that it was often difficult for family carers to have a break from their duties and when they did leave their post, participants were left very isolated with no access to support. In the below extract, the woman speaking, cared for by her husband since a brain injury subsequent to a stroke in early adulthood illustrates this (extract 13):

**I: Would friends be a big part of your life?**

**P: Not, not everyday. Like if Jim is away at a rally for the weekend, he does results and timing on most rallies in Ireland.**

**I: Very good, Jim is your husband?**

**P: Yes. So if he is away at a rally there's every chance that I would see anyone for or even talk to anyone for 48 hours.**

**I: Ok, and how do you feel about that?**

**P: It can get a bit lonely but he needs to get away from being a carer.**

**I: Yes.**

**P: He needs his escape and the way my sight is I can, letting me loose to walk around to a friend's house on the road would be not a great idea.**

In summary then, the difficulty of navigating services can mean that the support of family or informal care resources is crucial for those living with ABI. The informal care provided by families however presents challenges to families and can work against increased independence for those affected by ABI as well as result in over-burdened or even inappropriate carers as well as reduced access to appropriate professional health care.

### 03 The variability and complexity of the needs of those affected by brain injury

The third theme related to the *variability and complexity of the needs of those affected by brain injury*. The participant group were very heterogeneous and reflected the diversity of needs in those affected by ABI. On the one hand, there were some participants who were capable of independent living and on the other hand there were participants who need full time care and support. Many participants mentioned difficulties they encountered as a consequence of their physical limitations, such as paraplegia, hemiplegia and blindness. These physical challenges were added to the memory, emotional and cognitive problems that participants also experienced. Others lived with behavioural and cognitive changes and no physical mobility limitations. The following sequence from an interview with a man who sustained his injury as a consequence of a 'one punch attack' illustrates many of these issues (extract 14):

- P: I was fiercely independent 32 year old man doing very well in my career and because of something some reckless idiot did. I mean I remember when my family found out what happened to me, because I mean I said to my mum I said first of all I said 'Mum, would you, my glasses are on my bedside locker, if you bring them in to me, I think they will help me to see' and she had to break the news 'it's not the lens in your eyes that's the problem, you are blind because the optic nerve is severed' I mean I was like 'Oh goodness, such a loss'.
- I: **Is that the biggest change that you experienced, before and after your injury?**
- P: That would be the biggest change. But then also with a brain injury you have got cognitive and emotional behavioural issues.
- I: **What else would you have, do you think the sight would be the biggest one?**
- P: The sight would be the biggest one.
- I: **What would be your next one?**
- P: My short term memory was quite bad.
- I: **Is it any better now?**
- P: It is much better now because I have learned different tricks on how to train, like the first thing when I heard we were coming to meet you, Orla, I thought how I can remember Orla's name is, I used a technique I learned in the national rehab hospital in Dun Laoghaire, called visualisation. So when I met you, the first time I met you I knew your name was Orla, I linked the sound of your voice with someone else I know called Orla, when I hear your voice I see my friend's face. That's Orla, they are just little tricks.
- I: **Okay. Little tricks.**
- P: ...Oh it has yes, emotional I'd say I have always been a big music lover, I always loved music and I mean I couldn't listen to a song that was emotional

or a sad song before, I think about 100 times, and you know I could understand it's a sad song but it wouldn't you know I wouldn't get emotional but now sometimes if I hear a song that means a lot to me I would, welling up...

In this sequence, the participant's anger and sense of loss over his situation is apparent in his description of his attacker as a 'reckless idiot' and his sense of loss for his sight (referred to as 'such a loss'). The grief and loss for one's pre-injury self is also evident in this sequence - the participant begins by positioning himself pre injury as a fiercely independent and successful career person in direct contrast to his present dependent situation and the difficulties he subsequently talks about. Like many participants he reports grieving for this pre injury life. It is interesting too that this participant does not refer to his physical mobility limitations which have left him confined to a wheelchair, which to an observer would appear to be very significant. Rather he orients to his emotional, cognitive and behavioural issues and in particular he gives examples of short term memory difficulties and emotional sensitivity.

Like the above account, participants' injuries were often associated with aggression, alcohol use or road traffic accidents. And similar to the sequence above, the circumstances surrounding the acquisition of their brain injury was often reported with considerable emotion and some respondents had not succeeded in making sense of these circumstances and their injury and the circumstance surrounding it remained a source of distress. And as in this account, this distress and emotionality was often close to the surface, primed in this case by as little as a 'sad song'.

Participants also spoke of a sense of fatigue, depression and social isolation which was linked explicitly to their condition. One participant in comparing his preinjury life to his life now stated (extract 15):

**'I am much more isolated. I can't, I find it really difficult to go into crowded places. I have vertigo as well. I have very little stamina. I get fatigued very easily... too much to concentrate on. There is so much, there is too much stimulus for my brain and I have to, yes, there's**

too much going on, it like I have to go on 'shutdown'... and then I find it difficult to think, to talk, to walk. And it becomes very frightening and frustrating. It can be quite frightening.'

Another participant in describing difficulties he experienced around a loss of inhibition linked his altered post injury behaviour in this anecdote to a conversational faux-pas and ultimately his well-being. Extract 16 below offers an account of his thoughts:

I: **And are there other issues?**

P: Depression, depression and fatigue.

I: **Yes.**

P: **And sometimes, talking, talking to people. Like we had a big meeting there four weeks ago with the council because we are trying to transfer out of here and they messed up a bit, well a lot. But we ended up: we had a big meeting with the top people you know. And I said 'you do most of the talking' but I ended up, I talked, because sometimes that's the way I am too, I over talk. But I was talking and then they say, I would have trouble finding words and stuff like that but they were very patient with me. But at the end I remember just going... The guy, I said to him at the end I said 'You are not as big as you look on the television' you know. And his secretary, one that was there, she was laughing, you know. But I was expecting a big, big man because I'd actually seen him on the televised council meetings you know. And he looked huge for some reason. But when I met, he was only my size you know. And he says 'Well but am I as good looking' you know and I say 'Well you're younger looking' I says you know. But you know I said that and I didn't say, I wasn't trying to make a joke, I was making a statement. And sometimes you can do that, you can make statements, to you it seems normal, but it's not. A statement saying to people, someone who didn't have a brain injury wouldn't say you know. But that's all to do with the loss of, what's it again, can't think of it now, you know, when you,**

I: **Inhibition, is it?**

P: **Inhibitions yes, loss of inhibition you know. And that happens a lot you know. And then the missus would give you a dig in the ribs you know. (Laughing). You know. Well in a way, you call a spade a spade. You know. And it doesn't get me in much trouble but, you know sometimes you'd be sorry afterwards, 'what did I say that for' you know... I am very happy with the clinical psychologist, if I have a problem I go to him you know like, like I went to him, I could talk to him you know even though I could have gone to other counsellors or whatever but no. He'd help you and you know he's basically; he's always there for me you know. If things are bad you know, I'm in a bad spell, I can go every week you know and that.**

In summary the difficulties experienced as a consequence of the injury can make social interactions fraught and are linked by many participants not only to their social worlds but also more generally participants sense of self-worth (extract 5) well-being (extracts 14, 15, 16). These additional concerns for those affected by ABI make their needs more complex than attending to the integrity of their physical health. Participants came to their injury with a range of life experiences, including for some of them, very difficult life experiences. As an example one participant found living in sheltered accommodation after his injury as particularly difficult as he was a survivor of institutional abuse. His prior experience of institutional living was brought into relief when he became a resident in an ABI residential facility which he believed affected his health and engagement with services. This participant explained his situation as follows (in extract 17):

**'...when I was a child I was in the institutions, the old Irish institutions, and it never bothered me that much after I left there, but my accident seemed to bring that back and bring it to the fore... I don't like living here because this is the same crowd basically that I was in with, survivor of the institutions, you know.'**

Equally many participants had full lives at the time of their injury with the associated array of adult responsibilities that remained a source of concern after their injury. One participant, a single parent,

stated for example (in extract 18):

'...it would have taken a lot of burden off my children because they were so frightened and at one stage my youngest daughter said we need an adult in the house, you are only half a one... Support for my kids as well because there's great support for adult carers, there is no support for children carers, they are the hidden carers.'

This account emphasises the particular problems faced by parents negotiating ABI in their middle aged years where their children remain their responsibility. Given the age profile of those affected by ABI, it is not surprising perhaps that the ability to actualise responsibilities towards their children was an ongoing concern for parent participants.

04

### The role of group activity as a means of social engagement and meaningful doing

The fourth theme related to *the role of group activity as a means of social engagement and meaningful doing*. Many participants reported that the main goal of their days was rehabilitation activities and they saw doing these activities with others as evidence of their recovering. The ability to undertake meaningful activity, activities such as cooking, visiting friends or family or reading was taken as evidence that undermined any sense that their injury was 'disabling'. In extract 6, the participant tells us that in attending mass every day, an activity that was very important to her, was something that 'getting someone to push her across' to get to mass was important as 'I didn't want to be dependent on anybody'. In short the achievement of this activity independently though it relied on the kindness of passing pedestrians was taken as indicative of her independence. The activity was an end in itself. Another participant explicitly states that the craft activity she has learnt through supported services has been a lifeline in adjusting to her condition. She stated (in extract 19):

'Since I joined ABI, I am doing more crafty things like, I have discovered loom knitting, you can do that with one hand and I am amazed, that's brilliant and I am doing weaving. I mean it sounds boring... but if I didn't have ABI I wouldn't be doing weaving and stuff, I would

probably be sitting there crying and so I am getting out and you know, out and about... you know I am in a much better place now than I was sort of even four years ago I didn't really, I didn't really see anybody'.

Evident in this extract is not only the ability to engage with meaningful and useful activity but also equally important was social contact in supporting this participant's psychological well-being. In doing these activities, she saw herself as 'getting on' and more importantly avoiding 'sitting there crying'. Perhaps because of the different way that those affected by ABI are treated by both their families (extract 9) and their wider social circles (extract 3), many participants saw particular value in group activities with others affected by brain injury doing of these activities with others who had been affected by brain injury. Consider extract 20 below where a participant is commenting on the differences in his life pre and post injury:

'You feel kind of important because you're good at your job and because people treat you that way... They ask you to do something and they know you're going to do it. And now it's different. People don't you ask you stuff because they not sure if you know... You kind of lose your standing a little bit. People are nice to you too. People are all the time helping you out and making allowances for you and stuff. That's why I like the Thursday group because we don't here. We kind of treat each other like as if we're at work. Do you know that? If you're making shit of something we'll tell you, you did. It's all good fun; no one loses their temper or anything. But yes, it's different.'

This extract reflects several issues that have already arisen. It highlights the sense of loss that interviewed ABI affected people reported feeling. In this instance, the loss was associated with a lost occupational role (as was also evidenced in the loss of the sporting role in extract 4), it also highlights the impact of the injury on social networks here in terms of social interaction and status (People don't ask you stuff because they not sure if you know) and it also speaks to the inadvertent disabling of people affected by ABI (People are all the time helping you out and making allowances for you and stuff). On the other hand, this participant highlights the value of meaningful activity provided in the Thursday rehabilitation group

(a gardening group) he attends. It is particularly worth noting that the value of the group contexts for those affected by ABI, which here is described as an honest and engaged network of peers, resulting in the activity being likened 'to work', the very activity that has been experienced as a loss. In this way rehabilitation activities can be perceived as an end goal in and of themselves and rehabilitation and group activity was a central and supportive component of the lives of those using the services to support those with ABI.

A key challenge for those seeking to engage with the services was having access to transport so that they could attend relevant activities. This challenge was in evidence for that resident in both rural and urban locations. Those in rural locations, where public transport was unreliable or absent were over-reliant on car transportation and if their brain injury impacted their ability to drive this has implications for all other aspects of their lives. In the below extract, this participant an immigrant to Ireland, talked about the difficulties for those living in rural locations. He stated (in extract 21):

**P:** I think it's actually quite important for, especially living, if you are living outside of Dublin, that probably transport isn't that, if you need to go anywhere you're really need to be able to, some form of vehicle.

**I:** Yes you would find transport is a big issue.

**P:** Yes. We were living in (names village). We moved since, we have moved to [names larger town].

**I:** Ok so. You are a bit further out, a bit more rural.

**P:** Yes. (Names village) is a small village as well, just outside Limerick. It's about a half an hour drive from Limerick.

**I:** Ok and is there public transport?

**P:** No, well there is, there is a bus going to Limerick, but they have one in the morning and one in the evening, that's it.

**I:** Ok so not very often.

**P:** Yes, you need to drive to go to the GP, do the shopping, those kinds of things. So there was that.

Those living in urban locations were often challenged by travelling in public transport systems and this was not necessarily something that they could negotiate alone. Consider extract 22 below which illustrates the difficulties associated with public transport use for this wheelchair using participant who had worked hard to become '100% independent' since his brain injury:

'Well the DART does me head in, having to get someone to throw down the ramp every day. And sometimes there's no-one there to help you do it, and then I have to ring Dun Laoghaire for someone to come up. Like that's an everyday struggle. I go to college five days a week. And is there's no-one in Sandymount then I have to ring Pearse station for them to send someone down. It's a nightmare. It's not like the bus. The bus ramp just falls down. Sometimes that doesn't happen either, the ramp doesn't work in the bus, but nine times out of ten it might, will work. But the DART's a joke. 21st Century Ireland, we're back in the Stone Age. I'm not asking them to get every ramp in every carriage, just one carriage for wheelchair users. We're treated like third world citizens in this country. It's disgraceful, I think... Everyday. I didn't want to get the DART, I was going to get the bus but to do that I'd have to get the bus into town which takes me an hour and then get a bus back out. Sure I'd be getting up at half five in the morning to do that, so I'm just relying on the DART... but there is one lad down there he's a pure p\*\*\*k. Robbie's his name, he's there about 40 years, and he's a law unto himself. But the rest of them, he's the only one I've hassle with, but the rest of them are lovely, he's just a clown.'

This quotation demonstrates that one element of the difficulty for those with limited mobility is access to transport and the practicalities of getting around. The support in our public transport users is clearly not seamless from a wheelchair user's perspective. However for those who struggle with social interactions (see extract 6), the need to engage with those staffing public transport systems can also be challenging and here our participant describes 'hassle' with a staff member in the DART system responsible for the ramp.

In all interviews where individuals availed of services, transport to and from these highly valued activities was raised as an intermittent or sometimes ongoing problem that worked against the ability of ABI affected participants to engage independently with activity. Given the importance of 'meaningful doing' in participants accounts, transport would appear to be an important practical challenge to long term recovery and rehabilitation.

### 05 Adaptation and resilience of those living with brain injury

The first and final theme was an overarching one. All four themes appear to be linked to this final theme which related to adaptation and resilience of those living with brain injury. Many participants in their accounts of their injury and their lives post injury work up an account in which they frame their injury in a positive light. This is not to suggest that there are not themes of loss as described earlier (extract 14), however there is also evidence of considerable optimism. Participants in reporting devastating injuries portrayed themselves as having being 'lucky'. Typical of this was the below extract from a participant who had a major stroke in his twenties just prior to the birth of his first child (extract 23):

*'I am quite happy to say, I think it makes me a, it's probably a little bit of a cliché but it does make after you have an experience like this, it does make you look at things differently, appreciate having, make me appreciate a lot more, appreciate events, just walking around and having, I was always thinking when I was the first week in (hospital) I was in before for a week in the hospital, couldn't move made me thinking... Yes I think yes, I am lucky, a very lucky case.'*

This extract (23) in part reflects the participant's sense that he has survived and recovered well from his ABI. However this participant also orients to the learning he has acquired as a consequence of his experience which has allowed him to appreciate life more. Appreciate is a word he uses and reuses in this conversation to emphasise his gratitude for events and belonging - even very basic activities such as 'walking around'. This active reframing of the acquired brain injury in an attempt to orient to the positives still

available in life was a core theme across interviews. Similarly another participant, a qualified and accredited engineer prior to his injury and who, after a road traffic accident lived with serious cognitive and behavioural impairment in describing his time in the National Rehabilitation Hospital stated (extract 24):

*'Yeah, I served my sentence there but I'm good. (Laughing) I'm a lucky person in a lot of ways. I have my life for starters but besides that I look on the bright side of things. Naturally. I look on the bright side of life. So then there's that thing, every cloud has a silver lining, I see the silver and go yeah there's a cloud around it or whatever like but I focus on the good things in life.'*

Participants also report that their injury also allowed them to see the best in others. Stories of family loyalty, love and perseverance were seen as sustaining the affected participants during difficult periods of recovery and rehabilitation. These stories included extraordinary support such as the 15 trips to Australia and extensive fund raising reported in extract 2 as well as much more mundane and ordinary everyday support - equally as extraordinary in its consistency of people being driven to work every day by their spouse for upwards of 10 years because of driving ineligibility associated with the injury.

Finally though the complex psychological needs of participants were often evident, participants highlighted a capacity to persevere with life in the aftermath of their injury and drew strength from their sense of their own staying power. This is reflected in the account offered in extract 8 of a participant's engagement with the rehabilitation services more than a decade after her original injury. The description of 'quite an achievement' when this interviewee recalls making her way to pick up the post at the end of the drive is clear in this account. Others described 'pushing themselves' in speech and language therapy and physiotherapy to foster skills development, to allow job retraining and even in terms of integration into available social networks. For example one participant stated (in extract 25):

*'I just did it. Fake it until you make it, you know persevere. You just kind of think 'Well there's no us and them' It can happen to anyone, you know my brother*

used to come into the hospital 'Oh why did it happen to you? Why did it happen'. It has to happen to somebody, it can happen to anybody... you can't look at someone and go you know, I will never be in that situation because you could be and I have kind of got around it in my head by saying whatever happened to me could happen to anyone and there but for the grace of God you know... so you know get out there and I would say to people persevere and mix and everybody and you now just accept other people you know into your life and you'll be the better for it I think.'

This ability to persevere and push yourself was often talked about by participants as 'having a strength that they didn't realise they had'. This orientation was supported and reflected in their sense of their 'brain injury having changed life'. Life rather than being deficient or damaged was now different. This sense of being different was described eloquently in our final quote (extract 26):

'It's like getting reset. Some part of your head gets reset and it makes you a different person and that's it. And I spent the first couple of years trying to be the other person that everyone thought I was and not understanding why I couldn't be that way anymore. And it was only when I kind of gave in and just be who I am that I kind of relaxed and bit and things started to make sense again to me.'

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# Discussion and Conclusions

# 03

This study set out to explore experiences and understandings of ABI. The open-ended qualitative approach allowed experiences to be considered from the perspective of the person with ABI. The 5 themes constructed were as follows 1) the role of families in supporting those affected by ABI, particularly as a consequence of their often reduced social worlds; 2) the difficulties encountered by those affected by ABI in navigating and securing support services; 3) evidence of the particularly complex needs of those affected by ABI; 4) the role of group activity as a means of social engagement and meaningful doing and 5) adaptation and resilience of those living with brain injury. These findings complement existing research and theory, and provide a more intricate consideration of ABI and the current, immediate needs of people living with ABI in Ireland.

Families have the potential to offer a great deal of social and emotional support in the aftermath of ABI. However, families need professional support to help them anticipate and manage the complex array of changes, for both the individual and the family unit, as a result of brain injury. Families are the site of social enrichment, facilitating engagement with services and organising transport to and from important health care and rehabilitation activities. This is in line with previous research from within Ireland and beyond (Miller et al, 2014; Walsh et al, 2015). The economic value of this family support, which often relieves the statutory services, merits further consideration.

The reliance on family support is not without its downsides. The data emphasises the particular problems faced by parents negotiating ABI in their middle aged years where their children remain their responsibility. Furthermore, families are not professionally trained and they can be disablers as well as supportive enablers, hindering the individual with ABI's attempts towards independence and participation. This is not suggesting that it is intentional on the part of families but rather out of concern to try and make things easier for their relative. Professional support is likely to deliver additional benefits, over and above family support, to those affected by ABI. In addition, families often need care and respite themselves to sustain their ability to

care in the medium and longer term. For these reasons families need multi-disciplinary support and should not be used in lieu of professional support.

The centrality of support to community, occupational and social reintegration of those affected by ABI is clearly evidenced in the available literature (Brasure et al, 2012; Walsh et al., 2014). Given the depletion of the social and occupational networks reported by our participants in the aftermath of their ABI, group based activity is an important conduit for building social resources post injury and in particular for those who feel the 'othered' by their injury.

There is an obvious value to providing and facilitating group-based approaches after ABI as these provide a critical component of rehabilitation and support which extends over and above the economic benefits. The World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF; WHO, 2001) has strongly oriented rehabilitation to focus on enabling people to participate in socially-valued activities rather than focusing on deficits. Overall, the purpose of rehabilitation should be to 'reduce disability and increase participation in valued activities' (Hart & Evans 2006, p. 142). Certainly our participants corroborate the value of this approach for the future.

Most individuals affected by ABI are keen to engage in meaningful activities, viewing these activities as central to post-injury adjustment. While some individuals may be able to return to paid employment, other individuals with ABI need support to engage in meaningful activities at home or facilitated by external support services. These activities are seen as pivotal in driving rehabilitation by our participants. Our data indicates that the ability to engage with meaningful and useful activity is important. A key challenge for those affected by ABI is accessing adequate transport to attend these activities. Many of those affected from ABI are not permitted to drive, those living in rural locations face difficulties with poor public transport and those in urban locations can have difficulty negotiating the public transport system because of their condition.

Transitioning from acute rehabilitation to the community appears to pose great challenges for ABI affected individuals and families. At present, there appears to be a service gap for those leaving acute care with many of our participants reporting difficult periods of adjustment, often without support. There is a need for follow-up assessments in the aftermath of any ABI. Many individuals and families are not aware that cognitive, emotional, and social changes are as a result of brain changes post-injury. An automatically-generated follow-up assessment may reduce the likelihood that vulnerable people do not get access to the neuro-rehabilitation and psychological support services they need. At present, the existing post-acute services are reported to be difficult to source, access and navigate. There may be an opportunity to map the existing services and make this information available to people affected by ABI and their families.

People affected by ABI are not homogenous and differ according to injury location, injury severity, individual differences (e.g., pre-injury functioning, cognitive reserve), and contextual factors (e.g., social support, rehabilitative care during acute injury phase). As a result, this group has highly complex needs requiring multidisciplinary support. The data from the research illustrates a particular need for psychological supports. While the research participants in this study were often very positive in their approach to dealing with their condition,

reinterpreting difficult circumstances positively, there was also at times a sense of loss, sadness and social isolation in their accounts of their lives. Support for those affected by ABI is not just support to assist individuals in overcoming physical challenges but also support beyond the immediate aftermath of the injury. Importantly this multidisciplinary support is required over the long-term to attend to physical, social and psychological needs of this very vulnerable group. Finally, although the complex psychological needs of participants were often evident, participants highlighted a capacity to persevere with life in the aftermath of their injury and drew strength from their sense of their own staying power. This sense of personal strength and growth was often seen as crucial by those striving for recovery as well as by those who had completed their journey to recovery.

# Policy Considerations and Recommendations

# 04

This qualitative research report and the themes identified in the interviews of those affected by ABI raise a number of issues in terms of policy and service provision. ABI is a chronic and ongoing condition that can affect the lives of those affected as well as their families for months, years and even decades after the initial injury. Some of those affected by ABI will never return to independent living, others will have independent but altered lives and there will also be those who return to their pre-injury lives.

Given the very different and medium and long term needs of those affected by ABI there is a clear need for a range of services and supports for both the individual with ABI and their families. These first person accounts of living with ABI show that services are patchy and often limited. Lack of access to appropriate services is linked directly to recovery and rehabilitation. Interviewees' accounts include stories of resilience and return to meaningful family and social and economic activity. Reintegration and recovery is routinely attributed to strong psychological resources, social support and appropriate professional services.

More specifically and arising from the main themes of the analysis, service planners and policy providers should consider:

**01** In the wake of an ABI, families are often crucial supports to affected individuals ensuring they receive the appropriate services. It is important to remember that ABI is a condition that can have consequences for months, years and even decades. Families, from the outset, need to be supported and advised to prevent both fatigue from caring and alienation from the service providers and provision system. The long term protection of families, who provide an important economic contribution in terms of informal care, is in the interests of the health services. Quality driven, ABI specific services that sustain the family carer in their role are essential.

**02** While the role of families in the provision of informal care and social support is invaluable,

families are not health professionals and cannot and should not be relied upon in lieu of appropriate professional support. In particular families concerns about their loved ones can act to reduce the independence of those affected by ABI and is best guarded against by involving health professionals in the development and adherence to rehabilitation and recovery programmes. Community-based neuro-rehabilitation services are essential to provide families members with the necessary clinical expertise in their role of carer.

**03** The first-hand accounts of individuals experience on the wake of their ABI are littered with stories of service gaps in particular for those leaving acute care. The risks to affected individuals and their families by the failure to recognise ongoing problems as a consequence of ABI are excessive and the failure to recognise and support those dealing with the aftermath of ABI interferes with long term rehabilitation process and causes unnecessary disability. The ABI pathway from acute hospital care to home should be reviewed immediately with an aim of developing seamless and comprehensive support for those recovering from the acute phase of brain injury and to support a seamless transition from hospital to home. The ABI pathway needs to be clearly defined and resourced appropriately to address the gaps, prevent delays in the rehabilitation process and ensure that people with ABI are gaining timely access to the services they require to recover.

**04** Individuals report that services are not easy to navigate or access even where they become aware of service provision. Often, due to the nature of their injury, those affected by ABI have difficulties negotiating services which can require persistence, concentration, verbal fluency and literacy for example. Information on available services and further investment in case management for those affected by ABI should be considered as a matter of urgency.

**05** The needs of those affected by ABI are complex and chronic and include psychological, social, cognitive and mobility issues. To effectively support those adjusting to ABI access to multi-disciplinary teams in the community are essential.

**06** The needs of those affected by ABI are highly variable. Some need lifelong support and care, others need intermittent access to support and some need once-off time-limited access to rehabilitation subsequent to their injury. Service planning and case management needs to be systematic and individualised to maximise rehabilitation and community reintegration. Further investment in community neuro-rehabilitation teams supported by a range of neuro-rehabilitation services (residential, transitional community, home, vocational) that can respond to the highly individualised nature of ABI is urgently needed. There must be policy recognition that some people with ABI may need life time support and others need to have the possibility of re-engaging in services when needed.

**07** Community reintegration of those affected by ABI allows affected individuals to make a social and economic contribution to society as well as facilitating a return to a meaningful and fulfilling life. It also tackles the feelings of isolation and exclusion sometimes experienced by those affected by ABI. Community integration is made more difficult for those affected by ABI in both rural and urban settings because of practical challenges associated with getting around. These include for example mobility issues associated with ABI, inability to drive as a consequence of ABI and the challenges associated with negotiating available public transport for those affected with altered cognitive function.

There must be much more awareness and attention paid to developing transport options for people with ABI which in turn should be integrated into the case management system.

**08** Group based approaches to rehabilitation, recovery and reintegration service provision as well as being economical, offer benefits to those affected by ABI. The development, planning and provision of group based rehabilitation activities must orient to and protect this valuable peer based support which can counter the perception of the social stigma that individuals report. There is a lack of availability of these services across the country and investment is needed to grow their availability and ensure equity of access.

**09** Resources to support group based activities are likely to yield the intended outcome (for example learning a new skill) as well as benefits in terms of health and wellbeing. Further research to evaluate the social, psychological and economic benefits of this approach is recommended.

**10** First-hand accounts of recovery from ABI highlight that rehabilitation activity is central to recovery experience. Meaningful activity is central to all our lives and this is equally true of those affected by ABI. Service provision should offer a range of gender and age appropriate rehabilitation activities for those affected by ABI.

**11** These first-hand accounts of those affected by ABI are stories of remarkable resilience and strength despite often life changing injuries and the struggles and challenges associated with rehabilitation and recovery. These stories need to be told and shared. Brain injury is largely hidden. There is a need to increase public awareness of ABI and educate a wide range of stakeholders about the consequences of living with brain injury. First person accounts and ABI in general also requires more explicit and direct attention in the policy sphere from policy makers and decision makers in terms of resource allocation.

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# References

- Brasure, M., Lamberty, G. J., Sayer, N. A., Nelson, N. W., Ouellette, J., Butler, M. E., & Wilt, T. J. (2013). *Multidisciplinary Rehabilitation Programs for Moderate to Severe Traumatic Brain Injury in Adults: Future Research Needs: Identification of Future Research Needs From Comparative Effectiveness Review No. 72*.
- Braun, V. & Clarke, V., (2014). *Thematic analysis. In Encyclopaedia of critical psychology (pp. 1947-1952)*. Springer New York.
- Cruice, M (2007). *Issues of access and inclusion with aphasia. Aphasiology, 21:1, 3-8*.
- Fleming, J., Sampson, J., Cornwell, P., Turner, B., & Griffin, J. (2012). *Brain injury rehabilitation: The lived experience of inpatients and their family caregivers. Scandinavian journal of occupational therapy, 19(2), 184-193*.
- Hollway, W., & Jefferson, T. (2012). *Doing qualitative research differently: A psychosocial approach*. Sage.
- Mays, N. & Pope, C. (2000). *Qualitative research in health care: Assessing quality in qualitative research. 320 (7226), 50-52*.
- Miller, L. S., Colella, B., & Green, R. E. (2013). *Environmental enrichment may protect against hippocampal atrophy in the chronic stages of traumatic brain injury. Frontiers in Human Neuroscience, 7, 506*.
- Murray, S. A., Kendall, M., Carduff, E., Worth, A., Harris, F. M., Lloyd, A., & Sheikh, A. (2009). *Use of serial qualitative interviews to understand patients' evolving experiences and needs. BMJ, 339, b3702*.
- Neurological Alliance of Ireland (2010). *The future for neurological conditions in Ireland: A challenge for health care; an opportunity for change. Retrieved from [http://www.nai.ie/assets/70/7F0DE6E9-D279-0C61-137BD29D602E9570\\_document/NAIDraft3-1-44.pdf](http://www.nai.ie/assets/70/7F0DE6E9-D279-0C61-137BD29D602E9570_document/NAIDraft3-1-44.pdf) 31 March 2017*.
- Nicholson, S., Sniehotta, F. F., Wijck, F., Greig, C. A., Johnston, M., McMurdo, M. E, Dennis, M. & Mead, G. E. (2012). *A systematic review of perceived barriers and motivators to physical activity after stroke. International Journal of Stroke, 8, 5, 357-364*.
- Peoples, L. A., & Fortune, D. G. (2011). *The role of pre-morbid personality in predicting rehabilitative outcome in people with acquired brain injury: a systematic review. The Irish Journal of Psychology, 32(1-2), 61-71*.
- Smith, S., Horgan, F., Sexton, E., Cowman, S., Hickey, A., Kelly, P., & Wiley, M. (2010). *Cost of Stroke in Ireland: Estimating the Annual Economic Cost of Stroke and TIA in Ireland*.
- Walsh, R. S., Fortune, D. G., Gallagher, S., & Muldoon, O. T. (2014). *Acquired brain injury: combining social psychological and neuropsychological perspectives. Health psychology review, 8(4), 458-472*.

# About ABI Ireland

ABI Ireland is a dedicated provider of community-based neuro-rehabilitation services for people with an acquired brain injury (ABI) and their families. As a brain injury can affect a person's ability to manage their own life, ABI Ireland works in communities across Ireland to support and empower people to rebuild their lives. ABI Ireland also campaigns, educates and advocates for the rights and needs of this hidden group in society.

## ABI Ireland's Origins

Acquired Brain Injury Ireland (Formally known as the Peter Bradley Foundation) was founded in 2000 by Barbara and Maurice O'Connell. Following a road accident Peter (Barbara's brother) acquired a brain injury. They set up the organisation to address the complete lack of neuro-rehabilitation services for Peter and others with an ABI.

## ABI Ireland Services

ABI Ireland provides a diverse range of accredited neuro-rehabilitation services. The core services include:

- Clinical neuro-rehabilitation team
- Residential rehabilitation
- Transitional living
- Day resource/clubhouse
- Home and community rehabilitation
- Case management

Additional support services are also provided and include: ABI information, psychology (Cognitive Behaviour Therapy/family therapy), social work (family support services) and carer supports.

## ABI Ireland's Vision

People with neuro-rehabilitation needs and their families receive the highest quality personalised services and supports as and when they need them.

## ABI Ireland's Mission

To enable people with neuro-rehabilitation needs to lead meaningful lives in the community by providing personalised quality rehabilitation and support.

## ABI Ireland's Ethos and Values

ABI Ireland's ethos places relationships at the heart of the work. The values that drive this ethos include promoting the person's dignity and respect, enabling choice and valuing everyone's contribution in everyday life.



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Acquired Brain Injury Ireland is the business name of the Peter Bradley Foundation

