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Title	Living with acquired brain injury
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Publication date	2014-12-01
Original Citation	DALTON, C., KINGSTON, A., MARTIN, A. M., O'RIORDAN, J., CAPLES, M. & EDWARD, C. 2014. Living with an acquired brain injury. Dublin, Ireland: National Disability Authority. http://nda.ie/Policy-and-research/Research/Research-publications/Living-with-an-acquired-brain-injury/
Type of publication	Report
Link to publisher's version	http://nda.ie/Policy-and-research/Research/Research-publications/Living-with-an-acquired-brain-injury.html
Download date	2026-11-01 21:28:42
Item downloaded from	https://hdl.handle.net/10468/1781

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Living with an acquired brain injury

Barriers and facilitators to developing community supports as a basis for independent living, the experiences and perceptions of people with acquired brain injury



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December, 2014

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Acknowledgements

This piece of research was funded through the National Disability Authority's Research Promotion Scheme 2013. It should be noted that the views expressed in the report do not necessarily reflect those of the National Disability Authority.

The Research Team would like to acknowledge the assistance and support of Headway Ireland, in particular Ms Liz Owens, and individual group co-ordinators, which assisted in the organisation of both the focus groups and face to face interviews. The artwork for the cover page was painted by Catherine Keane. Catherine says the painting depicts her sitting with friends prior to ABI in lots of light and post ABI surrounded by dark clouds and loneliness as no one understands.

More particularly, we would like to thank the thirty six individuals who participated in this study and shared their experiences of living with Acquired Brain Injury (ABI) with us with such candour. We wish to express our gratitude to them for their insightful contributions and for their time.

We hope that this report will contribute to understanding the experiences of people living with ABI and ultimately positively influence policy and service development and provision.

Executive Summary

This study, funded through the National Disability Authority's Research Promotion Scheme (2013), aimed to give voice to people with Acquired Brain Injury (ABI) in Ireland. Its specific focus was to explore their experiences of the role of natural community supports in facilitating independent living. With this in mind, the research objectives sought to explore people with ABI's experiences of natural community supports and the barriers and facilitators encountered by them, in living independent lives. A qualitative research approach was adopted; four focus groups and ten individual interviews were conducted with individuals who availed of Headway services.

The use of Headway clients does reduce the generalisability of the research to the total ABI population but as the aim of the research is build the evidence base on what can assist people with ABI to engage with natural supports this was not seen as an issue.

The concept of independent living appeared to have different meanings to the participants. For some it was linked to living alone, for others it was reflected in the interdependency and reciprocity evident within personal relationships. Being in control of their lives was viewed as important to all regardless of the nature and extent of their requirements to live independently.

The main findings of this study indicate that the suddenness of a head injury is a dramatic life changing event for both the injured person and his/her family. The impact of the ABI necessitated the rebuilding of people's lives. It is evident that ABI is very much a hidden disability, and this fact impacts on people's ability to access supports and achieve independence. Furthermore, it is clear that natural community supports are essential in supporting people to build independent lives, most specifically those provided by immediate family, close friends and peer support networks. The involvement of broader natural community supports such as those provided by community and sporting groups is less evident and needs to be strengthened.

It is also evident that formal supports, such as the 'come dine with me' initiative and the art classes are essential in facilitating people to live active lives and engage in their communities. Interestingly, formal support services were also seen to bridge the gap between the person with ABI and their broader community support network and facilitate integration into local communities. However, it is clear that this role is one that needs formal recognition and further development. It is recommended that formal support services be resourced and developed comprehensively locally and nationally to provide long-term support for people with ABI and their families.

A multitude of barriers to re-integration and independent living have been identified including limited availability of broader natural community supports,

lack of public awareness, the invisibility of ABI, engagement in sport and leisure activities, employment and financial issues. These barriers again are reflective of poor public awareness of ABI. The recommendations which close this report are targeted to address gaps in understanding ABI, natural community supports and independent living. In addition, the lack of interconnectivity between supports and services needs to be addressed, to facilitate independent living.

Chapter 1: Introduction

Background

This project, funded through the National Disability Authority's Research Promotion Scheme (2013), explores natural community supports that enable people with acquired brain injury (ABI) live independently. In conjunction with the National Disability Authority a decision was made to focus on those individuals with an ABI who availed of services provided by Headway[1].

Acquired brain injury

An ABI can be defined as "Multiple disabilities arising from damage to the brain acquired after birth. It results in deterioration in cognitive, physical, emotional or independent functioning. It can be as a result of an accident, stroke, brain tumours, infection, poisoning, lack of oxygen, degenerative neurological disease etc."(Australian Institute of Health and Welfare, 2007, p. 2). Each injury is unique leaving the person with temporary or permanent physical and/or psychosocial impairments. The most common causes of ABI are external injuries to the head through traffic accidents, falls or assaults. Internally caused injuries include strokes, haemorrhages, brain tumours and viral infections (Headway Ireland, 2009).

Approximately 13,000 people in Ireland sustain head injuries every year and over 10,000 people are admitted to hospital with a diagnosis of stroke. These figures, however, are believed to be an underestimate of the prevalence of ABI as there are no reliable statistics to confirm this. Lack of regional and national reporting of cases makes it difficult to establish the prevalence of ABI in Ireland (Finnerty et al, 2009; McGowan, 2008). Headway estimates that there are up to 30,000 people in Ireland aged 16 to 65 living with long term problems following an ABI.

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[1]Headway, a not-for-profit organisation, founded in 1985 by families and interested professionals seeks to address the needs of people with ABI, their carers and families through the provision of a range of community based services for those aged between 16 and 65. The organisation also seeks to heighten public and political awareness of ABI and the impact it has on individuals, families and carers. Headway provides services in Dublin, Cork, Limerick, Kerry and the South-East, along with a National ABI Information and Support Service and website. Headways services include a wide variety of services ranging from day services to supported employment to family support services and a national telephone helpline. For further information on Headway services refer to Appendix A.

Project aim

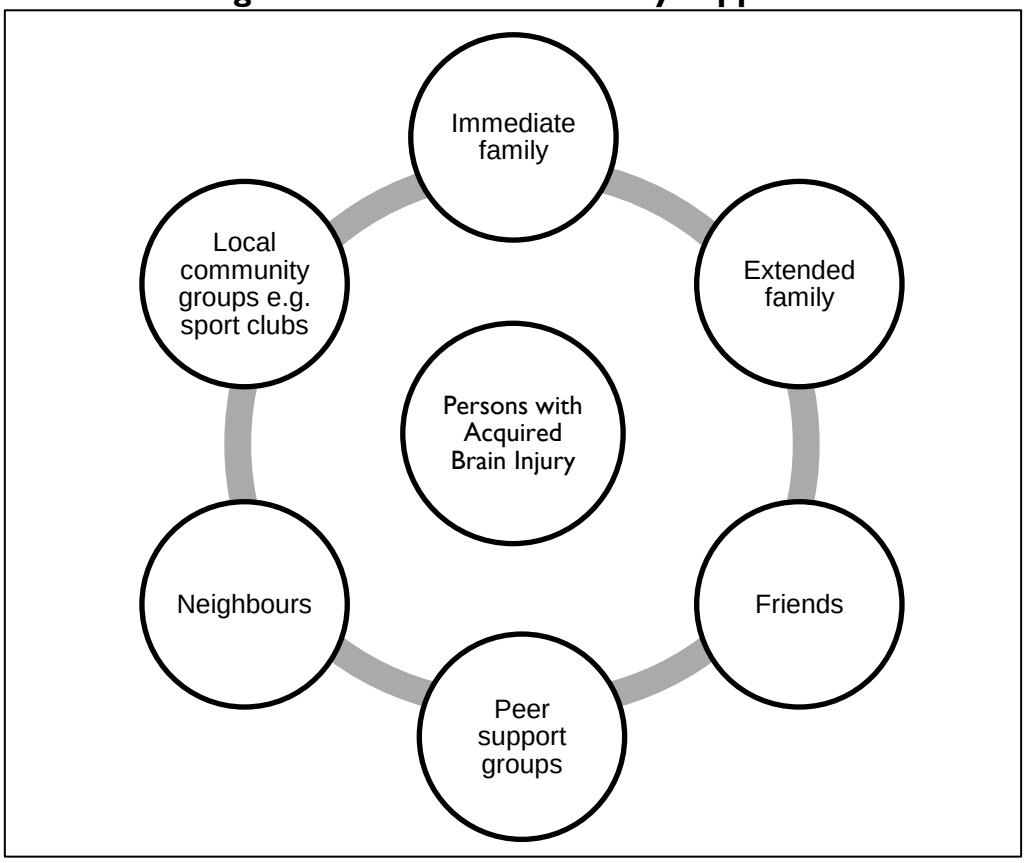
The overarching aim of this project is to explore barriers and facilitators to developing natural community supports as a basis for independent living as experienced by people with ABI in Ireland.

For the purposes of this project we understand 'community supports' to be wide ranging, and so have taken our lead from participants in the research themselves. These could include informal social networks that people are engaged in outside of formal support services as well as peer support or other networks available to people. The concept of natural community supports is linked to family, friends, acquaintances and local community groups (Figure 1) as distinct from formal services provided for people with ABI.

The following definition of independent living is identified as a working definition for the duration of the project:

> 'Independent living does not necessarily mean doing things for yourself, or living on one's own. It means having choice and control over the assistance and/or equipment needed to go about your daily life and having equal access to housing, transport and mobility, health, employment, education and training opportunities' (Office for Disability Issues, UK, 2008, p.28).

Figure 1: Natural community supports



Our concern in examining the presenting barriers and facilitators is to explore the interplay between other types of services and supports (such as Headway's personalised service to enable people with ABI to live in the community) and social/peer supports/networks commonly considered to be natural or community supports. For detailed information relating to project methodology please refer to Chapter 3.

Chapter 2: A review of the knowledge base of experiences of people with ABI living in the community

Introduction

This chapter identifies the knowledge base in relation to people with ABI who are living independently, with a particular focus on their experiences of natural community supports. The definition of independent living, as mentioned earlier, relates to the individual's choices and control over his/her day-to-day life (National Disability Authority, 2011). Natural community supports, often referred to as informal or community supports, are defined as supports provided by family, friends, acquaintances and local community groups. This chapter explores these supports in the context of themes concerning the person's construction of self, barriers to re-integration and community support networks.

In reviewing the literature, several search engines were used for this review, such as Web of Knowledge, JSTOR and Academic Search Complete. Search terms included "acquired brain injury and informal support", "community integration", "natural community supports" and "independent living". A request through the UCC Article Finder Alert using the keywords "acquired brain injury" produced several hundred publications over four months. The vast bulk of these articles had a medical/pathological focus on brain injuries. Furthermore, articles that discussed the individual's experience of living with ABI frequently looked at short-term rehabilitation outcomes. Thus, many of these articles were excluded because they did not contribute to our understanding of the role or experiences of natural community supports.

Attempts to identify research focusing on the role of natural community supports in relation to ABI and independent living more specifically yielded very few results and are often based on a small number of cases of people with ABI. The difficulty in finding research evidence of the role of natural supports *per se*, and specifically on their role in supporting independent living, is also documented in previous reports (National Disability Authority, 2011). Furthermore, it is also suggested that these concepts are problematic in the current disability debate as definitions remain unclear. In addition, much of the research in this area has focused on the role of natural community supports as experienced by those with an intellectual disability and such findings may not be reflective of the experiences of those with ABI more generally.

The supports people with ABI use may take the form of natural community supports, such as that provided by family members, friends and neighbours, or formal support, provided by paid care workers/professionals. However, this distinction, in practice, is blurred, and consequently is of great significance in service and policy planning (National Disability Authority, 2011). Therefore, in order to enable the development of informal supports and independent living

for a person with a disability, formal support services may need to be further developed and more closely co-ordinate with natural community supports.

The Value for Money and Policy Review of Disability Services in Ireland report (Department of Health, 2012) recommends a fundamental shift from current group-based services to a person-centred approach with a focus on individual choice. A focus on the evaluation of services for people with disabilities in general, and people with ABI in particular, is also a common international theme in research. In times of financial and legislative constraint and with proposed changes in the nature of service delivery for persons with disabilities in Ireland, there is a growing need for careful evaluation of the scope and nature of available supports and of service delivery.

Of significance is the lack of a distinct national policy or independent living strategy within Ireland although the policy document 'Towards 2016 Ten-Year Framework Social Partnership Agreement 2006-2015' does make a commitment to supporting people to live in their local communities. However, while some progress has been made in areas such as the provision of personal assistants to people with disabilities, overall, it is clear that national and international objectives outlined in this document have yet to be achieved (National Disability Authority, 2011).

The concept of interdependence versus independence occurs frequently in discussions regarding people with ABI and community integration (Minnes et al, 2001; Strandberg, 2009). Canadian researchers Minnes et al (2001) whose research explored aspects of socio-cultural integration of people with ABI and other minority communities, conclude that although the majority of their research participants were integrated in some areas such as with medical services, housing and social activity, they had little support in other areas, such as spirituality and productive activity. The authors encourage more work in order to facilitate reintegration in these areas by identifying the individual's disability-related needs and their support needs in the same way. They quote Carling (1992) who states that independent living is often perceived as "the absence of need of support from professionals when in fact what is needed is assistance to support growing self-reliance". Following their argument, the focus on community reintegration, then, should be on interdependence and the development of support networks (Minnes et al, 2001, p.9).

A useful definition of community integration is offered by individuals with ABI who participated in another Canadian qualitative study. Participants in this study indicated that "'having something to do' (occupation), 'someone to love' (social support) and 'somewhere to live' (independent living)" are hallmarks of integration for them (McColl et al, 1998, p.26). Indeed, several observations about the definitions offered by the participants in this sample are worthy of further discussion. First, are views of integration offered which are characterised by ideas that are relatively commonplace, like knowing the bus routes, knowing one's neighbours and having something worthwhile to do

during the day? The very simplicity of these elements reaffirms how fundamental and pervasive community integration is to the overall process of adjustment, and how grounded it is in everyday live, and quality of interaction.

Recent social scientific research has begun addressing the existing lacuna in relation to qualitative research on individual's experiences of living with ABI (McGowan, 2008; Strandberg, 2009). Emerging themes in this literature concern the Construction of Self, Barriers to Re-Integration and Support Networks and Community Integration. The following sections discuss each of these themes in more detail.

Construction of self

An ABI is a dramatic, life-changing event for the person and his/her family. The adjustments to be made post injury vary due to the heterogeneity of the individuals and the range of possible injury they have suffered, from mild to severe. Gelech and Desjardins (2011) in discussing findings from their Canadian research conclude that a person with ABI might lose certain aspects of self but constructs a post injury personhood based on elements from both their old and new self. Furthermore, they argue that the form of self, dominant in the Western world follows an ego-centric model where people are highly independent and private (Gelech and Desjardins, 2011), a trend that is applicable to the Irish context. From a social constructionist perspective, then, the personal construction of self relies on direct and indirect feedback and information from others. The participants in this study reported that their 'public self' had changed dramatically post injury and altered their links to society. Thus, their new social identity became associated with dependency and marginalisation and they also often experienced loss of spouses/partners and friends (Gelech and Desjardins, 2011). According to the authors, survivors of ABI, however, re-constructed their 'inner' selves resisting a discourse of loss and call for more research that explores the important role of others in this context.

Similar to Gelech and Desjardins (2011), Jennings (2006) focuses on the reconstruction of self post injury referring to the process as 'reminding'. 'Reminding' in this context is remembering who this person is "as a human subject – a person or agent – and how one must be treated by family and society" (Jennings, 2006, p.30). In agreement with Gelech and Desjardins (2011), Jennings (2006) argues that this process should involve the individual, care-giver(s) and the environment as the supports surrounding the individual may be enabling rather than disabling. The person with an ABI, then, is seen as an active agent in this process with both informal and formal caregivers considered 'trustees' rather than guardians (Jennings, 2006).

In an Irish PhD study, McGowan (2008) furthers the recommendation for the inclusion of others in this process and calls for a holistic approach and broader philosophy of interdependence rather than independence. McGowan (2008,

p.292–293) recommends a focus on 'self-sameness' and calls for more emphasis on enabling family and friends "to care for and perhaps love their partner, father or mother, son or daughter rather than see him/her as a stranger" post injury. This suggestion adds another dimension to the arguments made in previous studies of the need to include elements of the pre and post injury self in terms of the continuation of the social role that was held. This reiterates the importance of the need to consider the positive as well as the negative aspects of the experience. While there is recognition of the need to support the person in their reconstruction of their own personal identity, the influence of their natural support network is an important consideration.

Barriers to re-integration

Weafer and Weafer (2012) explored service providers' perceptions of the use of natural community supports to promote independent living among those with a disability in Ireland. Issues relating to funding were cited as the most significant barrier, followed by transport, housing and accessing services. Employment opportunities, access to information and nervousness related to living alone, were also identified. Some respondents identified public attitudes as the most significant barrier to independent living. The lack of knowledge about ABI among the public is also highlighted in another recent Irish study exploring families' and professionals' perceptions of ABI services. This uninformed society, in turn, leads to increased stress on family members trying to fight for services on behalf of the individual with ABI (McDermott and McDonnell, 2014). The authors, again, stress the need to have the topic of ABI clearly placed on the public agenda.

The physical and psychological implications of an ABI, such as fatigue, memory loss and depression (among others) are well documented (Doig et al, 2001; Stålnacke, 2007; Strandberg, 2009; Mahar and Fraser, 2012). Mahar and Fraser (2012) highlight that cognitive and psychosocial effects are often invisible to others in society leading to misconceptions and misunderstandings. Consequently, social networks diminish for the person with ABI and difficulties in forging new friendships are encountered. This reduction in friendships was also considered to be a barrier to the use of natural community supports to enhance independent living in a study by O'Connor, Gilbert and McGrath (2012). Together, these studies argue that a general education and awareness programme could address this lack of understanding in the community about how an ABI impacts on people.

The same conclusion is drawn in research conducted in Northern Ireland (Linden and Boylan, 2010) where members of the public were interviewed in order to determine their views towards ABI survivors. The researchers acknowledged the need for an increased public awareness of the challenges facing a person with an ABI. They concluded that most participants expected people to use wheelchairs or have visible physical impairments. Thus, there is

a general failure to recognise that ABI can be a 'hidden' disability and people with mild or moderate injuries 'slip through the cracks in an inclusive society' (Linden and Boylan, 2010, p.649).

Several studies discuss the important relationship between having strong informal support and returning to employment (Izaute et al 2008; van Velzen et al 2011). Being involved in productive activity, such as work or study has been found to be an important determinant in the facilitation of the use of natural community supports. Employment eases financial burdens, helps with a positive mental attitude and also the development of relationships and social networks. The importance of financial supports is frequently cited in the literature (O'Connor, Gilbert and McGrath, 2012; Weafer and Weafer, 2012). Lundqvist and Samuelsson (2012) used focus groups involving fourteen participants with ABI in employment to explore significant factors for returning to work. It was found that all participants with ABI struggled with complex problems despite average intellectual functioning. An impaired working memory, mental fatigue, impaired stress tolerance and stimuli sensitivity were cited as reducing their abilities to participate fully in employment. This was also identified in the study by O'Connor, Gilbert and McGrath (2012). Furthermore, the physical and psychological effort required to socialise led them to avoid social events. This, in turn, reduced opportunities to engage with their community. Furthermore, the authors point out the importance of the social context of returning to work as resuming a job is important for a person's self-image.

Interestingly, an Australian study focusing on ABI and employment found that part-time workers and volunteers were more socially integrated than those who worked full-time or not at all post injury (Doig et al, 2001). This could be as a result of attitudes, ability to fulfil expectations and demands of part-time rather than full time positions. Additionally, issues such as access to transport ability/non ability to drive are barriers experienced by people returning to employment (O'Connor, Gilbert and McGrath, 2012). Indeed, loss of the ability to drive has been identified as having a significant detrimental effect on the psychological welfare of individuals (Fleming et al, 2014).

People with disabilities have the same employment rights as other employees. They are also protected against discrimination in accessing training and employment under the Equality Acts which also set out obligations with regard to the provision of reasonable accommodations by employers. There are financial incentives for employers, for example, employers can avail of employment retention grants and workplace equipment/adaptation grants in order to retain people who acquire a disability. In reality, however, the legal obligation to provide this employment for people with a disability in general, and people with ABI in particular, is restricted due to the current economic recession where lack of employment opportunities is an issue for all. Lefebvre et al (2008) explored the long-term social integration amongst twenty two

individuals with ABI and their family care givers in Canada. They concluded that even ten years after the accident most participants were unhappy with their situation and cited several barriers preventing social integration, such as not being back in employment, suffering from depression and having problematic relationships. These barriers of uninformed societal attitudes, limited employment opportunities and manifestations of the ABI all significantly impacted on the potential of the person to integrate into their community and mainstream society. These issues and those identified under the theme of Construction of Self are frequently referred to in the literature alongside the importance of support group networks and community re-integration.

Support networks and community integration

Support networks have been identified as crucial to the integration of people with ABI in their communities. The importance of group rehabilitation is emphasised in a qualitative Swedish study (Månsson Lexell et al, 2012) analysing the experiences of eleven men and women with ABI. In a group, participants could share their experiences with people who had gone through the same life changes as themselves and mirror their new identities with others. This process provided tools to cope with changed routines in their daily lives. Similarly Nilsson et al (2011) found that the group sessions fostered awareness and acceptance of the ABI as well as encouraging independence and productivity. The conclusion drawn was that the participants were assisted 'to speed up the process of change' (Nilsson et al, 2011, p.972) in the group setting. More specifically, the programme helped to lessen the emotional impact of an ABI and improve cognitive functions. Other studies have shown that group sessions provide opportunities to participate in social activities, and to become involved in the community through personally-defined meaningful and mutually supportive interactions with others (Bellon et al, 2012).

Muenchberger et al (2011) also emphasise the importance of including social resources (informal support from friends, family and other natural supports in the environment) in community rehabilitation. This can be done through the creation of neighbourhood links and up-skilling of community groups. Paradoxically, McGowan (2008, p.76–77) argues that participation, such as talking with neighbours, meeting people, joining clubs etc., is subjective and perhaps unpredictable and highlights the fact that people do not necessarily have a good quality of life before they are injured, 'a point that is also often neglected in the literature'.

A large-scale UK study examined the relationship between injury severity and life satisfaction among people with ABI (Jones et al. 2011). It was found that more severe injuries were associated with strengthened personal identities and social networks. This somewhat surprising finding was explained in a more detailed analysis of survivors' 'significant identity work' (Jones et al, 2011, p.364). Some individuals felt, for example, that they had become stronger as a

result of their injury and their social relationship network had improved. This suggests that 'cultivating a survivor identity rather than a victim identity' could help individuals to make more sense of the changes to the self (Jones et al, 2011, p.364). Additionally, it is concluded that access to group membership is vital for the well-being of people with ABI in order to address negative experiences post injury.

It is evident that access to a community support network which promotes the inclusion of people with ABI in their communities is essential in promoting independent living. However, it is also evident that people 'experience a catch 22 situation' (National Disability Authority, 2011) in that individuals find it difficult to live independently due to the lack of a supportive network of friends. Conversely, people with disabilities experience difficulties forming friendships due to their lack of engagement in their local communities. Therefore, the available research suggests the lack of a broad support network impacts significantly on the capacity of people with disabilities to integrate and participate in their local communities.

Understanding gender interactions and differences

Swedish research on assessing community integration and social support amongst 163 individuals with ABI concluded that a large proportion of participants had low levels of life satisfaction three years post injury (Stålnacke, 2007). The study, furthermore, showed that females generally scored higher than males in terms of home integration (independence in performing tasks in the home) whereas men reported being more integrated in productivity (time spent outside the home including engaging in employment and school activities) (Stålnacke, 2007). However, it is suggested that this gender difference may depend on traditional gender roles rather than on post injury circumstances. The quantity of social support (availability of social integration) and the quality of social support (availability of attachment) were also assessed in this study. The results revealed significant gender differences, with males indicating that they perceived a lower number of potential supportive persons compared to females.

A gender perspective was also used in an Australian study undertaken by Muenchberger et al (2010). The authors evaluated a six-week community based self-management support programme where participants reported benefitting to a degree, but there was a noticeable gender difference. Female participants had slightly increased stress levels and decreased goal commitments after the programme had ended. The males, on the other hand, 'demonstrated a slight increase followed by a plateau' (Muenchberger et al, 2010, p.31). A possible explanation for this gender difference is that females entered the programme with inflated self-reported ratings of self-management compared to the males and, thus, did not appear to benefit from the programme. Another theory put forward is that females may have a greater

need for ongoing intervention from local support groups than their male counterparts.

Significant gender differences were also reported in an American study of sixty adults with ABI investigating family functioning and ABI rehabilitation (Barclay, 2013). Again, female participants reported higher levels of psychosocial distress and higher levels of family emotional response than men. Similar to Muenchberger et al (2010) recommendations are made to take gender differences into consideration when planning programmes after discharge as 'perhaps each gender tends to witness and document the capacity for family response differently' (Barclay, 2013, p.171).

Traditional gender roles in society, then, appear to influence how male and female individuals with ABI adjust to their new lives in general, and more specifically what type of natural community supports are available for them post injury and how these are experienced. Furthermore, it is worth noting the understanding that institutional analysis of gender dynamics have to offer. While not evident in analyses of living with ABI, they draw our attention to the close relationship between systemic gendered assumptions within employment, family, personal relationships and communications (see for instance, Acker, 1992; Connell, 2000). It is argued that such assumptions interact with gendered power dynamics to naturalise 'common sense' roles, identities and gendered ways of being.

Family support

Supports offered by families are seen as integral to facilitating people with ABI to live independently within their own communities. A study by Lefebvre et al (2008) found that when participants returned home from services, family caregivers filled the gap in services. This theme of informal family support is reiterated in several studies. It would appear that females are predominantly responsible for the primary care of people with ABI (Bellon et al, 2012). Often a female partner/family member becomes the primary caregiver assisting the person to carry on with daily tasks and social integration.

A Swedish qualitative study (Strandberg, 2009) explored the narratives of fifteen adults with ABI and found that informal support from close relatives was very important to the person's recovery and the changes experienced by them over time. This was particularly the case for males who described this as meaningful for their survival. Strandberg discusses his findings in the context of the different meanings of care: 'caring for' and 'caring about' as well as the term 'labour of love' (Strandberg, 2009, p.285). Thus, the participants' experiences of informal care (a wife caring for her husband for example) were both practical and emotional and had a significant importance as a driving force for the individual's rehabilitation training and adjustment to a new life.

Tomberg et al (2007) undertook a longitudinal study involving thirty-one people with ABI in Estonia to explore psychological coping strategies, social

support, life orientation and health-related quality of life. Similar to other international research, this study documented a high number of relatives providing support and this was considered an important factor for adjustment and emotional well-being post injury. Unique to this study was the finding that the level of satisfaction with these informal supports tended to decrease over the years, possibly explained by personality changes, financial difficulties and stress in the family.

The overwhelming stress experienced by family carers following the discharge of the individual with ABI from rehabilitative services is also documented in a recent Irish study (McDermott and McDonnell, 2014). One of the most devastating effects of ABI is a shift in well-established family roles and with negative changes in long term relationships. This was particularly the case for some spouses who found their new care-giving role difficult (McDermott and McDonnell, 2014). Professionals interviewed in this study also referred to this phenomenon as 'enforced altruism' and the researchers call for greater support for the whole family in the rehabilitation process.

There is also evidence that people with ABI worry about the well-being of their care-givers. O'Connor, Gilbert and McGrath's (2012) study found that participants wanted to do as much as possible for themselves rather than being seen as a burden. Indeed, an Australian study (Chan, 2008) exploring people with ABI's perspective on respite care found that participants' recognition of their carers' need for their own time and relief from stress were contributing factors to choosing respite. Reciprocity was also important to the participants, in this context. They tried to contribute or return help when possible. Where this reciprocity existed, the probability of requesting help increased.

The reliance on immediate family members for support may be linked to the previously mentioned difficulties people with disabilities experience in developing social networks. Barriers include the severity of disability and social skills of the individual and such issues as lack of amenities, poor public transport, lack of finance and stigma (National Disability Authority, 2011).

Conclusion

The emerging themes from the literature review highlight how natural community supports facilitate independent living and community integration for people with ABI. This support is mostly provided by immediate family members and becomes vital as the person with ABI reconstructs his/her self post-injury. Lack of other formal supports in society (employment, transport, peer networks) makes this journey difficult and creates several barriers to re-integration. Re-engagement in employment while perceived as important, can pose difficulties. Full time employment is often associated with greater levels of stress and can act as a barrier to associated social engagement. Part time and more flexible employment seems to enable social integration and meaning

in people's lives. Furthermore, it is important to recognise that people with ABI belong to a heterogeneous group with individual needs and backgrounds. Thus, several factors in the person's life pre injury, such as gender roles within the family, also impacts on the quality of life post injury. The lack of awareness and understanding from society is also frequently documented in research, highlighting issues related to the invisibility of impairments and the need for public awareness programmes. This 'invisibility' and lack of public awareness also impacts on the capacity of people with ABI to access natural community supports and integrate into their local communities. The available research would suggest that those with ABI need assistance to access natural community supports (National Disability Authority, 2011)

To conclude, although the available literature explores some aspects of the role of natural community supports in promoting independent living, it is recognised that 'the lack of data relating to natural supports and independent living is a significant obstacle to the development of policy and services in this area' (National Disability Authority, 2011, p. 81).

Of particular significance is the limited availability of research exploring the extent that natural community supports, support independent living for those with ABI. In a literature review undertaken in 2011, only one international study was identified with a specific focus on independent living outcomes for those with ABI (National Disability Authority, 2011). Most research in this area focuses on those with an intellectual disability. As previously stated those with ABI belong to a heterogeneous group, all who have individual needs. The extent to which natural community supports facilitate independent living for people with ABI has yet to be fully explored. Further research is required to explore the nature and role of natural community supports and to identify examples of best practice to facilitate independent living. Such research would provide the required evidence base to support the development of clear policies such as an independent living strategy from an Irish perspective.

Chapter 3: Methodology

Introduction

Having defined the parameters of the research proposal contact was made with Headway to negotiate access to potential participants. A steering group was established in June 2013 comprising Liz Owens, the regional manager for Headway and faculty from the participating schools in UCC (School of Nursing and Midwifery and School of Applied Social Studies). The focus of the steering group was to oversee the timely completion of the study.

Research aim

The overall aim of this qualitative research study was to explore barriers and facilitators to developing natural community supports as a basis for independent living as experienced by people with ABI in Ireland. A qualitative approach was suitable to meet the aims of the study and to capture the experiences of people with ABI in Ireland.

The objectives of this study were to:

- Explore people with ABI's experience of natural community supports and the significance they attach to them as a basis for independent living
- Examine the barriers and facilitators to the development of natural community supports for people with ABI
- Explore examples of good practice in facilitating community supports

Ethics

Ethical approval was sought and granted by the University College Cork Social Research Ethics Committee (SREC) and Headway Research Ethics Committee. All ethical obligations and responsibilities were upheld. Ensuring that each participant was fully informed regarding participation and their right to withdraw if they so wished were identified as needing particular planning. Hence, additional supports were put in place to ensure this requirement was met. This included ensuring that potential participants had information relating to the study at least a week in advance to afford them adequate time to consider participating or not. Participants also had the option of inviting an independent advocate to accompany them if they wished although no participant availed of this option.

Sampling

Sampling of participants was undertaken using a maximum variation sampling technique, which is a form of purposive sampling (Polit & Beck, 2012). This approach allowed a broad selection of individuals to participate, reflective of the diversity of individuals who present with brain injury. Participants who were using the services of Headway were selected. The diversity of Headway's services was advantageous as it enabled the research team to

access individuals with an ABI at different points on the trajectory post injury. For example, some participants had begun to access services comparatively recently while others had been availing of services for five years or more. However it is possible that Headway clients are not representative of total ABI population but as there is no population sampling frame for people with ABI it is not possible to check how representative the sample are.

The final sample included twenty-six individuals who participated in focus group interviews and ten additional people were individually interviewed. As with the sampling of respondents for the focus groups, a maximum variation sampling technique was used to identify potential respondents for the face to face interviews. In order to capture the diversity of individuals who present with ABI the research team reviewed the demographic profile of the focus groups prior to organising the face to face interviews. There were twice as many men compared to women; the majority of participants were aged between fifty and sixty four years of age and a greater percentage of respondents lived in rural areas. Cognisant of this, the research team requested access to a slightly higher proportion of female respondents; respondents who lived in rural areas and individuals outside of the fifty to sixty four age group.

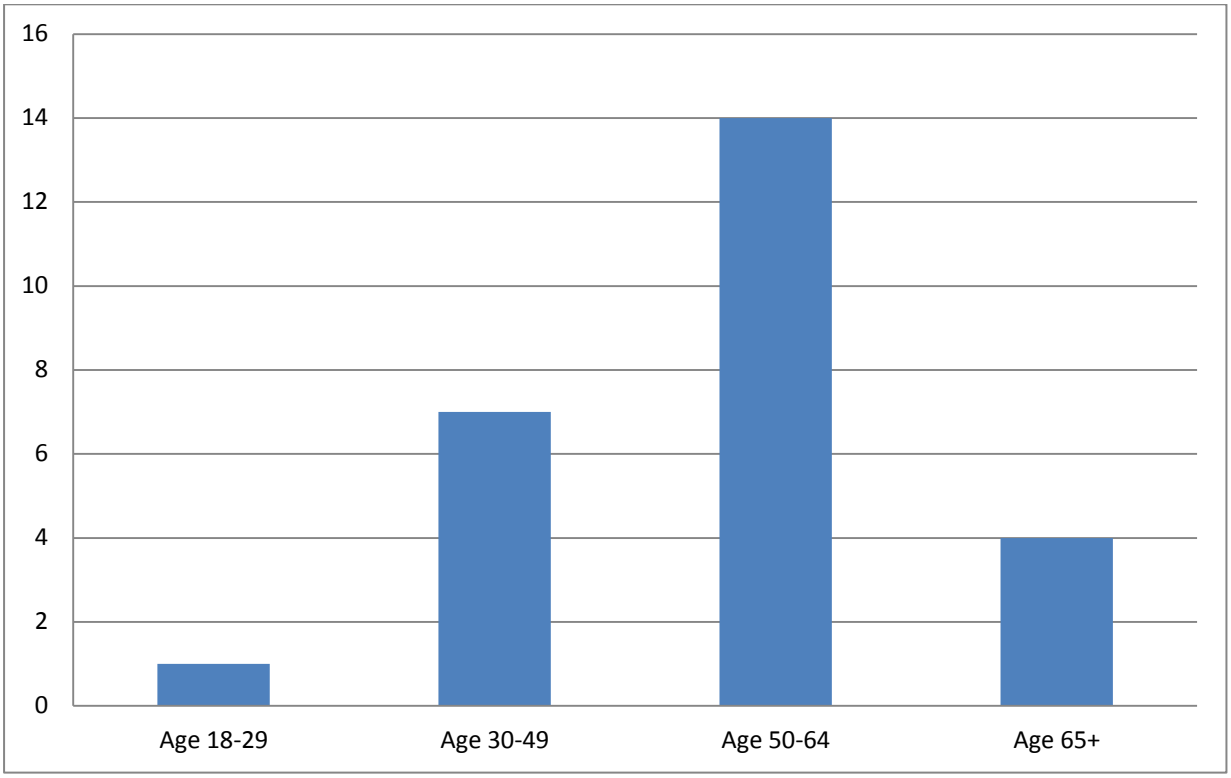
Table 1: Focus Group and Individual Interview Inclusion/Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Persons aged 18 and over	Persons aged 17 and under
Persons with an ABI	Persons without an ABI
Persons living in a community based residence	Persons not living in a community based residence
Persons currently availing of Headway services	Persons not currently availing of Headway Services

Focus group demographics

A total of twenty-six individuals participated in the focus groups, seventeen men and nine women, with the majority falling into the age bracket of fifty to sixty-four (Figure 2). Some participants did not complete all sections of the questionnaire.

Figure 2: Age Profile of Focus Group Participants



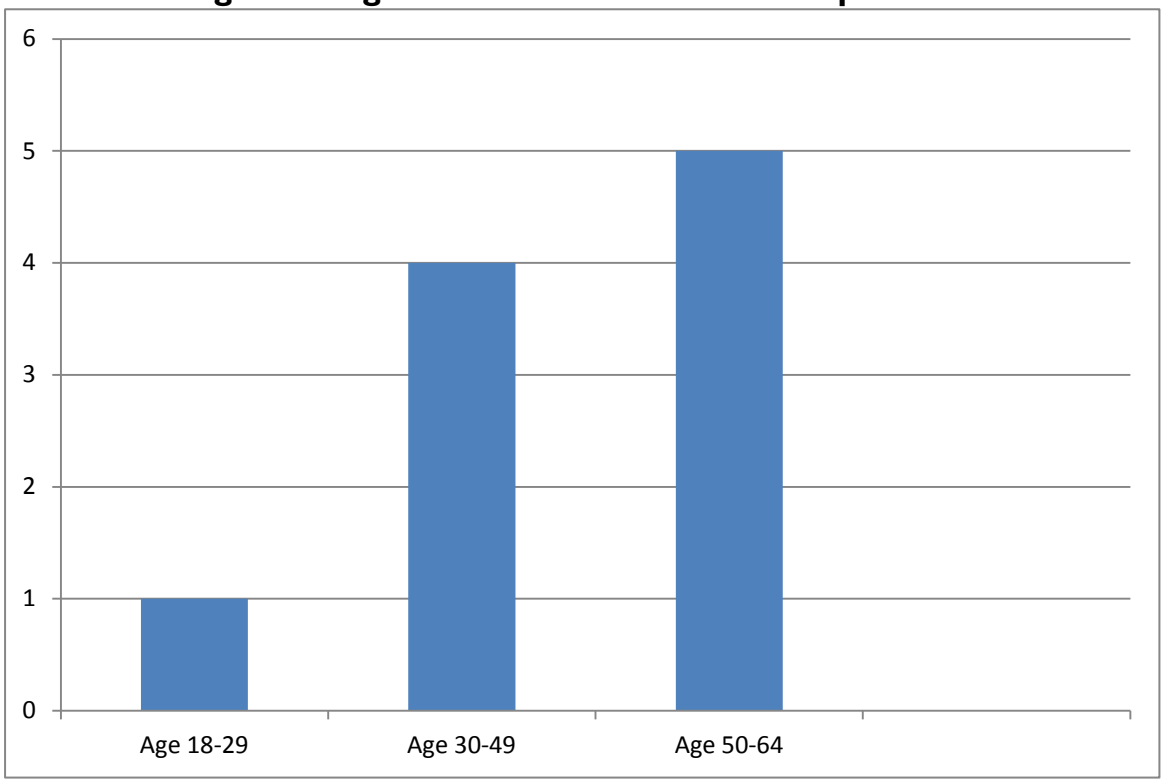
The vast majority of respondents were white Irish (n=25) with one individual of Asian Irish extraction. Eighteen participants lived in urban areas (n=18), with five individuals living in rural areas. Three individuals did not complete this aspect of the demographic questionnaire. The educational background of respondents was diverse ranging from Primary School education through to Junior and Leaving Certificate level with the highest attained qualification at science degree level. Twenty-four people indicated that they were availing of some form of social welfare payment such as a disability allowance and/or pension. The remaining respondents (n=2) did not complete this aspect of the questionnaire.

With respect to employment status, the majority (n=21) identified themselves as retired/unemployed, one individual stated he was a house husband. A further two individuals stated they were employed within Headway but again it is not clear if this constituted paid employment. Further clarification was sought from Headway who stated that clients are not employed by Headway but because there is a small attendance payment to clients who attend the rehabilitation training programme, some clients refer to this as their "pay" hence they may use the term that they are employed because of this.
The aetiology of the ABI varied, with respondents having received external traumas to the head (car accidents or falls) and internal injuries (strokes, haemorrhages and aneurysms).

Individual interview demographics

A total of ten participants from a heterogeneous group ranging in ages from early twenties to early sixties participated in the face to face interviews (Figure 3).

Figure 3: Age Profile of Interview Participants



Five male and five female individuals with ABI participated, with the majority (n=6) coming from a rural background and the remainder from urban areas.

Nine of the respondents had been engaged in fulltime occupation or education prior to the injury. Respondents had previously worked in the construction industry, hospitality and tourism sector and in transport. Only one individual continued in employment and this was on a part time basis. Respondents were mainly dependent on some form of social welfare allowance. These included vocational training grants, disability allowances as well as spouses' incomes. The tenth respondent, although a home maker, had been providing fulltime support to others within her immediate family and her local community.

The time lapse between injury and interview varied from three to four years up to thirty years. Again, the aetiology of the ABI also varied, with respondents having received external traumas to the head (car accidents or falls) and internal injuries (strokes, haemorrhages and aneurysms).

Access and recruitment

The co-ordinators in Headway's Dublin, Cork and Limerick services were contacted by a member of the steering group to inform them of the

inclusion/exclusion criteria for participation in the study. Following consultation a sample was identified. The co-ordinators met with the potential participants to inform them of the study. This was necessary to ensure sufficient time and accessible information was available to participants cognisant of their individual needs. Individuals were informed that participation was voluntary and they could withdraw at any stage in the process. Participants, who agreed to take part, completed consent forms at the start of the focus group and individual interviews. Prior to undertaking both the focus groups and the face to face interviews information leaflets and consent forms were distributed to each participant. This information was provided at least one week in advance to allow participants time to read, process and understand the project information.

Data collection

Data collection was divided into two stages: firstly focus groups, followed by individual interviews. Suitable times and locations to convene focus group and individual interviews were agreed in consultation with participants and Headway co-ordinators. On occasion, memory impairment may have impacted on individuals' capacity to remember events; services offered or previously availed of. The researchers facilitating the focus groups and interviews sought clarification as required. Clarifications were made by others in the focus groups or support staff from Headway. Every effort has been made to clarify statements made by individuals to the fullest extent possible.

Stage 1: Focus group data collection and analysis

Four focus groups were convened in Cork (2), Dublin (1) and Limerick (1). Each focus group was facilitated by at least two members of the research team. Broad open ended questions were used to initiate discussion as reflected in the focus group interview schedule (Appendix B). For some focus groups, all of the questions were put to the participants by the facilitators as they proved to be useful prompts for individuals who may have had issues in relation to memory loss or concentration. The conversation was more free-flowing in other groups, requiring limited intervention by the facilitators to keep the conversation on topic. Groups were audio recorded with the permission of participants and transcribed thereafter. Thematic analysis of the data was undertaken to guide and inform the second stage of the study; the individual interviews.

Stage 2: Individual Interviews

All those who contributed to the face to face interview process were new participants to the study. During stage 2, having identified emerging themes, an interview schedule was devised to guide the individual, semi-structured interviews (Appendix C). Ten interviews were undertaken with individuals who presented with ABI in the Cork and Limerick regions. Potential participants living in the Dublin region were identified. However, none wished to proceed with this stage of the research. Interviews were facilitated by one

member of the research team and lasted between 30–60 minutes. These interviews were also audio-recorded and transcribed verbatim.

Data analysis

Each audio recording and subsequent transcript was compared to ensure accuracy of the transcript. Data from both the focus groups and individual interviews were thematically analysed. The research team divided into subgroups of two. Each subgroup was allocated a selection of the transcripts to analyse. Following this, a meeting was convened where cross analysis of the themes identified was undertaken. Final themes were agreed upon following team deliberation and by unanimous consensus.

Limitations

As mentioned above, one potential limitation of this research is that the sample population was drawn solely from Headway. A limited number of individuals referred to getting supports from other services outside of those provided by Headway. This limits the generalisability of the findings to all people with ABI. Additionally, the majority of individuals who avail of Headway services are in the over forty age group therefore our sample was clustered in the forty to sixty age groups in the main. Without a population sample frame it is impossible to know if and by how much the sample is biased.

Chapter 4: Living with an Acquired Brain Injury: experiences, meanings and accessing community supports

Introduction

This chapter explores the extent to which natural community supports facilitate independent living, from the perspectives of people with ABI themselves. It is timely, at this point to restate that for the purposes of this study, 'natural community supports' are identified as supports provided by immediate and extended family members. They also include friends, neighbours, peer support groups and local community groups such as sports clubs, as distinct from supports provided by ABI organisations (see Figure 1). Furthermore, independent living is understood as being linked to the level of choice and control experienced by individuals as well as access to appropriate housing, transport, employment and health opportunities (Office for Disability Issues, UK, 2008).

Findings include a multiplicity of issues highlighted by participants during the course of this research which can be categorised into two overarching themes. The first of these concentrates on the experiences and meanings people associate with natural community supports and the significance they attach to them as a basis for independent living. The second focuses on the actual services and supports people have access to and avail of in going about their daily lives. It includes discussion on barriers to the development of natural community supports as well as facilitators which enable people with ABI to live independent lives.

Together, they offer a picture of challenges faced by people with ABI in coming to terms with the realities of their lives and the range and extent of supports available to them. It is also important to point out at this stage that natural community supports intersect with more formal service provision and, at times, the lines between the two becomes blurred in practice. Attention is drawn to examples of good practice identified in the research in the context of origins, development and significance.

A number of factors need to be addressed when considering the findings of this report. In order to protect anonymity some statements have been altered to obscure anything that might identify individuals involved. Also, some individuals stated that they did not avail of natural community supports prior to their ABI. Some participants had a limited circle of support in the form of family, friends and acquaintances prior to the onset of the ABI. Others were not heavily involved in community organisations such as local sporting or community groups. Therefore, the onset of their ABI was not always the main mitigating factor in the limited engagement of some participants, in their communities, nor in the limited support some received from families, friends

and acquaintances. However, the onset of the ABI could exacerbate their circumstances and lead to greater isolation, as is illustrated below.

Interviewee: I was kind of the loner type.

Interviewer: You were the loner type?

Interviewee: Yeah.

Interviewer: Okay, so that didn't change hugely then?

Interviewee: It has got worse (Interview 4).

Experiences, meanings and significance of natural community supports as a basis for independent living

At the outset, the study strove to identify what the concept of independent living meant to participants and the role of natural community supports in achieving independent lives. It became clear that people's experiences of natural community supports began at the point of injury. The manner in which people adjusted and regained independence followed a staged process as they moved across a continuum from 'acute services' at the point of injury; onto the 'rehabilitative phase' and then onto 'independent living within local communities'. This 'journey' from the point of injury to the present day will now be explored, identifying the role of natural community supports as individuals strove to reassert their independence.

Understanding independence and interdependence

The level of independence achieved by participants was closely aligned with the extent of the natural community supports available to them. It was clear that the presence or absence of appropriate natural community supports was one of the most significant factors to impact on the ability of people with ABI to live independent lives, with a reasonable degree of choice and control. Where natural community supports were available, they positively impacted on individual's level of independence. Those without such supports experienced significant isolation, frustration and limited independence coupled with an increased reliance on formal support services.

Furthermore, it was aligned to the availability of formal community supports and services. Over time the intersection between natural community supports and formal services became blurred, as will become evident throughout the report. Therefore, at this juncture, it is important that we identify participants' perceptions of independent living and its associated meaning within the context of the supports available to them.

A strong wish for independence was apparent among participants and the majority believed that they were in charge of their own lives, to a large extent. They could manage their own hygiene, feed themselves and go about their daily business relatively independently. However, the concept of independent living was interpreted differently by participants, depending on their various

personal circumstances. Some of the participants, for example, believed that an independent life was one where a person lived on their own and relied solely on themselves.

> Well, you live on your own and see after yourself (FG 1).

> I suppose doing things on your own…not really needing help to do anything...being able to stand on your own two feet (Interview 4).

> Living independently, living, this is just my interpretation, living without feeling that you have to have somebody there, helping you through everything, doing the chores that you used to or as you used to do best (Interview 7).

> Well the thing is I live alone independently...I won't ask for help from anyone, I try to do everything myself (FG 4).

Others stressed the importance of close family members as key supports to them, and without whom they would find it very difficult to manage on a day-to-day basis.

> I am married, I have three children, but they are all adults and grown up and gone. So it is just myself and my wife and so I would not call that actually independent living, really, like, with just the two of us at home. But if my wife was gone, I would be independent then, like, I wouldn't be able to cope, like, but I would still get a seizure and would always need someone there with me, like, you know, that kind of way, like. So independent living to me would be, kind of, on my own, you know (FG1).

> Where you would be living in your own apartment, flat, whatever it would be? Where everything you do is, you know, you need to depend on yourself for every function on a daily basis...It might be a case of five, six days a week then on a Sunday go home, maybe Saturday or Sunday, Saturday night, Sunday, go home and visit the mother, or something like that (Interview 5).

The majority of the participants, however, believed that independence was linked to having freedom of choice and being in control of one's own life, regardless of where one lived or with whom, as is illustrated below.

> I live in a [supported accommodation] but if I had a chance to live on my own, but I don't want to leave my mother and father down in case I was not able. That does play in my head a bit, so I just stay in a [supported accommodation] now for as long as I can and just live everyday now as I can...Well, I suppose in a way it is, being independent and to get out, to see my parents is a good thing, then, as well, like (FG1).

The example above is of particular interest as this man felt more comfortable in supported accommodation than in his parents' home, due to ongoing addiction issues. The gentleman felt better able to manage his addiction within a supported accommodation environment than the family home. He continued to have a close relationship with his natural community support network, spending time with his family in the family home, availing of their support in relation to his transport needs and socialising with his siblings. His situation highlights the sometimes complex nature of independent living and the role of natural community supports in such instances.

Other participants emphasised that it is possible to lead an independent life while living together with partners and family members.

> You can still be very independent and live with your partner or live with somebody and have your children in the house or whatever because, like, I led a very independent life and I reared three children, you know...and, like, I had a very independent life and I also had them...So independence isn't necessarily on your own (Interview 6).

> Independent living where you are able to get up and you are happy – get out of bed happy knowing that you haven't got to depend on anyone... Where your girlfriend is there but you know you haven't got to depend on her, she is going to be there no matter what (Interview 1).

> Able to do everything for myself and be able to control, you know, every situation, you know, I was well able to control every situation that went wrong. Like if something went wrong now, like, say the washing machine breaks down I am, kind of, asking my husband to get someone, before I would be straight on the phone to someone and now I, kind of, hold back from situations like that (Interview 2).

Therefore, it is evident that immediate family play an important role in facilitating independence and supporting community interaction for those with ABI.

The role of transport in promoting independence

In general, living independently in Ireland today often goes hand in hand with having access to transport to get to work, social activities, shopping etc. Not surprisingly, therefore, a key finding in this research was the strong link between a sense of independence and access to transport. Loss of the capacity to drive was a huge blow to some participants and they also felt a sense of relief in regaining this capacity. In this context, it is important to acknowledge that participants with ABI living in urban areas, with reasonably well developed public transport services, were less affected by the loss of ability to drive, in comparison to their counterparts in rural areas.

> It's frightening without a car because I was without a car till last November...I was just trying to get lifts. I can't walk to the bus stop. I couldn't go anywhere you see. I was in bed 24/7. I couldn't go outside my front door. I am living on a hill so I couldn't get to the bus stop so couldn't get the bus home, couldn't get on the bus…Yeah, and I have my mobility allowance, if they cut that, like, that is the end of my car, like, I couldn't have the car without it do you know...And then I will be stuck at home and there is no more independent living, is there? (FG2).

> I really wanted to learn to drive again and I was, like, determined to do it and I was scared of it but I was, like, I hated like being dependent, I hated, like, sitting at home and, as I said, I was surrounded by people that were helping me, like(FG 2).

> I have to be dropped or I have to be collected no matter where I am going. I used to have a motorbike before my accident for four years I was driving on my own licence...crash and didn't drive since then...The lack of independence is scandalous because I need my Dad to drop me, everyone, my partner, whatever. It drives me mental (FG2).

> Well, I have driven, but I don't have a car, I take my mother's...I am seizure-free, well, fingers crossed you know...it's not that easy, I mean it is, kind of, well, you know, taking her car, taking her independence away from her, you know (FG 2).

The four participants above were all physically and mentally able to resume driving again post injury, provided they had finances to keep a car on the road. However, the level of injuries that others sustained meant that they were prevented from getting back 'on the road' again.

> Like, my wife drives, so, if we go anywhere she obviously drives. I miss it, for if I wanted to get some groceries, it is okay if it is light enough, but a heavy shop, you know, I would like to be able to drive to the shopping centre, but I just accept it. I was really keen to get back driving, it was one of my prime objectives and when it didn't happen I thought I would be more disappointed than I actually was, but I just accept it now (FG 4).

Two female participants, in particular, felt being unable to drive meant a loss of independence for them, as they had both been very active and drove a lot pre injury. However, due to the extent of their injuries, the chances of them getting back driving again were slim, making them very dependent on natural community supports. In both these cases, this meant they relied on their husbands and is also reflected in high level of dependency on immediate family members across the study.

The role of carers and independence

Individual's cognisance of their reliance on their support network to get from A to B, meant requests were often times carefully considered; individuals differentiated between essential requests such as a request for a lift to a doctor's appointment as opposed to a lift to the shop to buy a bar of chocolate.

> In the line of independence, I will always be dependent on somebody, always. That is one factor that is never going to go away. I will always have to have somebody with me, I can't go out on my own or anything like that, you know (Interview 6).

> But I remember one day being at home saying, I would love a bar of chocolate, but I couldn't, well, I could have rang somebody but, like, it is fine to say, can you do this for me, but could you bring a bar of chocolate just seemed a little bit, kind of, as if everyone was my slave and I can't do that, and I thought, if I could only drive (FG 2).

While a loss of independence appeared to have a negative effect on these women's mental wellbeing, in contrast, a male participant who used a wheelchair, while saying that he missed the freedom of walking and driving everywhere, stated that he felt that he was living independently.

> Well, I think my life is independent enough...I am comfortable with it...at the moment it is okay...and I make my own decisions, all across the board... [Independence is] to make up my own mind and to decide what I want to do...and to decide some of the things like telly; what I want to watch (Interview 10).

Furthermore, this man had chosen who his paid support workers were – a neighbour was his home helper and a female relative was his personal assistant. He felt strongly that they should be paid for what they did for him, regardless of their relationship to him.

> I asked her to be my home help because she is my good friend...and I can trust her...and she's in my house anyway...I cannot afford them...and I cannot ask them to do this for nothing(Interview 10).

This man relied on a lot of support, both formal and natural community support. His positive attitude to his life, although highly dependent on others, could, perhaps, be explained by his ability to choose the individuals and the supports he required to facilitate him to live independently.

Paradoxically, a female participant who had severe disabilities post injury felt that she no longer had control over her life. She has no immediate family of

her own and a relative received the Carers Allowance to provide support for her.[2] She stated that this relative was in charge of all her decisions regarding both her social life as well as her financial life; 'I don't like it'. She also felt that this individual was in need of education and training in order to better understand her mental and physical needs.

Both these cases above draw attention to the blurred distinction between natural community supports and formal services. Close relatives and friends were paid by the State to support the persons with ABI, however it is unclear in the woman's case whether this was truly her own choice or not. In the man's case, his active role in the decision-making process was clear. Furthermore, some individuals expressed concern regarding the ability of family carers to fully understand the implications of the ABI and the supports required by those with ABI to live independent lives. Issues regarding education and training of family and friends were highlighted in developing appropriate care and in supporting independent living.

The influence of state support

Participants' understanding of their reliance on natural community supports is reflected in their recognition of the need that family members have to be supported by formal services, highlighting again close connections between independence and interdependence. One participant felt particularly strongly about the need for the State to provide formal supports directly to him in order to relieve family members of a caring burden.

> Independent living is really about being able to be…if you are disabled you need to be funded and supported either in the community, medically…You need to be able to live on your own without having to even have a family member with you only as support...I am in the process of applying for [personal assistant], but it is hard to get it...Government set up this independent living so that you weren't institutionalised, you know...they haven't replaced that with anything, you know(FG 2).

This view was echoed by a younger woman who felt that the State's financial support was vital in sustaining her and her young family's independence. She had subtle support needs herself but she was able to provide support for her

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[2]Carer's Allowance is a payment made by the Department of Social and Family Affairs for carers who are looking after someone who is in need of support because of age, physical or learning disability or illness, including mental illness. It is a means tested payment and mainly paid to carers on low incomes who live with and look after certain people in need of full-time care and attention.
http://www.hse.ie/eng/services/list/4/olderpeople/carersrelatives/Carers_allowance.html
(Accessed on the 7/2/2014)

two young children. She considered her independence within the context of her family's interdependence.

> Yeah, yeah sure they will cut the disability allowance as well, like, sure how could they do that to some of us...That is what I have, I have nothing else...I have that and my rent allowance, but what's that, like. If I didn't get my disability I would have to move back in home and that is not going to happen, like. Okay, how could I move my whole family back into my parent's house? (FG 2).

Another male participant insisted that his elderly mother depended more on his support than he did on hers. However, he stated that 'I wouldn't like to say that to her because she would get offended, like'. This man said that it was his choice to live with his mother and that other people might choose to live differently. Again, the theme of interdependence features strongly in people's perceptions of independent living.

> But I don't know, I would find some people, depending on their personality, would be a bit lonely in the place on their own. That is why a lot of people like to share apartments, flats, whatever...I mean to me personally, I wouldn't mind it because I would be, kind of, independent, always have been, but I think my mother, like, I wouldn't like to leave her on her own because of her age and just to make sure she is okay, you know, so (Interview 5).

Influence of living arrangements in supporting independence

Overall, people's perception and experiences of independence was positive, but the theme of loneliness also arose in this context. It was evident in the case of one female participant who had moved out of her parents' home almost a decade after her injury. In discussion with her it became obvious that this was, perhaps, not something she had chosen to do, but a way of preparing her for days to come, when her parents would no longer be around. This woman had a large family living nearby and supporting her and she ate all her meals with her parents. However, in the evenings when she was alone in her own home she felt lonely and isolated.

> I've lived on my own for...about eight or nine years. I feel, like, you know, I was getting in everybody's way and...I had to, kind of...see if I could manage on my own...It is hard, like, you know, I will say, I love going out and I love being with people but I hate being on my own at night especially, very lonely(Interview 8).

In this woman's case, epileptic seizures meant that she sometimes falls at home and has to be taken into hospital. This might cause her extra concern and could possibly contribute to her sense of insecurity and loneliness.

> I get an epileptic fit or anything...if I am on the ground at home, like, you know, the lads are ringing me and they will come down and find me on the ground and they will, sort of, have to call the doctor(Interview 8).

The experience of independent living then, was, at times, difficult due to post injury medical conditions. In the case of the woman above, it would seem that it was decided in conjunction with her family, that she needed to find out if she could live on her own, despite her epilepsy. Another younger male participant had an ongoing serious medical condition which played an important part in decisions regarding his living arrangements.

> I don't know if I could live on my own. I could, like, but it is a big step...it doesn't bother me that they [parents] are protective it is kind of safety conscious...But I think I will be able to handle myself (Interview 4).

Similar to younger participants in the study who were still living with their parents, this young man expressed a wish to lead a more independent life but accepted that he still depended on his parents to a large extent. This feeling was echoed by a young female participant who discovered how dependent she was on her parents during occasions when she away from home.

> I can be right narky and it is only when I realise, when I am away from home, that, kind of, I don't know what the word would be, dependent on them [parents] FG4).

In conclusion, the concept of independence was interpreted differently by the participants in this study. For some of them, independent living meant living completely on their own and making decisions to suit their own preferences; a concept of independence that is linked to a trend in western societies that emphasises personal privacy and detached individualism. Other participants, however, interpreted independent living more in terms of having a degree of control and choice over their own lives. The interdependent and reciprocal nature of family life was also identified as an important construct in peoples understanding of independent living.

One key finding was that not all participants appeared to have been consulted adequately regarding the support structures around them. Nevertheless, natural community supports played an integral role in supporting independent living for people with ABI. Specifically, where the resultant injury left the person with severe ongoing medical conditions, the support of family members and close friends was essential across all aspects of daily life. Whilst individuals might have craved more independent lifestyles at times, there was recognition that the level of support they were receiving was reflective of their needs.

Being consulted about and having a choice in who provided supports, irrespective of whether these supports were drawn from informal or formal support networks, was important. Choice and consultation regarding who provides supports and the form they take can be viewed as good practice in developing appropriate care and in facilitating independent living.

Identified barriers to independence were the loss of the ability to drive, lack of transport and serious medical conditions that impeded lifestyle choices. These barriers were also viewed within the context of the additional burdens placed on the natural community support network and quite an amount of consideration was given to how essential a request for support was, prior to making it.

As previously stated the concept of interdependency within families was very evident throughout the study. The experiences of participants highlight the interdependent nature of independent living and also draw attention to the interconnectivity between natural community supports and formal support services. While participants voiced concerns regarding the extent of formal state supports available to them, they reiterated the importance of such supports to them. All participants in the study indicated to some extent, that formal state supports need to more actively engage with people with ABI and their natural community support network to support independent living. There was a recognition amongst them that, in some instances, due to the extent of the support required, the caring role could not be shouldered alone by family, friends and close acquaintances, an issue that we return to later in this report.

The 'moment' of ABI: The need for natural community supports

In all cases the onset of the ABI was experienced as a traumatic, life changing event with sudden and serious implications for the individual and their loved ones. Regardless of the time that had lapsed between acquiring the ABI and their participation in this research study, individuals described 'that moment' in their lives with great clarity and depth of emotion.

In some cases, individuals referred to the presence of their loved ones at the actual moment when the ABI occurred and pondered the impact of this experience on them. This is reflective of the interconnectedness and shared experience of the individual and their support network in the immediate aftermath of the ABI.

> Interviewee: I was just after my shift, after an hour I stopped breathing and I remember the manageress asked me if I was okay. I couldn't speak as well and I try, and he gives me a chair and I hear the ambulance is on its way, and that is it.
>
> Interviewer: You can't remember anymore?

> Interviewee: No (Interview 3).
>
> ...from my point of view, our two eldest came on me, you know, they were just coming from school and there was a crowd gathered around their father but, like…they saw with their eyes, we don't know sometimes, we ask what implications (FG3).

The shock and trauma experienced by their families was recognised, as is very obvious from the extract below.

> That's what I am saying, they, families were very upset, it is like a death in the family, there is part of you, there is part of me, and you, gone and putting you as my partner now okay, there is part of me and you gone in accommodating life(FG4).

Individuals repeatedly discussed their lives as 'before' and 'after', outlining the beginning of the development of a different life for them post injury.

> Because, you know, I suppose when something, kind of, traumatic happens to you, you keep hankering back to your old life, you know, and it is probably never going to be the exact same again but, you know, you win some, you lose some, it is just a different type of normal(FG 2).

Individuals described the distress and confusion they experienced immediately post injury when they were extremely unwell and required intensive medical care. Some indicated that the fight to regain their life, to regain their independence, commenced immediately, with one person stating that this began while she was in a coma.

> And there was always this need to, kind of, crawl, and I remember crawling [when I was in the coma] like, my knees all being cut, because I was crawling through stuff, to get out, you know. And sometimes now I look and I think, you know that, kind of, fight to be alright and to look after yourself and be alright, like, there was something in that coma that somehow prepared me [for the fight to regain my life] (FG 2).

At this stage natural community supports, mainly in the form of immediate family members, were highly valued, even when all that could be done was to 'be there' with their loved ones while they received medical care.

> Oh, everything, like, you know, like, from the time that I came out of the coma, you would hear their footsteps, you know, coming up the corridor and you would just know you were going to be okay, you know. They would come in and give you a hug and just love you, like, and it didn't matter (FG2).

Transitioning from acute care services

As the recovery process slowly began and individuals moved from acute care facilities into primary care and support services, their experiences varied. For some, this transition occurred in an *ad hoc* manner, with little evidence of interconnectivity or integration between acute hospital services, community based rehabilitation facilities and long-term community support groups. Some participants were discharged from hospital with little information or contact details for community support services, provided by either state or voluntary bodies. This lack of information heightened the stress experienced by them, their families and friends, increasing their reliance on natural community supports from the outset.

> He was working full time; he had to give up work because I was sent home from hospital with a bottle of morphine. I was discharged, actually, quite quickly. I had no rehabilitation, nothing. I was sent from Cork to [hospital] and they kept me there for a while and they probably needed the bed, so I was discharged (Interview 2).

In other instances, people expressed confidence in the manner in which services were provided at this stage, with good communications between and within services. This led to a more smooth transition for the individuals involved and contributed to reduced stress and anxiety for them and their natural community support network. All involved were supported in adapting to changed realities.

> …and then I was carried to the [hospital] and from there, then, to [another hospital] and there was a medical team with me. They came with me. I was six months or six weeks in intensive care, then I was in [another hospital] and then home for two weeks, three weeks, then up to the rehabilitation centre in Dun Laoghaire, and I was there for over two years (FG4).

Professional Supports

The level of knowledge and support provided by individual health care professionals also varied. For some individuals the support of particular health professionals was central as they began to rebuild their lives. Others suggested that some professionals had little insight into ABI and limited knowledge as to which service they might refer a participant, and what supports they required in general.

> Because you are left on your own, no offence to the medical medics, but you see a neurologist or whatever, and your own GP and you have great support, but then when you have finished all that 'there you are, you are on your own'. Your family don't know anything about it, you know, how to deal with it (Interview 7).

> Interviewee: They didn't know, the doctors said, well, I don't know where to send you, or what to do.
>
> Interviewer: Okay, had they never seen that type of affect from a [condition]?
>
> Interviewee: No, no, I think they were quite surprised that I survived it, because a lot of people don't survive [condition] and I think they were, kind of, lost as to what to do with me then, that I had survived and they just didn't know what to do, and I felt that, I thought I was the only person out there with [condition], with an [further complication] (Interview 2).

This, in some ways, meant that many immediate family members took on a role more associated with a professional, with regard to meeting complex care needs, and providing practical care and services. This in turn, increased reliance and demands placed on natural community support network as participants struggled to recuperate, accept the ABI and re-establish their independence.

Acceptance of ABI

Oftentimes, the extent to which people availed of natural community supports was influenced by their acceptance of the ABI. Participants might lack insight into the extent of their ABI, might be in a state of denial, or might only gradually become aware of it. In order to be ready to accept and develop natural community supports participants first needed to accept their ABI.

Some individuals indicated that, initially, they had a lack of insight into their ABI and simply did not recognise it. This realisation brought a renewed awareness of the impact of the ABI on their natural community supports reiterating the shared nature of the experience for all involved. One man indicated it was over eight years before he recognised that he had an ABI.

> ...[x] asked had I any injury, no says I, all I remember was my side was sore. You had no injury, no eight years later I realise, I could have been told it before that I fractured my skull, but I forget, but I am not saying that from a sympathetic point of view but from the point of view, what would my wife and family have had to go through during those eight years? (FG4).

Others went through a period of denial where they refused to recognise they had an ABI. This orchestrated a situation where individuals would not ask for help or refuse offers of help. This could be related to a fear of 'being found out'; a reluctance to accept the realities that surrounded them post injury, and/or frustrations associated with these new realities. In this context, a lack of availability of natural community supports was not the central issue; it was a readiness to avail of such supports which proved to be a stumbling block.

> And as I say, when I had the stroke...it was like I just cut everything off, I never had a stroke...never (FG3).

> The help has been offered to me, but I have refused it and I struggle to do everything myself without asking, so it is not that the services haven't been offered to me, it is just I say 'ah, no, sure I am grand, I don't need that at all(FG3).

> Well, the thing is they would be only willing to come round and help. I won't, you know, I won't ask, same say, with different friends and all that, I won't ask. Everything is alright grand, grand, grand, and I just shut them off at the pass then (FG3).

For others, the extent and impact of their ABI only gradually became clear, sometimes in unusual ways. For example, while carrying out mundane tasks such as grocery shopping.

> I remember going into Dunnes Stores and walking around and it was so frightening, I couldn't remember, we'll just say I wanted, maybe, cheese and ham and, whatever, milk, the usual things...I was walking around, and walking around, and I remember not picking up anything and being aware of being very frightened, like a child. But seriously, ignorantly if you like, I didn't know it had anything to do with my ABI (Interview 7).

It is evident that this period of adjustment was a difficult one for people with ABI. It is also evident that the natural community support network, even if limited to only a few people, was invaluable at this time as people began to rebuild independent lives.

Accepting and living with the new normal: the role of natural community supports

As is clear from the discussion thus far, reconstructing and living with their new selves became a key part of living with ABI in parallel with the development of natural and formal support networks. It involved a process of slowly coming to terms with this new reality and negotiating lives within the emerging and forming interdependencies of family, friends, livelihood, public interactions and engagements.

> It is things that would never have entered my head before and I, I just, it is, like, I am living with somebody else, like, some other person has taken over my head and I don't want them there. I want them to go away but it is, it is, but they, I don't like the person that has actually taken over my head, I know I am not the person that I was (Interview 2).

People grappled with the emergence of their new self as they tried to re-establish independence. They often had difficulty in accepting and living with ongoing fatigue, memory loss and any number of physical difficulties. Sometimes they became angry and frustrated, and came to accept that they now lived with recurrent mood swings. The extent of the impact of the ABI had obvious implications in terms of the level of independent living that could be achieved for the individual. The availability of natural community supports along with the understanding and accommodation of the changed individual, impacted on the person's level of independence, their self-esteem and self-confidence.

> It is just so different; it is a big change (FG1).

> I miss who I used to be, not the angry person, I wouldn't miss most of the rest of it (Interview 1).

> I mean I was a normal person … and I woke up and I didn't know who I was and I have had to, kind of, it is like being reborn again and I have to start back and figure out what is going on here (Interview 2).

> I mean it is, like, I remember saying 'when will I ever be normal again', you know. There is this girl who is lovely to me, who I go to see and she does physio for me, and she does acupuncture and Chinese medicine, and she used to say it will just be a new type of normal and that is exactly what it is now, you know, a new type of normal, you know (FG1).

The complexity of adjusting to post injury realities is also highlighted as both new constraints and opportunities emerge with the new sets of circumstances and considerations.

Strengthening relationships

Individuals often tried to hold onto their former lives where they had been providing natural community supports to others. Now, the tables had turned and they were the ones in need of support. One woman grieved the loss of her contented and independent life pre injury. At the same time, she considered that the extent to which, for instance, her mother had previously depended on her had been excessive

> It was a burden really, in a way, but that has been taken off my shoulders now…I tell her I can't do it anymore. I have had to say 'no' for my sake, for my own sake (Interview 2).

One man found that while his circumstances had changed considerably post injury, since it, he and his partner had more time to spend together and had

holidayed together more than they ever had. Before his injury he had worked very long hours and was now unable to do so.

> Interviewee: In [abroad] two times.
>
> Interviewer: You were [abroad] two times?
>
> Interviewee: After I get sick.
>
> Interviewer: Oh after your stroke, okay.
>
> Interviewee: I have been in [abroad, holiday location 1] and [abroad, holiday location 2].
>
> Interviewer: [X] and [X] yeah.
>
> Interviewee: We travel a lot after [condition], than before (Interview 3).

Where strong close relationships existed prior to the ABI, some individuals reported that these relationships improved and particular people became an integral part of the individual's natural community support networks. Appreciation for the support provided by them was echoed by several participants.

> And then I have my sisters, they don't live with me but they are great help, they are amazing, amazing, you know…my partner is amazing, like…when in hospital, when people said 'look that part of your brain is dead, it won't come back' he kept like saying, you know, 'never say never' we will keep going, he is amazing…And every time I fall, I ring him and he comes (FG2).

However, some participants found family members over-protective and in some instances, could not understand this. Again, as participants became more fully aware of the implications of their ABI, sometimes, they recognised the need for these supports. This worry and feeling of over-protectiveness is real for family members. It demonstrates the level of support needed as well as burden of responsibility felt, as families struggled to provide the practical supports required to support individuals to live independently.

> No, well you see for a long time I didn't realise that they were only helping me. I always thought they were telling me what to do, you know? And I, kind of, think if only I had known as much as I know now, Jesus, things would have been a lot easier (FG4).
>
> Yeah, and as I said, my wife is at home, like, and, basically, I am capable of looking after myself but she would always be there, just in case, I could get a seizure, you know…Because I could get

> a seizure like that, but it is a long, long time now since I did get one of them, like. But she would just be in the background, just in case, which is very good, like, because I could get it, it is a long, long time but it is always there, like (FG1).

> It is, at the moment I can't go nowhere, or do nothing, like. I am not allowed near the cooker except to plug in the kettle and making a cup of tea... Yeah, I would have to go somewhere to…I wouldn't know if it was turned on or turned off and I forget half the things anyway. I couldn't remember what I did now yesterday (FG1).

Weakening Relationships

In other instances, key supports did not always emerge from what had been strong close relationships prior to the ABI, leading to feelings of deep hurt. Some participants felt let down by the absence of support from those upon whom they previously thought they could rely.

> I am very disappointed, he got married there...just before I got sick, actually, and I have seen very little of him since. Before, he used to come home regularly...I am very disappointed because they are both [professional occupation]...but they tend to have other things to do…Oh, I have seen him, but he only mainly comes home if there is one of his friends here…we used to have a great relationship (Interview 2).

So while a resounding theme from all participants was appreciation, to varying extents, of the support their natural community supports were providing, this needs to be understood within the context of the 'ABI journey'. It intersected with the breadth, depth and tensions associated with relationships with family and friends pre injury. It was also influenced by participant's own adjustment to and acceptance of their ABI as well as that of their family members and friends. Furthermore, post injury outcomes and networks cannot really be determined, as some quite close pre injury relationships deteriorated acutely post injury. Conversely, for some, relationships were enhanced and became essential to the support network of individuals. Some participants had extended circles of supports while others had more limited support networks. However, despite the emotional turmoil experienced, participants recognised what their families were doing for them and recognised their important contribution in facilitating individuals to live independent lives. Whilst some did not appear to look to the future, others reported experiencing fear of a future without these supports.

> I fear, yes I get thoughts in my head now that I never thought I would get before. It is probably things that I would never think about, I could be sat there some days and think, what is going to happen to me, what if anything happens to my husband, what's

> going to happen to me, where am I going to end up (Interview 2).

Reforming and developing new relationships

For some, efforts made in the initial stages post injury to maintain existing networks and personal interests often faded with time. Relationships often changed as fatigue, memory loss, transport and associated issues, impacted on the lives of participants. However, while some networks diminished, new networks also developed and many participants believed that they discovered genuine friends during their post injury journey. Additionally, they appreciated the effort some old friends made in order to maintain their relationships, which sustained and strengthened friendships. Thus for some, their natural community support network developed organically, involving those of importance to the person pre and post injury.

> Since before the accident, it would be one close friend, yeah…Yeah, he is still there, yep…I would go to him before I would go to my family…If I needed help for anything...he knows that I am different…No, he wouldn't judge me, definitely not, he definitely would not judge me, where I feel my family judge me for who I am now (Interview 1).

> Oh friends, yeah…They changed after the accident…Yeah, they changed, yeah. Because when you are not going out in the same circle, you are not going out where they are going, like. You have to accept things…They move on like you lose some and make others. I mean I have friends now from Headway that I have had a couple of years (Interview 5).

> I have different friends now, I still have the same old friends but I don't see them as much (Interview 4).

Gender and age considerations

The different ways that men and women adapted to their lives post injury as well as their experiences of natural community supports, were evident during the course of this study. The female participants, in particular, who had been in full time employment and/or in charge of running their households, seemed to struggle more than male participants to accept their 'new selves'. These struggles impacted on the manner in which they engaged with the natural community support network available to them. It seemed to be particularly difficult, when their pre injury selves were ones associated with competence in managing diverse aspects of their own public and private lives and when involved in caring for members of their family. Women could find it very difficult to ask for help and support for themselves, and in some cases, did not do it at all. For instance, in making reference to doing and organising washing at home, one woman commented.

> I might get very frustrated because of that. I have to take them [the washing] out in bits and pieces or I have to ask my husband, which is for me, being such an independent person before it's, what should I say, it is against my nature almost to ask for help because I could do everything for myself and now, it has took away a lot of my independence in that respect (Interview 2).

Furthermore, asking for help or support from family, friends and neighbours also appeared to be particularly difficult for women living with less obvious limitations post injury, such as memory loss, fatigue or sensory difficulties. They seemed to experience a particular lack of understanding from others as their injuries were quite 'invisible' and so others generally assumed that they were now fully recovered – back to their 'old selves'. We can consider this in the context of the closer association women tend to have with care in the private sphere than that of men. It would also be worthwhile to consider this within the context of inter-relationships and inter-dependencies common within close family and friends and the adjustments that have to be made when a reliable figure is no longer available to call upon. As previously mentioned, moving from being the person providing natural community supports to being the individual who requires such support is a seismic change in anyone's life. Again, the loneliness of invisibility and issues relating to lack of understanding arise.

> They all know I had a [injury] and they now see that I'm over it...what do I say? 'I'm actually not over it?' ...I nearly feel that if I did say it, number one, they wouldn't want to hear it and, number two, they might just think I'm overreacting...'you look fine'...and it's actually a lonely place to be...you're out with friends and they're talking and next thing you lose the whole conversation...and you're so lonely, you pretend, your usual smiling face and you can't wait to get back home (Interview 7).

> I have all wires and coil in my brain but nobody can see those. If I had a stick or a wheelchair they would see there was something wrong with me but because I have nothing to show, nobody understands the emotional affects that it has on me (Interview 2).

Changes in personality and relationships

Another issue that arose at this stage in the post injury journey was changes in temperament. One man found that since his injury he had become angry and aggressive and found this difficult to deal with. He commented that his anger was something that his male relatives could not understand and, and sometimes acted in a way he found to be provoking. This is something worth considering in the context of societal assumptions and stereotypes concerning men's association with violence. It highlights the manner in which such

assumptions can normalise behaviour that the man, himself, considered a symptom of his injury.

> Since my accident I have become very angry where I will lose the head for no reason...and they [male relatives] would look at you and just say 'oh yeah, he is just an angry person. Deep down I am not an angry person...my [male relatives], now, like, I have told them all, 'look I am like this because of a ABI' and...they still push you...like…they keep going and keep pushing, and keep pushing, so like, it ends bad then (Interview 1).

This man considered his partner to be his only natural community support. She has remained with him, despite his changed personality and increased volatility. He expressed feeling guilty about this and said that he had asked her to leave him on several occasions but she refused.

His injury has had consequences for their social lives to the extent that he finds participation in social events challenging and possibly something that fuels mood swings. He spoke about not being able to fully join in at a social celebration to which they were invited. That his partner understood his feelings and did not push him to participate where he felt he could not, highlights the importance of the interplay between relationships and actions/activities. Her understanding of his situation had a role in affirming and supporting his changed circumstances. The support given by his partner shows a deep understanding of this man and is a significant contributor to his ability to manage and accept his life. It has to be recognised that this level of understanding can only be provided by natural community supports as those providing such supports not only 'care for' but also 'care about' their loved ones. This could also be interpreted with reference to aspects of care and caring that are more associated with women in family and in society. This again alerts us to the interplay between the manner in which gender is embedded into family roles, responsibilities and relationships.

> So like, for instance, I was at the [social event] with my girlfriend and I walked into it and people just started staring, I just walked back out and stayed in the hotel room for the night...She respected my decision, she asked me if I would go down and I said, 'no'. All I said was 'no' (Interview 1).

It is also worth noting the different reactions of his male relatives and his partner to his mood swings. His symptoms are accentuated by his male relatives who see him as an angry young man and their actions and reactions to this contribute to his increased frustration. On the other hand, his partner's reaction in facilitating his circumstances enables his re-construction of self in much more positive ways. Where partners, family and friends come to understand the realities of the person's life and provide love and support they become instrumental to the person's new life. Where this is not the case,

individuals are placed at a severe disadvantage and the need for formal support services increase. So here, we can see the different and complex role of family members. Adapting to the changed situations requires adjustment from the person with ABI and from those who make up their natural community support network. However, it must be recognised that supportive adaptation might not always be forthcoming from partners, siblings, sons, daughters, friends and so on.

Some participants, as time went by, extended their network of family and friends. Some individuals stated that people who did not know them prior to the ABI accepted them just as they were now. So, for example, for one man's daughters, who had been born after the ABI, there was no 'before'. His strategy of taking a nap to manage ongoing issues of fatigue was not seen as a 'coping strategy'; it was just what 'dad does'. This reflects how coping strategies, overtime, become a normal part of daily family routine.

> Interviewee: I am happy enough, I am okay in my life, I am healthy, do you understand, if they [old friends] don't want to accept it that is their own business nothing to do with me.
>
> Interviewer: Okay, so they couldn't accept the new you so to speak?
>
> Interviewee: Absolutely that is the word I am looking for absolutely, they couldn't accept the new me...They are still thinking I am the guy from before, I am not, I have changed...Now my two daughters they don't know me any differently (FG3).

Supports required and feelings of guilt

Participants also discussed how they felt guilty as a result of the demands they were placing on their family. This added another dimension to the renegotiation of roles and relationships. It seemed to stem from an awareness of the amount of support they were receiving. Being unaccustomed to needing and seeking support to carry out activities that would have previously carried out independently appeared to intensify their guilt.

> I didn't like it because I felt guilty because I was asking too much. Because I have a bad memory, did I ask you last week to do this for me? I didn't know (Interview 10).
>
> It is hard for her, and I don't like doing that to her, do you know. I remember when she was going away…she sent me a text, 'on the flight, I won't be away from you for long' and I was bawling in the middle of the road, oh, I can't tell her [about an incident that had happened] (FG2).

Participants' awareness of the burden that was being experienced by their families was reflective of their level of acceptance of the ABI. As time passed, they began to more fully recognise the extent of the shared experience of living with ABI for their immediate family members, who formed the bedrock of their natural community supports.

Arriving at a crisis point and accessing community support networks

Despite the level of support, primarily provided by immediate family members, participants reported reaching a critical point where they could not continue to function and cope. This strain was felt by both the participants and those supporting them. It is clear that the natural community support network were meeting those needs that are generally considered important, such as having somewhere to live and someone to love. However, people with ABI and those supporting them struggled to fill the void left by the lack of something to do. The lack of meaningful activities and engagement, employment and limited social circles often left individuals largely unoccupied and made their days difficult to fill.

> You know, it kind of, makes the day a lot better than what it would normally be if I was at home, you know, because before Headway, like, my life was, like, I was in a dungeon, you know (Interview 6).

Oftentimes when people had recovered sufficiently to begin to engage more publically, they found that there were few options open to them. Previous activities, employment and hobbies were, largely, no longer fully accessible to them for a variety of reasons. Meeting new people and developing new skills arose in the context of finding a purpose to their lives and putting a structure on their activities. While this can be viewed as part of a normal transition through the life course, it is important that the role and significance of living with ABI is not underestimated in the manner in which the transitions are experienced. This was often the impetus to seek formal community-based supports which some did almost immediately, while others did so after a number of years.

Extending the support network: getting the balance right?

Similar to earlier stages of their post injury experiences of community supports, participants indicated that they had to be emotionally ready to accept their need for formal supports. However, it was clear that even when individuals recognised their need to access formal supports for the first time, whilst positive, it could be a difficult experience for many.

> And I would go back to Headway, I found a life changing experience learning how to deal with it, the various strategies they used here, right, it was absolutely brilliant. But I can also say, speaking from my own experience, you have to be ready to

> come in here because it was quite a number of years after my accident that I came here (FG3).
>
> When I came in here first of all, I roared and cried. I cried, I didn't know what to expect, I got a shock, more than a shock, I don't know what it was, except that I was injured and, I suppose, the shock of seeing different injuries of different people, do you know what I mean? The wheelchairs, the whole lot that shocked me, and then as the manager sat down and brought one client in to tell us what it is all about, and what they do here, and that, we are all friends, everyone will be friends, there is no bickering or fighting, that doesn't go on (FG4).

Interestingly, no participants discussed returning to the last point of formal support, acute or rehabilitative services, to identify sources of on-going formal support. Accessing formal supports was often problematic as many participants and their families had to take the initiative in finding formal support, highlighting inadequate links between acute services, natural community supports, primary care services and long term formal support services. Issues include inadequate availability of information regarding support services and groups and lack of knowledge among professionals considered to be a suitable first point of access.

> Because you are left on your own, no offence to the medical medics but you see a neurologist or whatever and your own GP and you have great support, but then when you have finished all that, 'there you are, you are on your own'. Your family don't know anything about it, you know, how to deal with it (Interview 7).
>
> Yeah, been to my GP and he actually turned around to my girlfriend and said, look, see if you can find anywhere and we will try and get him in and the girlfriend she had tried Headway Dublin before and they were to get back to her, but never did and she was looking on the website at Headway Limerick and she contacted them there (Interview 1).
>
> Interviewer: September last year, so that is about fourteen months, now, and before that you had no support.
>
> Interviewee: No support from no one.
>
> Interviewer: And who put you in touch with Headway?
>
> Interviewee: The girlfriend found it on the internet (Interview 1).

> I went to my doctor one day and I was just in such a state…so depressed and I thought there must be someone I can talk to, you know…and then 'oh there is a place down there it is called Headways' so she referred me to here and it was the best thing that ever happened to me (Interview 2).

Having successfully sourced community based formal supports, participants experienced relief and hope. A new found network was discovered that reduced isolation and provided an outlet for participants to rebuild their lives. Accessing these supports also reduced the care giving burden experienced by natural community support networks and so proved to be far reaching. They attended to the macro and micro elements of organising events. Typically, Headway provided a range of supports including, skills teaching and retraining, organisation of social activities and advocacy services. People were supported individually in relation to logistical aspects of their lives, such as transport, budgeting and scheduling and support is also offered for specific issues relating to the ABI e.g. memory enhancing strategies.

> Sometimes we go on do's, we, it is like, we have it recorded on 24th of this month…They do every few months or a few months of the year we go out, we go to the same restaurant…that bit is social (FG1).

Promoting self-advocacy

Additionally, as part of self-advocacy initiatives individuals with ABI had begun engaging with and educating health professionals such as general practitioners in relation to ABI and the support services available.

> I am in an Ad. Group, National Advocacy Group and we have it, is the National Advocacy Group of Headway's and what we have decided [is] that [we] give information to everybody, say, you are the doctor you take down the information about Headway and what Headway and Brain Injury is all about, and you do the same, that is what we are bringing up now (FG4).

In Headway, they met people in an environment where they didn't encounter social stigma or lack of awareness. The embarrassment and self-consciousness experienced by many became insignificant while the shared understanding of the experiences of ABI provided security and safety. In this setting, participants didn't have to wear the 'mask', they otherwise wore.

> It's a lonely place to be...we're wearing a mask, really, and people don't really understand (Interview 7).

> Interviewee: I mean I carry a stick now and people know there is something wrong with me but [name] is walking around there.

> Interviewee: And nobody knows.
>
> Interviewee: What I am saying is we are the walking wounded, people don't realise that we have a brain injury (FG4).

People valued having a support group to come to on a regular basis where they could talk to people who shared similar experiences. Participants drew strength and confidence to re-engage in social activities, from this new network of friends. This, again, reiterates the manner in which supports offered formally and informally intertwine, as those relationships become mutually symbiotic.

> Like, we wouldn't be able to, it's grand here because every one of us understands each other, like, we would tune out. You would lose concentration or you might tune in to a different conversation, do you know what I mean? But if you are with your own or family or anything like that, no, I wouldn't have the ability to keep up a conversation (FG2).

Meaningful engagement in the community

Headway support groups also organised social events such as 'nights at the dogs', Christmas parties and 'come dine with me' nights. Participants did not need to consider the accessibility of the location for these events, bookings or co-ordination of the event, as Headway took responsibility for them, from inception to conclusion.

The initial high intensity support offered by Headway sometimes faded out to the point that participants organised these outings independently. One such example found was that of a group of women taking over the organisation of 'come dine with me' nights. These involve a mix of cooking, dining and home-based socialising as an alternative to the publicly-located social activities more dominant in Irish society. 'Come dine with me' nights matched needs expressed by participants to be more in control of their environment as well as a reluctance to be in busy or noisy social spaces which all found frustrating to varying degrees post injury. More generally, it also feeds into women's association with food, care and cooking in society and represented an enjoyable and positive way of socialising and making new friends. While this success was not relevant to all initiatives, it does demonstrate an example of good practice. The people who participated in these nights experienced achievement, inclusion and independence.

As mentioned previously, without these social events and activities, many participants experienced boredom and monotony that, for some, negatively impacted on their mental health. The activities provided stimulation, helped develop new friendships and patterns, and generally empowered participants. It is important to note, however, that for the majority of participants, while

attending Headway increased their social networks some did not meet socially outside of this.

Developing coping strategies

Beyond providing social opportunities, Headway taught individuals strategies to maximise their independence and take more control of their lives. Coping strategies included the use of routine, scheduling, diary keeping and white-boards in the home to increase independence. These skills would not have been attained without support from Headway and they alleviated many of the challenges experienced prior to engaging with formal supports. This empowerment increased the awareness of participants of their need for formal services as they were taught new ways of coping with daily activities such as cooking, baking and self-care within the boundaries of their abilities.

> There is great support in here, like, from the minute you walk in to, the minute you walk out there is always someone there, like (FG1).

> You know, you would get angry with stuff but you would talk and stuff would really bother you, but I am talking down to someone sitting in my seat, I could flip you know?...Nothing like that bothered me before…Yeah, I am trying very hard to control it and since I have been going to [formal service] I am controlling it better (Interview 1).

> The one I use quite often is the white board at home where I put each week on it. If I didn't do that I would miss appointments, or I would miss what I had to do, or I would miss appointments, as well (FG4).

Post formal support services?

Generally, participants appeared to be dealing with current issues in their lives but, perhaps, had not made plans for a future beyond Headway. This is of note as it emphasises the value they placed on the service as well the absence of other long-term support services. One participant expressed her concerns over the fact that her time in Headway was limited and that she would be left to her own devices again.

> You've gone so far after your brain injury, you've got your physio and then you're left on your own, and really, the family member, no matter how good they are...still not understanding...not even your friends...so they [Headway] lift you and bring you along for another two years...and then you're on your own again.... (Interview 7).

The suggestion that Headway's services would finish for them, even for those availing of such services long term, was generally greeted with horror and

described as disastrous. Where attempts were made to phase people out of the service, it was not always successful and sometimes services were then reinstated.

Community supports- where is the balance?

As already stated, because of the nature of this particular study, Headway was the formal support service most availed of by participants. Although other services were sometimes available to participants, many were unaware of these. Again, relevant information was often not available at key times or from where they expected to find it. However, some participants did avail of GPs and Allied Health Professionals, Personal Assistants, Social Work, Complimentary Therapy, Counselling and Respite Services. One participant who was availing of Acquired Brain Injury Ireland's services commented.

> [Wife] died…of cancer and so that was another blow for me, again, because we got on very well and she was used to me, as well. And then, I went back to independent living, as they call it, and then I went back to Acquired Brain Injury. Now, has anybody heard of it? They come into the house and do cooking and they do cooked meals each week, and they also do literacy, and I also did a story for them, and I have taken it up now, and [am] also publishing in their literature (FG4).

> But I love the place in [respite] and when I stay there, hopefully, a few more people, a few bits and pieces...the usual place, she is coming back to stay… just and stay over. But luckily it's that, that was just a magnificent place…just reach out, like, an amazing place for people, relaxed chilled all that, you know (FG1).

However, this research found poor interconnectivity between supports provided by Headway and the other services being utilised. Greater connectivity might help address issues related to provision of more appropriate supports and services that meet more individualised needs. One young man made reference to the fact that he did not feel that Headway's services were the most appropriate for him, as he was far younger than the majority of other people availing of their service in his local area. However, he continued to use Headway's services in the absence of information on and access to other services.

> Interviewee: It is better than sitting at home, sitting at home, listening to music and reading.
>
> Interviewer: So it does get you out?
>
> Interviewee: Yeah (Interview 4).

Participants then, co-ordinated their supports to the best of their ability, in conjunction with their natural support network. They required services such as home-help and/or personal assistance, transport, mental health support and education for themselves and their families, to achieve independent lives post injury. However, insufficient information, with inflexibility and retraction of service provision, coupled with the effects of ABI made seeking out services and accessing them a tedious task. Difficulties in articulating the exact services and supports required can make self-advocacy difficult and result in a reluctance to continue to engage with available services. For example, one participant required a home-help service but inadvertently requested a personal assistant[3] and expressed frustration about the inflexibility of services. Furthermore, as a result of the invisible nature of her disability, she had difficulty meeting eligibility criteria.

> Kind of, I suppose, they call it personal care now, very infuriating really, you know, because, like, personal care, you wouldn't see my disabilities too much, you know…But with personal care, what they will offer you is somebody to come in in the morning to suit you, whatever time, to wait 'till you have had a shower, so that is not suitable for everybody, you know…But I do need a hand with housework, you know, but they call that a luxury, so they don't actually offer you that. That is now called 'the luxury of today', for somebody to clean your house (FG2).

Recently, the Health Service Executive has curtailed the role of home help services to assistance in 'essential domestic tasks' only, and within this understanding, services such as cleaning and ironing are no longer provided (HSE, 2013).

On a more positive note, accessing formal support services ensured people were educated in relation to their ABI. Knowing what to expect, symptom management, coping strategies and explanation of the unknown were

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[3]The HSE Home Help service aims to provide support and assistance to people to remain within their own homes for as long as possible. The service is especially aimed at older people, and people with disabilities. Access to the service is based on a care needs assessment and currently only personal care and essential domestic tasks are now considered under this scheme. http://www.hse.ie/eng/services/list/2/PrimaryCare/pcteams/mw/KIpcc/homehelp.html (Accessed on the 10/2/1014). Personal assistants enable people to live independently in the community. They may assist a person in going to and from work and may help them in working, studying, or participating in social life. They may also provide assistance with bathing, dressing, cooking or other personal or household tasks. http://www.enableireland.ie/adults/benefits/community-care (Accessed on the 10/2/2014)

considered to alleviate stresses, anxiety and validate unique experiences. This rippled out to family members and other natural supports.

Once people made contact with and became involved with formal services they became an integral part of their lives and extended the scope of supports available to them and to their families. Those providing formal supports and natural community support collaborated closely in addressing the needs of individuals. Moreover, where the interconnectivity between formal support services and natural community supports was established for a long period of time, the distinction between them become blurred (this is discussed further in Chapter 5). In the main, over time all involved worked together to support individuals and facilitate independent lives.

Engaging with the wider public: Identifying and meeting challenges

The importance of natural community supports, in the form of family and friends, in facilitating independent living is clearly evident in the discussion thus far, as is the interaction between these supports and those of formal services. We now turn our attention to a number of issues identified by participants, that shed light on the breadth of challenges they face in re-building their lives, with a focus on engagement at community levels and more publicly, in general.

While, at times, issues arising interconnect, for purposes of clarification we discuss them under the following headings; public awareness, engaging in sports and leisure, employment and learning new skills, and financial issues. Together, they offer an overview of pertinent issues that arise and impact on people as they re-engage with the wider community. They show the interrelationship between these factors and a person's ability to be accepted and engage socially as well as in employment contexts. Thus, they can act as pointers in the development of appropriate supports, for instance by more informal community groups, sports clubs, and within public life more generally.

Poor public awareness of ABI

Poor public awareness of ABI and the impact it can have on people was an issue for almost all participants. It limited the extent and nature of all their activities and framed the decisions they made in all areas of their lives. Lack of / limited awareness was encountered in their personal lives, close relationships and wider society. This lack of awareness manifested itself in many ways; for example while socialising with friends participants were sometimes not allowed into night clubs as security staff assumed they were drunk. As discussed earlier, participants spoke of wearing a mask, and a key reason for the necessity of this mask was poor public awareness of the extent of their post injury contexts.

> No, no, my mother didn't believe that I could be sick, she is, she, kind of, was in denial and she still is in denial that I actually got sick (Interview 2).

> [brain injury] Not understood whatsoever, it is not (FG3).

Moreover, participants reflected on their own lack of awareness of ABI prior to their injuries, even in the context of their involvement in fundraising for Headway.

> I am a fundraiser and I do a lot of funding for them [Headway], with them, but that is the main, 'What is Headway's'. Even myself, before I ever had my stroke, I always thought Headway's was a hairdressers (FG3).

This lack of awareness contributed to an acute concern for participants, related to their presentation of self, and of any visible feature they acquired arising from their injuries as well as the more invisible aspects of their ABI. Sometimes this led to people limiting their social engagement.

> Physically, I could go out, but I just couldn't look at the reactions of people looking, and staring at me, and that…At first, they stared at me, no matter where I went. Strangers just staring at me, you know, you feel the eyes burning in the back of your head, like (Interview 1).

One male participant particularly felt the impact of the public gaze. This man had visible physical impairments due to his ABI and believed that people judged him because of these. He commented:

> I see them in the street, people look at you in the wrong way, they look at me in the wrong way (Interview 4).

The message portrayed in his term 'in the wrong way' is poignant. While it can be construed as a generalised comment, his message, as the subject of this gaze, portrays a sense of being singled out as different, and the object of suspicion. He is very aware of the visibility of his injuries to the wider public and views this visibility negatively, in all probability, reflecting the reality of poor public awareness.

> You can see it [a scar] here, in the cold weather they show and go red, and you could see them looking at me, and the side of my head and everything, and I just said, 'no there is no point'. This will end badly if I stay here (Interview 1).

Poor public awareness of ABI, then, as well as a stigma associated with it, became obstacles to public engagement and interaction, and obstacles that this man, at least, considered to negatively impact on him.

It was suggested that awareness of the implications of ABI needs to be increased, specifically in the understanding of ABI in general and, in particular, its long-term nature.

> This is the only way to be tramping out, the more we do work on it, the more people do something for us to make awareness. I mean, to do things for making awareness is fantastic (FG4).

Participants all expressed to some extent or other, the need for a public awareness campaign so that people and society in general would have a better understanding of the implications of ABI. It was thought that if people were aware of the obstacles facing those with ABI, greater consideration would be given to making the required adjustments to ensure people could engage more in their local communities.

Engaging in sports and leisure

As is evident from the discussion that follows, engagement with local community-based events could become problematic post injury, as the norms associated with them were often no longer tolerable. In a broader social context, people's social lives, interaction with others, in community events, general leisure interests, sports and so on, changed considerably post injury. When speaking about their interests, some made reference to involvement they had, for instance in sport and socialising, pre-injury. At all times, as conversations developed, it became evident that quite an amount of pre-injury involvements had been curtailed and sometimes stopped post injury. For instance, it was common that participants would no longer attend live sport matches, or view the televised games with others in the pub, as had been their previous practice. They were more likely, post injury, to continue their interests by watching sports matches in their homes. This lack of communal engagement and participation inevitably led to the loss of friends and lower levels of interaction with sporting clubs within their communities.

Some tended to avoid social situations they expected to be crowded, too loud or busy, feeling that they simply would be unable to cope with the level of diverse activities and aspects of such occasions.

> Interviewee: I loved hurling and imagine me not go to a hurling match [because I cannot deal with the crowds and the noise].
>
> Interviewee: No, I watch it on television now, but I am not a lover of television since I got the stroke, because of the glare, it is terrible, so I mean, I am not interested in television, it could be on and wouldn't worry me.
>
> Interviewer: Would you listen to it on the radio?

> Interviewee: Oh, I would, I would listen away to the radio (FG4).

> Interviewee: They move on, like, you lose some [friends] and make others. I mean, I have friends now from Headway that I have had a couple of years. When I was hurling or cycling or whatever, I have moved on, I still see all of them but not as much. I used to hurl as well and play rugby as well; I still meet them around town (FG4).

> As I said, before my accident I was a good hurler myself, a very good hurler myself, and then the year I got my [ABI] I wouldn't go on my own to a match, it just isn't feasible. Not that I couldn't afford it, but just to go on my own…Going on your own is a different thing…Here, you just go and show up and that is it, like, like, whereas a GAA match you go somewhere after, maybe the Red Cow, or go somewhere else on the way home...I wouldn't go to a lot of matches, it's not the same (FG4).

However, for others, the experience was different. They continued with their interest in sports, attended matches and interacted with their friends who also had an interest in sports. However, they devised strategies to ensure that they controlled social situations rather than more aimlessly following common social practices. In devising these strategies, they weaved their ways around social and gendered assumptions, for instance on the custom of round buying of drinks in pubs. Interestingly, men tended to make reference to being in pubs and involvement in round buying, whereas women tended to make reference to a more broad range of social interactions and less on buying rounds. One man commented on how he devised a strategy around socialising in pubs.

> So, the best thing I used to find was, just pick the fella you went in right behind and he, you'd say, 'I'll get the first one, what are you having' and make it just two and then say 'grand', out the door. Because you have much more control over it then, because if you are lured into this full round system, it is not going to end well, like (Interview 5).

Additionally, participants expressed embarrassment when staff or individuals assumed they were intoxicated because they might, for example, have difficulty tracking a conversation. Others made reference to being embarrassed at being asked to leave and/or being refused service when buying a drink. Here, again we are reminded of the low levels of public awareness of the realities of living with ABI and the isolation that this brings to constructing a new life.

> I got into serious trouble, then, in the local pub. I wasn't drunk but he [the barman] wouldn't serve me a pint. I only had four pints up to then and there was money on the table, so, it wasn't a question of money, he wouldn't serve me, and I took offence, and a row started then (FG3).

A young woman found that she had difficulty in gaining access to a disco, commenting:

> Well you have bouncers at half eleven at night and you are trying to get into a disco and he is telling you 'sorry you can't come in, you have had too much to drink' you know, and you are drinking 7up all night. The one alongside me is plastered and gets in the door, like, you know (FG 4).

Given these type of encounters, participants tended to feel more comfortable in establishments where they were known which, at times, limited their social activities and narrowed options open to them. Some made specific arrangements, either to meet people in places that were very familiar to them, and/or had a small circle of family/friends with whom they socialised. One woman tended to organise her evenings around meeting friends at a local hostelry.

> I can go up to [venue] at night and I have them [friends] there at night, like, you know, around me because like I find it, like, in the evening time, you know, it is there you can sit down with them, have a chat with them, to talk, to like, you know. Because, I suppose if it wasn't, kind of, you know, kind of, even in the evening time, sort of, you know, kind of, I find this time the worst time, winter time (Interview 8).

Another man always made sure he didn't share accommodation when he went away with his friends on sports trips, due to his fear of having an epileptic seizure in front of them. Thus, we see the manner in which he ensures that his mask is secure, even in the company of friends and close acquaintances.

> Well I have said it, you know, [to friends playing pitch & putt] we have gone away for weekends and when we go to a hotel I would always pay extra to have a room on my own...So that is the situation, it is always there, it is always present in your head, but thank God, nothing has ever happened (FG 2).

It is evident then that the social activities of participants and involvement with others became curtailed, as some social settings were no longer accessible for people with ABI. The question obviously arises on the inter-relationship between the social setting and the subject of interest. For instance, it is worth considering how engagement in sports can be reconstructed to take into

account less tolerance for crowded, noisy environments. In addition, learning about conditions common to living with ABI, such as epilepsy can lead to greater social acceptance, facilitating people to remove their 'masks' in more contexts.

Employment and learning new skills

The importance of employment extended beyond the financial independence it provides to people. The realisation that a job was about much more than money arose. A job provides, among other things, structure, engagement, purpose and identity; all of which have to be re-negotiated post injury. Participants continuously referred to the detrimental impact of unemployment, in terms of their self-esteem, validation of self, a sense of role and purpose in life and, most importantly, in having 'something to do'. In these areas the role of formal supports had a significant and positive impact on the lives of participants, providing them with somewhere to go and something to do. For instance, training courses offered people opportunities to up-skill or re-skill themselves in the hopes of accessing employment opportunities in the future.

Being in employment, especially for those in younger age groups, was perceived as really important in contributing towards their sense of self and independence. However, planning could become very important and sometimes stressful, and included close attention to transport details, suitable clothes for work and so on, often taking quite an amount of effort and time outside of working hours.

> I always thought a job was about money but, Jesus, no way. I come here Monday for work experience and get my clothes ready on a Saturday, just, you know, so I know I have somewhere to go on Monday (FG 4).

For all, continuing with pre- injury employment proved to be a challenge; in this study only three participants resumed their old employments post injury. However, once they had resumed their employment it became evident to all of them it was no longer a viable option for them. Thereafter, their experiences differed, depending on the degree of flexibility present in their workplaces.

In one case, the risk of reoccurring strokes prevented a woman from maintaining her managerial job, from which she then had to withdraw, and this emerged as a barrier to her acceptance and adjustment to her post injury self. Another woman, previously employed as a nurse, felt she was unable to continue in her job and took early retirement. In another case, a traumatic injury had left a man with memory problems, so he could no longer keep up with the high demands that his previous position entailed. In his case, his employer re-constructed his position in recognition of his new constraints while continuing to draw on his expertise. At the time of this research, he was

working part time and envisaged a time when he might return to a full time position.

These participants experienced changes in their employments quite differently; bringing attention to the close connection between identity and employment. The man was very positive about the re-organisation of his IT support role; put in place for him post injury.

> They were saying that after I went out on sick leave they had a load of problems in, no one knew how to fix them; they had to get in somebody else. I was the only one there that could fix them, that was amazing, like (Interview 5).

Having had to withdraw from her managerial position, one woman, however, experienced her changed personal and employment situation as negative and resisted accepting her post injury self.

> It's very hard to step into the new self, the new person with a head injury...so speaking for myself; I still try to be the same person that I was before the ABI (Interview 7).

Her situation reflects the more general context, where participants found that because of fatigue, memory loss and difficulties in managing competing demands in the workplace, those who had been in full-time employment generally had to forego their employment post injury.

> I tend to work at a much slower pace than those around me…but they don't accept that…if they leave me alone it will get done (FG3).

So while continuing to have the skills they had gained pre injury, the norms and practices of employment now generally meant that they either retired or resigned. However, finding more suitable employment then arose as a challenge, given the limitations imposed on them post injury and the norms associated with employment. Some attended training courses, often identified by Headway services; and in a small number of cases participants had been able to access part-time employment with the assistance of formal services.

Through these new-found skills they also developed new interests and widened their potential outlets of community integration. For instance, a male participant was hoping to retrain as his double vision now prevented him from going back to his old job, indicating a level of acceptance of the new realities that framed his life. He had undertaken a FETAC boat building module, through the support of Headway, and was waiting to commence work experience in boat building as he had developed a real interest it.

> Interviewee: I am actually going off work experience with the (new potential career)

> Interviewer: For the [new potential career]?
>
> Interviewee: Yeah
>
> Interviewer: Okay, is that what your interest is?
>
> Interviewee: My interest would be cars and that. So, I would like to get into being outdoors, use timber and make things out of timber (Interview 1).

However, it is important to note that integration seemed limited and was generally supported by family members and formal services to which they had access. Again, here we are reminded of interdependence in social networks, and of the two-way process of integration which requires dynamic adjustment, not one way movement/action, on the part of the person with ABI and her/his support network. There was little evidence overall of a marked effort on behalf of previous employers to explore all avenues available to facilitate a return to work on behalf of the person with ABI.

Financial issues

Limited employment options coupled with the increased expense associated with having an ABI, alongside the limited funding provided by the state, impacted on the access participants had to specialised services. Here our attention is drawn to increased levels of stress in families, dilemmas participants faced in making decisions on spending and, subsequently, their overall quality of life.

> I am paying for drugs that I have to get every month because I developed epilepsy as well, since, now I have only ever had two seizures, thank God, but I take the medication every night. But it costs me a lot of money and I have got to the stage where you are getting a bit more confident and I don't need the medication, so I cut back on the medication because I can't afford it and that's dangerous, you know(FG3).
>
> And I am, like, I can't really bring a bill like that on myself every week, so I am, like, no, we will manage away and we will do it. It's, it's just scary because, like, you really are trying to manage as best you can and I feel like I am lucky, you know, I am lucky compared to some people I have seen, you know(FG2).

These additional medical expenses were met by spouses and family members. Therefore, a small circle of people provided large amounts of emotional, practical and financial support. Such a narrow bedrock of individuals providing wide ranging supports was felt by many to be unsustainable. The importance of adequate state financial support was strongly expressed, as was a

perception that the dilemmas they faced because of the high cost of drugs/medical services were not taken seriously by the state.

> My wife she is…because she is working, that is the only reason that we are keeping our head above water, because basically, we wouldn't survive on disability alone, it wouldn't certainly it wouldn't keep us going (FG3).

> If a TD walked in here now, I would walk out, out that door and gone. I hate that every one of them TDs up in Dail Eireann (FG1).

Overall then, as participants attempted to widen their social and income generating scope, and engage with the wider community, a lack of public understanding poses a key challenge to their re-integration into society. This spans social and employment aspects of people's lives and has very negative consequences for them financially.

It is also important to recognise that in re-constructing their lives, people view themselves and are viewed by those around them, in gendered ways, and thus, experience public and private interactions as such. This manifests through the different contexts of the experiences and subsequent strategies that women and men devised in negotiating their wider public engagement. For instance, the practice of having to negotiate 'round buying' of drinks in pubs arose as an issue for men and is a practice that is more traditionally associated with men and masculinity. Furthermore, both negative visibility, where a person feels singled out and negative invisibility, where people did not get the support they required, are key factors to be considered. These factors need to be addressed to bridge the gap in natural supports at community level.

Developing new interests and ways of engaging in the local community seems to help in building a new life and the supports required to enable independent living. It is evident that people with ABI have done much as individuals in terms of developing their own strategies to allow them to access natural community supports, such as local sporting organisations and widen their scope of social engagement. However, whilst there was some evidence of attempts being made to accommodate people in local shops, pubs, and clubs, where they were known to individuals, this did not occur on a broader social level, causing distress and contributing to isolation. This also orchestrated a situation where the ability of people to re-establish a broad social network was thwarted. It is evident that natural community supports, in the form of immediate family and friends, met many of the needs of those with ABI, specifically in relation to having 'somewhere to live' and 'someone to love'. However, the support of formal support services was required in providing people with 'something to do'. The provision of services such as training courses, and work experiences was fundamental in supporting people to live active lives. Formal support services also served to bridge a gap between

immediate family supports and those provided in wider communities. Indeed, in some instances, formal service initiatives directly led to the development of broad community support networks. For example, in some instances, where people were afforded the opportunity to network with others in ABI support services, friendships developed and people began socialising together within their communities. These social networks then developed and expanded, independent of the formal support service.

Chapter 5: Discussion

Introduction

This research project explored barriers and facilitators to developing natural community supports as a basis for independent living, as experienced by thirty-six people with ABI in Ireland who are clients of Headway. This chapter offers an analysis of the divergent themes and aspects of people's lives already discussed, in summarising their experiences of natural community supports.

It became clear through the course of the study that supporting independent living involves an interplay between acute hospital services/community based rehabilitation facilities at the point of injury, and then onto natural community supports in the form of immediate family and close friends. At this point it is important to identify that natural community supports, appeared to be comprised of two distinct groupings. The first grouping involved immediate families, friends and peer support groups; the second is comprised of neighbours and local community groups such as sporting organisations. Natural community supports provided by immediate family and others were fundamental in facilitating people with ABI to live independent lives. Broader community supports seemed to be more on the peripheries and offered more limited support to these individuals. The lack of involvement of broader community groups in some ways precipitated individuals accessing formal support services, often at the point where they were ready to more closely engage with wider society.

The involvement of formal support services produced an interesting anomaly whereby peer support groups initiated by formal services over time became key components of participants natural community supports, reflecting difficulties in distinguishing between natural community supports and formal services. Building on the previous chapter, this discussion now focuses on key factors identified in the research that facilitate or present as challenges to independent living.

In the first instance we summarise key elements of the experiences and meanings participants attached to natural community supports as facilitators of independence for them. Then, we summarise issues arising in coming to terms with the 'new normal', as the period of initial adjustment to people's new realities arose as significant in the research. The interdependent relationships that emerged at this point went on to form participants' immediate natural community support networks. Thereafter, we turn our attention to key aspects and considerations arising that facilitate independent living to clearly identify the nature of natural community supports. We also explore the interrelationship between them and formal services.

In attempting to more fully re-engage with broader aspects of society our attention is drawn to the role of formal supports and the, often, close

connections between these services and immediate natural supports in facilitating independence. Throughout the study key barriers were identified that impede social and other engagement and a summary is offered of the manner in which these present.

Experiences, meanings and significance of natural community supports as a basis for independent living

The research clearly identifies the fundamental changes experienced by the person and their families. There is a real sense of a 'life interrupted' and the development of a new life for the individual and their family which becomes, for them, a 'different kind of normal'. It is evident that natural community supports, most specifically those provided by immediate family and close friends were integral to the rehabilitative process and the re-establishment of independence. Irrespective of the time that had passed since the injury and even when individuals had been rehabilitated to the fullest extent possible for them, formal supports were still required for protracted periods of time.

As previously mentioned individuals had to be 'ready' to avail of these supports and implement strategies to support independence. Furthermore their experiences of natural community supports were linked to their perception of independent living, their level of understanding and acceptance of the ABI, the availability of natural community supports and people's interaction with formal support services. Moreover, individuals' experiences of natural community supports changed as their needs evolved at pivotal points post injury as they moved from the acute phase to re-establishing their lives.

The majority of participants in this study felt that they were living independent lives. It is evident that being independent was very important to them, and that the majority of individuals were independent in relation to a wide variety of activities in their daily lives. However, it became clear that people interpreted the concept of independent living in a variety of ways, most of them associated in some way with interdependencies, confirming findings in previous research (Carling,1992; Strandberg 2009). These interdependencies highlight key intersections between formal community supports, health and medical services, immediate informal natural community supports and broader natural community supports. Again this draws our attention to the very complex nature of independence in society (National Disability Authority, 2011). The concept of independence, then, can be conceptualised in three key ways: independent living/living alone, interdependent living and dependent living.

For some independent living was perceived as living on their own. However, the majority understood independent living as having control over one's life and the ability to make choices, irrespective of where and with whom they actually lived. This closely aligns with Carling's (1992) assertion that independence needs to be understood as assistance in supporting self-reliance.

For instance, this finding is reflected in the perspective of the man who asserted that he was living independently as he had some choice and control over his day-to-day living. The fact that he resided in a supported living environment was simply an expedient arrangement in light of his personal circumstances. It is also reflected in the genuine choices another man made regarding the make-up of paid formal support around him. What was important was that he chose who provided the help he needed, thereby having decision making control over his circumstances. This finding is reflective of the definition of independent living adopted in this study (Office for Disability Issues, UK, 2008, p.28). It also more specifically draws our attention to the key role of decision making and control in the conceptualisation of independence for those involved.

One striking finding was that some participants had not been consulted adequately in relation to their requirements. For instance, one woman, felt she no longer had control over her life. A relative whom she stated was in charge of all her decisions received the Carers Allowance to provide support for her. She felt that this individual was in need of education and training in order to better understand her mental and physical needs. Her perspective brings to light the blurred distinction between formal/informal supports and the need to develop supports appropriate to a person's wishes and needs. Furthermore, the extent and nature of the ABI meant that making decisions and choices could be difficult for some, without the support of others.

In the above cases, close relatives are paid by the State to support the persons with ABI. However, it is unclear in the woman's case whether this was truly her own choice or not. Here, we are reminded of the need to be cautious regarding the nature of close family relationships. Where people with ABI employ family members or friends as carers, those family and friends involved need to clearly understand their role and responsibilities as they negotiate the role of friend and carer and become part of both the formal and informal support network. In this context, it would be prudent to ensure an independent advocacy service is available to fully safeguard the rights of individuals. It is important that the development of an independent advocacy service recognises the risks as well as the protections that can be associated with employment of family members as formal carers.

Paradoxically, for some the occurrence of the ABI meant they no longer could provide supports for others which required a period of adjustment for them in which they recognised they were no longer the 'go to' person. This released some from situations which had placed severe demands on their time. Conversely, the interdependent nature of human relationships is clearly evident. One man provided supports for his mother and another woman provided supports for her young family. It was obvious that this was a choice they had made and one they were happy about. Indeed, the often

interdependent and reciprocal nature of family relationships is reflected in other studies (Weafer and Weafer, 2012).

A new type of normal

In tandem with people's reconfiguration of the concept of independent living is the process of coming to terms with this 'new person'; developing a 'new type of normal' life as the ABI not only impacted on the health of people but also on the level of independence and community integration that they could hope to attain. A key part of coming to terms with this 'new normal' involved negotiating lives at a multiplicity of levels. Thus, began a period of adjustment for all those involved as new constraints, opportunities and interdependencies emerged along with a new set of circumstances and considerations.

At this juncture, it is important to note that the manner in which gender roles, responsibilities and assumptions are embedded into family, social settings and practices was implicit throughout the research. It manifests mostly in relation to care orientation and roles both within and outside the home as people reorganised their social lives. Individuals view themselves in gendered ways and are viewed by family and friends in gendered ways. The female participants in our study were more reluctant to ask for support and appeared to feel more guilt in relation to their new dependency in comparison to their male counterparts. This mirrors international research documenting gender differences in community integration for men and women post-injury (Stålnacke, 2007). Also, women appeared to be more negative as regards accepting their 'new selves' than men, as previously documented (Muenchberger et al., 2010; Barclay, 2013). Recognising additional factors such as age, rural/urban divide and the extent of the disability will contribute to understanding people's experiences. This insight will facilitate the development of supports which best meet the needs of the individual for example, the woman as mother and carer, sister, friend, wife. Jennings (2006) also emphasises the importance of attention to people's environment in developing appropriate and sustainable supports. Understanding the context in which people live their lives is vital to developing appropriate and responsive supports for them and their loved ones.

Furthermore, while the experience of living with an ABI on a practical level varied, every participant needed support to some degree due to the spontaneous and unpredictable nature of some of their symptoms. These related to the ABI (e.g. haemorrhage, stroke), physical health (e.g. seizures, falls), cognitive ability (e.g. memory loss, confusion) and emotional well-being (e.g. anger management, emotional stability).

All participants in the study lived with ongoing fatigue and memory loss. Becoming over-tired brought loss of concentration, impacted on memory, on relationships and on people's well-being in general. This was sometimes accompanied by anger, frustration and mood swings. However, coming to terms with these realities could take time and intersected with the need for

regular rest and rejuvenation. In this respect it is important to note that this 'flies in the face' of an increasingly competitive and busy society where such is less and less accepted as normal practice (Inglis, 2007; Share and Corcoran, 2010; Galech and Desjardins 2011), even when it is in the best interests of the person involved.

People's struggles in accepting this 'new normal' was reflected in the struggles of their families and friends in meeting the challenges of this new situation. An understanding of these aspects of living with ABI by their immediate natural supports is important in building confidence and validating their experiences post injury. Other studies have indicated that people with ABI are 'active agents' in this process (Jennings, 2006) and that construction of self depends on feedback from others (Gelech and Desjardins, 2011). In this context, positive feedback was primarily generated from immediate natural community supports, formal services and peer groups.

At all stages post injury, interconnectivity and good communication facilitated participants in rebuilding their lives and achieving independence and was particularly important when participants were first discharged from acute hospitals and rehabilitation services, and returned home. However, as also identified in other studies (McDermott and McDonnell, 2014), experiences of formal supports, at this time varied considerably. For most participants, there was little evidence of interconnectivity between acute hospital services, community based rehabilitation facilities and long-term community support groups. Where people were unsupported in these transitions their stress significantly increased and anxiety as well as feelings of isolation negatively impacted on the rehabilitative process. Participants also expressed concerns in relation to the impact of their ABI and lack of information or/access to formal avenues of support on their immediate natural supports. They made reference to the emotional effects on their families of coming to terms with their ABI and watching them go through the rehabilitative process. As in Jennings (2006) findings, they clearly identified the necessity of access to formal supports for families as well as for the individual at this stage of the recovery process.

Facilitating independent living

In particular in the early stages of their lives post injury, the vast majority of the participants in this study had a high level of dependence on an immediate family member who came to form the nucleus of their natural community support. This generally comprised of one single person, to support them as they went about their daily lives. They were primarily partners, mothers, fathers, children and siblings, and often, although not exclusively, reflected gendered caring roles more associated with women than men. This mirrors national and international research (Tomberg et al, 2007; Lefebvre et al, 2008; Strandberg, 2009; Bellon et al, 2012; McDermott and McDonnell, 2014) where immediate family members, and often women, fill the gap of formal service provision as people with ABI are discharged from hospital and adopt support

roles. Participants acknowledged this support as invaluable and could not envisage a life without it.

In some cases, this led to a greater reliance on the support of family and friends than the person themselves would have liked. The majority of people recognised that they did, indeed, need such supports. However, studies have also indicated that in some instances families can become overprotective (Weafer and Weafer, 2012). More generally, long term medical conditions often required on-going management and people had to balance their wish to be independent against the practical supports they required from others. In some cases people did not recognise the extent that they relied on family and friends for support until they were away from them. Others recognised this dependency more immediately and stayed close to those within their immediate community support network.

Immediate family members provided practical, emotional and financial supports and changed their lives to accommodate the needs of the individual. Thus, they often became carers and experts in ABI, sourcing information, services and addressing complex needs. For some, this also involved becoming the main bread winner for the family, a role many had previously not held. However, it must be recognised that assumptions cannot be made about how relationships develop and change post injury. For many, the post adjustment process was both a positive and negative experience; relationships changed. Some relationships strengthened and became quite supportive while others faded away and/or reconfigured as barriers to confidence building and reconstruction of selves. The latter do not contribute to developing natural community supports around the person living with ABI and are often a source of hurt and disappointment. The importance of and reliance on support from immediate family members is well documented in the available research as is the manner in which relationships fade and develop (Strandberg, 2009; Gelech and Desjardins, 2011; O'Conner et al, 2012).

Furthermore, while deeply appreciative of the natural community support available to them, participants could also be extremely fearful of the 'what if'? 'What if something happened to my husband'; what if my support services are cut'? This fear seems, in some instances, to be linked to a fear of having to live on one's own (Weafer and Weafer, 2012). It is compounded by the fact that there was little evidence of other forms of natural community support outside of those provided by immediate family and friends. Over time it became clear that individuals providing formal supports could become integral to the lives of the people with ABI. Indeed, individuals emphasised the importance they placed on accessing formal supports in maintaining their independence and in developing new relationships, skills and interests, highlighting the close intersection between community and formal supports.

As time went on and people strove to re-establish their lives, while it was evident that the majority of people, more or less, had somewhere to live,

someone to love, they did not have something meaningful do to (McColl et al, 1998). The 'something to do' is to some extent addressed by formal services, which provided opportunities for individuals to develop new skills, undertake training and, thus, find meaningful ways to fill their days. The significance of their engagement with Headway highlights a dependency on services in this respect. Those who had completed formal training programmes found that they were once again at a loss as to how to fill their days. In a number of cases, given the detrimental effect it had on them, services were reinstated to continue to support the person.

Moreover, the intersection between natural community supports and formal services could now become blurred as pre injury friendships drifted away and new ones were formed. In this context, having access to a peer group with whom they could share post-injury experiences was of specific importance to all participants. Access to peer groups was organised through Headway, often facilitated by family members, and became significant components in re-constituting social lives. It was here, particularly, that people could express themselves without fear of judgement, pity or pre-injury expectations. In all instances this brought about a real sense of interdependence, camaraderie and support between support group members, and it was clear that real friendships formed. The establishment and facilitation of peer support networks is evidence of the interrelationship between formal services and natural support networks. It is clear, over the passage of time that peer support networks moved from being considered part of formal services to natural community supports again reflecting the pivotal role formal services came to play in the development of broader community support networks.

Extending the support network: getting the balance right?

As previously stated this study identified two key components of natural community supports; those provided by close family and friends and those associated with the broader community, including acquaintances, and community groups such as sporting organisations. The latter did not appear to play a fundamental role in supporting the majority of people in this study to live independent lives. Since immediate natural community supports, in and of themselves, cannot facilitate independence in isolation it is imperative that broader community support structures be developed. When people with ABI were trying to engage more widely within their local communities, they had to access formal community support services to achieve this.

In this context, recognition must be given to the role of formal support services and their intersection with natural community supports. This is nowhere more evident than in the context of peer support networks. Their development transcends the intersections between formal supports, natural community supports and broader engagement in the community in developing alternative social spaces for people with ABI. It could be argued that peer support networks reaffirm people's identity, as reflected in other studies

(Gelech and Desjardins, 2011). Empowering people to re-engage in the community more generally, potentially contribute to developing a more general visibility and subsequent awareness of ABI in society. However, given the feedback from our participants it is evident that this potential in terms of public awareness is at an early stage.

In some situations, people were not perceived as requiring support as aspects of their disability such as memory loss, fatigue or sensory difficulties, were not obvious to others. Thus, the invisibility of the ABI coupled with reluctance to ask for help, masked their support needs, a finding also identified by Maher and Fraser (2012). As a consequence, people within their wider community may have remained unaware of these needs and thus support was not offered to individuals. This lack of support may also reflect wider changes in society, as people lead busier and more individualised lives (Inglis, 2007; Share and Corcoran, 2011). It is also evident that transport figured strongly in terms of people's capacity to be independent and to engage with their wider community, such as accessing social and community activities. Weafer and Weafer (2012) found that transport issues were cited as the second most significant barrier to independent living. People in urban areas with reasonable access to public transport were less affected by an inability to drive than their more rural counterparts. Asking for a lift could be problematic; people managed such requests dependent on priorities and in the context of managing general support requests. Negotiating public transport could also be difficult; remembering which bus to get, and keeping timetables in mind needed to be thought out in advance. So, in essence, what are often considered mundane day-to-day activities became activities that needed consideration and planning.

An example of good practice identified in the research is the support provided by Headway and family members in developing strategies to address the challenges identified above e.g. using mobile phones as reminders, diaries, lists, familiarity with timetables and traffic training geared towards the specific needs of individuals.

Barriers to reintegration

As alluded to in the discussion thus far, people encountered a number of barriers to independent living. These include assumptions relating to natural community supports, public awareness and factors which impact on engaging and contributing to society. Together, these emphasise the obstacles facing people with ABI as they attempt to reintegrate into society and draw our attention to the nature of integration itself.

Natural community supports

A striking finding is the assumption of the existence of broad natural community supports. For the majority of participants, independence was facilitated through the combination of immediate natural community supports

and formal services. Prior to contacting formal services individuals indicated that they had fewer friends than before, they socialised less. Consequently, it often became the norm to stay at home. Interestingly, people's engagement with formal services such as Headway led to the development of broader community support networks. Examples of this are the 'come dine with me' initiatives, in opportunities opened up through retraining and the emphasis participants placed on simply engaging with those they met in Headway who had a full understanding of living with ABI. It could be concluded that, in general, broader community supports do not respond to the needs of the individual but can be constructed through the intervention of formal supports. Formal services can act as a bridge between the needs of the individual and the development of meaningful community networks. However, it must be acknowledged that not all those with ABI have access to or avail of formal services. Additionally, the participants for this study all attended Headway services and their experiences may not be reflective of the experiences of those attending other services.

Headway came to be perceived as the place they could go to and where they would find acceptance and friendship. Participants came to think of Headway as a form of broader natural community support available to them and for them. Here again, the difficulties associated with differentiating between formal and natural community supports is evident and in itself presents as a barrier to independent living. What is required, in reality, is recognition of the interconnectivity of natural and formal supports in living with ABI and the effective drawing together of these supports to meet the needs of individuals.

Lack of public awareness

Lack of public awareness arose as another key barrier to community integration and independent living as reflected in other studies (Linden and Boylan, 2010; Weafer and Weafer, 2012; McDermott and McDonnell, 2014). This lack of awareness manifests in a number of ways including lack of understanding of the impact of ABI on the individual, refusal of access to social settings and assumptions of drunkenness. It also very negatively impacts on people's employment prospects.

The 'invisibility' of ABI intersected with an assumption of the absence of injury, thus, supports were not offered to and, often times, not asked for by the person with the ABI. Where a visible manifestation of the injury was present this sometimes led to negative assumptions about the person's character. This orchestrated a situation where people limited the social settings they engaged with, their social circle and some eventually opted to remain largely at home. This has also been identified in other Irish studies (O'Conner et al, 2012), indicating that social isolation is an issue which must be addressed in promoting independent living in Ireland.

For some individuals pre-injury friendships were maintained but for others it was clear that friends drifted away with frequent reference to people not

understanding or not knowing how to relate to the person post-injury. The social distance that emerged between participants and their pre-injury associations/friendships indicates, even at a surface level, an inherent lack of societal understanding of ABI and an argument for the development of greater public awareness around it. Socialising with new friends and acquaintances with ABI proved important in restructuring social lives in a way which suited individual needs. Whilst, in the main, the support of others with ABI developed through formal support services, these relationships quickly evolved and became part of people's natural community supports network, as identified in other studies (O'Conner et al, 2012).

There was also evidence that people with ABI were proactive in devising strategies to facilitate independent living in the face of a lack of public awareness. They devised strategies for getting to and from places, avoidance of the 'round buying' culture and negotiated barriers to engaging in activities such as attending sporting events.

Individuals identified the need for a public awareness campaign aimed at all levels of society including the general public, medical and health care professionals as well as family and friends. It was felt that this would go a long way in addressing the challenges faced through misunderstanding and misinformation relating to living with ABI. Other similar studies have also called for public awareness campaigns to highlight then needs of people with various disabilities in Ireland (O'Conner et al, 2012; Weafer and Weafer, 2012; McDermott and McDonnell, 2014)

Sport and leisure Interests

The reconstruction of self and the adaptation required post ABI is very evident in terms of rebuilding one's social life and leisure activities. Many individuals no longer engaged in sport and leisure activities for a variety of reasons, while others had to adapt how they engaged with such activities.

There was little evidence of broader natural community supports assisting people to continue with their previous interests. Again, supporting individuals was left, in the main, to immediate family and close friends. There was no evidence of community groups such as sporting organisations working with the person to support them in continuing their association with these groups. However, as previously mentioned, not all individuals were heavily involved in local groups prior to their ABI, which might account for the lack of interaction and inclusion post injury for some individuals, as also reflected in other studies (McGowan, 2008).

The question obviously arises on the inter-relationship between the social setting, the subject of interest and how the social aspect of and engagement in sports and leisure interests can be reconstructed to take into account reduced tolerance for crowded, noisy environments. The onus seems to be placed on the individual to adapt with little expectation of society changing to

meet the needs of people with ABI, leaving them at risk of marginalisation and isolation. People with ABI did develop innovative coping strategies to allow their continued participation in sport and leisure activities in conjunction with the assistance of their immediate natural community support network. This required advance planning and a high level of organisation and adaptation on behalf of the person themselves. However, despite this some issues such as the noise levels at large sporting events were still difficult to control and manage, a finding reflected in other studies (O'Conner et al, 2012). Therefore, the attitudes of individuals in supporting people engaging in sport and leisure activities must be adapted through education and increased public awareness. Engagement at organisation level with groups would assist in devising strategies to support people with ABI. Such adjustments are currently seen in adaptations already made by organisations to accommodate those with a physical disability which are very successful.

Examples of best practice come from people with an ABI, themselves, as they developed strategies to enable them to continue to socialise and engage in activities. These include strategies to control their environments such as managing the culture of 'round buying' so pervasive in Irish society. What is required is the development of social spaces that better accommodate the needs of people with ABI. Once again, education of community groups and others involved in organising sport and leisure activities would contribute to deepening their understanding of the realities of living with ABI.

Financial and employment constraints

Lack of employment and financial constraints significantly impacted on the lives of people with ABI as continuing with pre injury employment proved difficult. In the case of individuals who returned to their employment post ABI difficulties arose which in some cases required them to leave their jobs. The exception to this was the case where the employer was supportive of a man's changed situation and facilitated his return to work on a phased basis. People responded to this situation differently, in light of the connection between employment and identity. While people made reference to financial issues, loss of their employment role and the poor support received from state agencies no reference was made to any entitlements they might have had under employment law or the development of any such provision. Any employer obligations to them were also not discussed. That employment is an issue from an Irish perspective is made clear both in terms of the findings of this study and those of Weafer and Weafer (2012). This is also reflective of broader international concerns relating to employment (McColl et al, 1998; Minnes et al, 2001).

While those involved had a variety of qualifications and skills to offer, the impact of the ABI overshadowed their potential contribution to the labour force. This orchestrated a situation where people were limited to the following options in addition to the above:

- Retraining
- Supported employment
- Reliance on state support mainly disability allowance
- Early retirement where this was an option

These limited options draw our attention to the role of a job/career with reference to one's sense of self and independence. It makes clear the dynamic role of employment which as well as providing the individual with an income also provides a role and a goal in life, as well as a structure and a routine to follow. Indeed, many participants spoke of wanting a job, not just from a financial perspective but within the context of their own self-worth, engagement and interaction with others and having something to do. That the majority of respondents were dependent on disability allowances is indicative of the issues faced by people with ABI in the workforce and reflective of barriers such as fatigue, epilepsy and public attitudes.

Financial issues also played a part in the extent to which people with ABI could live independent lives. Time and again, participants indicated that financial formal supports from the State were essential; arguing that without this support their lives would be seriously limited. Indeed, people revealed they were cutting back on essentials such as medication even within their current level of support. Furthermore, they were fearful of future cuts in financial supports in the light of the current fiscal situation. This concern was not only expressed in relation to the impact such cuts had on the person with the ABI but also their family members. They acknowledged the extent of their reliance of the income of family members in order to maintain a basic standard of living drawing our attention to the increased stress on immediate natural support networks. In some cases, means testing meant people were not eligible for services and had to go without essential medications, equipment and services as they lacked the financial means to pay for these privately. Financial constraints caused increased tensions and frustrations, adding to the stress and anxiety already experienced and contributed to marginalisation and social isolation. The need for the State to provide formal financial and other supports in order to relieve family members of an excessive caring burden was voiced by participants and, at times, was considered a vital component of maintaining independence.

Conclusion

The focus of this study was to explore the experiences of people with ABI of the role of natural community supports in facilitating their independent living. As previously stated, during the course of the study it became apparent that

natural community supports were comprised of two distinct groupings. The first grouping involved immediate families, friends and peer support groups; the second is comprised of neighbours and local community groups such as sporting and activity based organisations and groups.

The findings of this study indicate that living with ABI involves a process where the person moves from acute high intensity health services onto rehabilitative services and then onto re-establishing independent lives. It is evident that smooth transitions and interconnectivity of services are essential in facilitating this recovery process.

Instrumental to the recovery is the support of immediate family and close friends, who form people's immediate natural support network and go a long way towards facilitating individuals in rebuilding their lives. A key finding of this study is that broader natural community supports do not appear to play as central a role in supporting individuals to live independent lives when compared to the role of family and friends. Indeed the lack of involvement of broader community groups, in many ways, prompted individuals to contact formal support services. For the majority of participants, independence is facilitated through the combination of immediate natural community supports and formal services.

Regaining independence is also supported by access to formal services such as Headway which open up new social, employment and training opportunities as well as providing a peer support network. Of significance, is the role of formal support services in developing these broader community support networks as well as the blurred divisions between the two, i.e. formal services and broader community support networks.

Such networks facilitate the empowerment of people with ABI and engagement in local communities. It is recommended that the role of formal supports services in acting as a bridge between the needs of the individual and the development of meaningful community networks, be formally recognised and further developed. Additionally, the importance of the role of broader natural community, supports such as those provided by community and sporting groups must be enhanced. Greater awareness of the issues faced by people living with ABI and its often invisible nature is necessary in this endeavour.

It is important to recognise that issues impacting on independent living are multifactorial and intersect, for instance with age, gender, employment, qualifications and so on. A lack of public awareness of ABI was found to be a key barrier to independent living, along with issues relating to socialising, access to employment and finances.

The findings of this study reflect the complexities of living with ABI and the need for holistic support that is cognisant of the factors which impact on

integration. It is vital that flexible, personalised services are developed which are fit for purpose and meet the needs of not only people with ABI but also their immediate natural community support network. Recognition of the intersection between immediate/ broader natural community supports and formal services is also key to developing the comprehensive and practical supports required to achieve an independent life.

Recommendations

The findings of this study lead to the following recommendations.

- The important role played by immediate natural community supports in supporting people with ABI must be acknowledged and supported.
  - Partners and immediate family members need additional supports to augment their role as carers. This includes provision of appropriate respite care and financial support.
  - The impact of the ABI on family units requires greater recognition. Counselling and educational supports need to be provided, not only for the person with ABI, but also their immediate support network.
- Broader natural community supports, outside of immediate family, are limited. The lack of these supports significantly impact on the capacity of people with ABI to integrate and participate in their local communities. Immediate natural supports and formal support services are struggling to meet the needs of people with ABI.
  - A national database needs to be established of people with ABI to ensure appropriate and effective service planning and development.
  - It is recommended that formal support service be resourced and developed comprehensively locally and nationally to provide long-term support for people with ABI and their families.
  - The role of formal services in developing broader community supports needs to be recognised and resourced.
- Statutory services, voluntary organisations, community groups, family, friends and peer support networks all have an ongoing role to play in the lives of those with ABI.
  - An understanding of the interdependence of those involved with the person with ABI needs to be more comprehensively developed through the development of regional and national fora.
  - National and regional fora and services need to be comprehensively resourced to ensure services are provided according to the prevalence of people with ABI and their needs
- It is evident that ABI is very much a 'hidden disability'. A national, government supported public campaign is needed to raise awareness and improve the public's understanding of ABI.
- It is evident that there are considerable difficulties when transitioning from acute services towards independent living. Communication between acute care services and community based supports must be strengthened to facilitate recovery and independence. Responding to ABI requires person-oriented rather than task-oriented approaches to services.

    - The development of interconnectivity or integration across agencies is required to provide cohesive services across the continuum from 'acute services' at the point of injury; onto the 'rehabilitative phase' and then onto 'independent living within local communities'.
    - Such services need to be regionally responsive and linked with their local communities.
    - In keeping with the recognition that a person exists within their family, supports need to be put in place for families as well as the person with ABI.
- Recognition that statutory services and voluntary groups also have a key role to play in educating those in community services and supporting them to facilitate the involvement of people with ABI in their local communities.
- Independent advocacy services should be provided to individuals with ABI who require them.
- The lack of employment opportunities for people with ABI needs to be addressed.
    - People with ABI need to be aware of their rights under employment and disability legislation.
    - Supports need to be put in place to facilitate a return to work where possible.
    - Greater flexibility in employment and consideration of part-time employment options needs to be given greater consideration.
    - Educational opportunities need to be provided for those who need to identify alternative career pathways following their ABI.
- The concept of making 'reasonable adjustments' to support people with ABI living in their local communities must be addressed within health and social policy, both at governmental and local level.
    - Exploration of diverse approaches to accommodation and housing provision needs to be undertaken in addressing changed circumstances, relationships and promoting independent living.
    - Support for the redevelopment of social outlets must be reflective of the needs of the individual with ABI.
    - Development of regular public awareness education campaigns will be required to achieve this.

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Appendices

Appendix A: Introduction to Headway

Every year in Ireland, approximately 8,000 to 10,000 people are admitted to hospital with a head injury and a similar number suffer from a stroke. Additionally Headway estimates that there are up to 30,000 people lining in Ireland between the ages of 16 to 65 with long term problems following a brain trauma. Every injury is unique and effects can range from mild to severe. Headway offers support, guidance and services to those affected by ABI and their families.

Headways mission is to bring about positive change in the lives of those affected by ABI. With this mission in mind, Headway provides services which:

- Are person centred
- Flexible to respond to the needs of the individual
- Promote the individual's independence and quality of life
- Promote the integration of people with ABI and reflect goals set in individual plans
- Respect the dignity, rights, needs, abilities and cultural values of the person, and their family/caregivers

Background to community based rehabilitation services

Through a range of community based rehabilitation services, Headway offers support to people who have been ill (e.g. through Stroke) or injured (e.g. Road traffic accident) to rebuild their skills to achieve the best quality of life that they can.

Community based rehabilitation such as that offered by Headway is recognised as an important and often essential component in the recovery and social reintegration of people with an ABI (Powell, 1999). Through their involvement in such services, individuals with ABI are encouraged to participate in normal everyday activities in the community in an effort to identify with roles they have filled prior to their injury. Headway supports individual use of facilities that are available to them in their local communities such as gyms, cinemas, shopping centres, voluntary work placements, public transport etc.

A person centred approach is utilised in all of Headway services, to ensure that the needs of clients are met. In this context, the individual with the ABI is part of the rehabilitation team and there is a strong importance placed on empowering him/her to become active participant in their own care. Specific services such as Headways Community Integration service facilitates individuals with an ABI to participate in social, leisure and recreational activities within their own communities. The individual focus of the work

carried out by this programme is supported by findings by McColl (2007) who suggests that the most successful programmes are those which are tailored to the individuals needs as they take into consideration the complex, multi-dimensional factors associated with the individuals actual injury and build a customised solution.

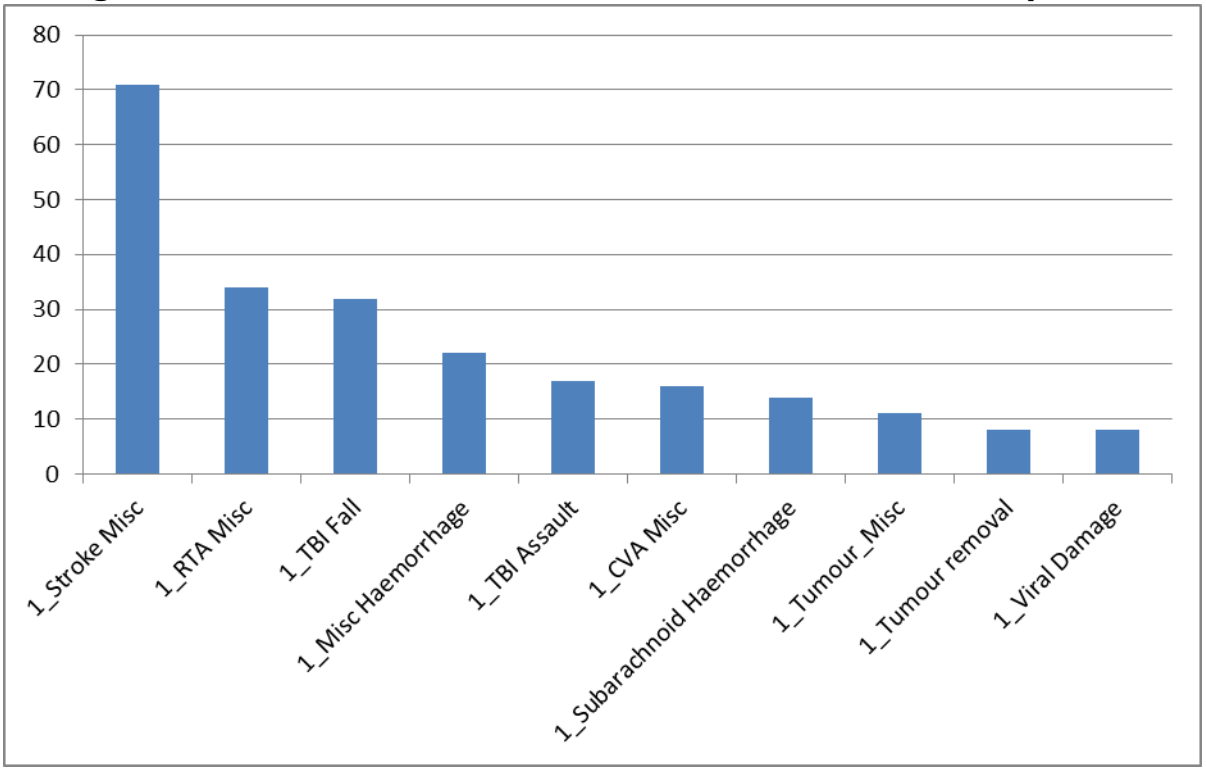
Due to the multiple varied effects of ABI, people often have difficulty living independently, working or returning to education, participating in social and leisure activities and maintaining family roles or personal relationships. The impairments caused by ABI for an individual may be physical, psychological, emotional, behavioural or social. It frequently involves a combination of these which have a long lasting effect on their lives and the lives of those close to them.

Community based rehabilitation, irrespective of age, is recognised as an important and sometimes essential component in the recovery and social reintegration of people with ABI (Powell, 1999). Riley, Brennan and Powell (2004) suggest that a core aim of rehabilitation following an ABI should be to facilitate participation in valued roles and activities. Rehabilitation such as that provided by Headway, encourages those with an ABI to participate in normal everyday activities in the community and is an important aspect of most rehabilitation programmes because people identify with the roles they have filled prior to their injury.

Overall census of clients using Headway services

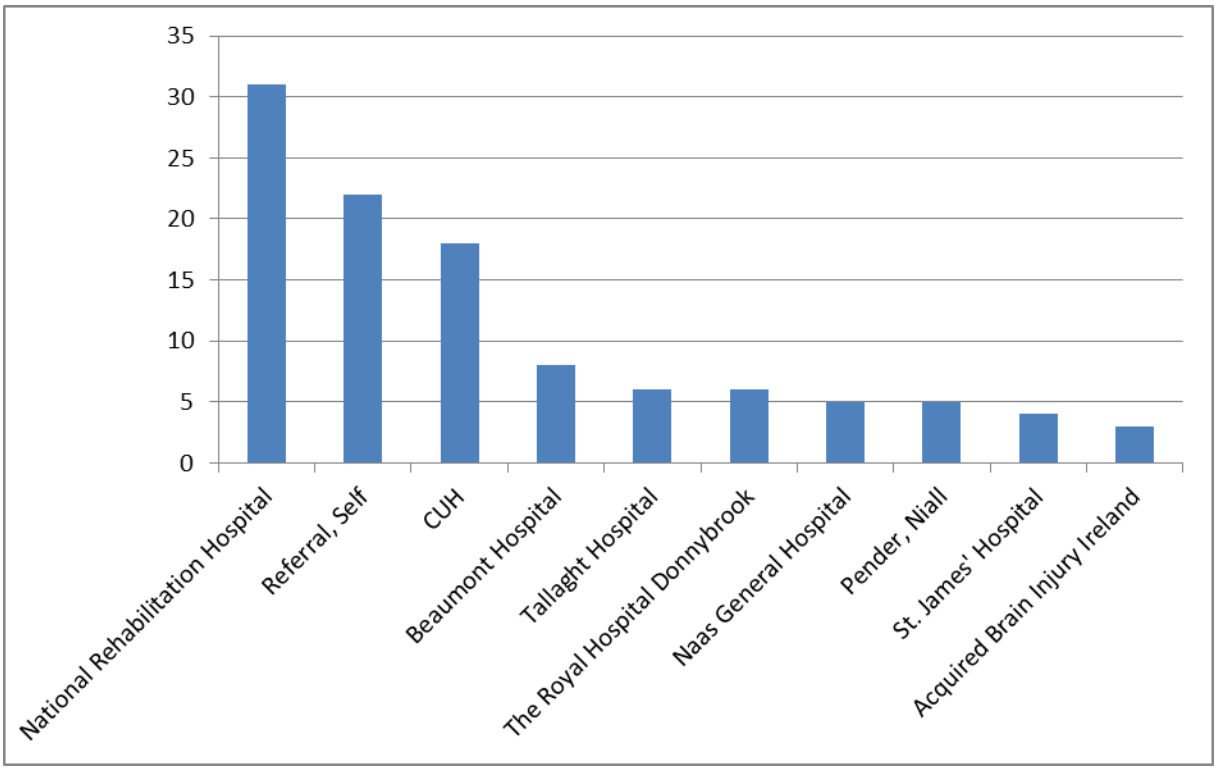
Considering the overall population available within Headways services for participation in the current research project, stroke is the primary presenting diagnosis and this exceeds any of the other diagnoses by more than 2:1. Road traffic accidents come in second place followed by traumatic ABI (TBI) resulting from falls. Haemorrhage of unspecified aetiology is the next highest diagnosis which is followed closely by TBI from assault, cerebral vascular accident (CVA) and subarachnoid haemorrhage. Tumours and ABI resulting from viral damage are among the lowest number of referrals in this population. Details of the causes of ABI in the potential population are outlined in Figure 4 below.

Figure 4: Predominant Causes of ABI for Clients of Headway



The diagnoses identified in this population are representative of the population seen by Headway on a regular basis but from time to time the order of presentation may differ.

Figure 5 Top 10 Referring Agents to Headway



Headway recognises the importance of linking in with referral sources to ensure that clients are given the opportunity to link in with community based rehabilitation services post discharge from hospital based services. Figure 5 above shows the main referral sources to Headway services.

Appendix B: Focus Group Interview Schedule

The following is a schedule of the questions asked in the focus group interviews…

- What is your understanding of independent living? Prompts – ability to interact with others to meet needs or get things done; accessing social opportunities, activities, hobbies, community services and employment/financial supports.
- Tell me about the support you currently have to facilitate independent living?
- What support do you currently need to facilitate independent living?
- Who currently supports you in living independently? What are the kinds of supports that these individuals provide?
- What are your feelings about accessing these supports?
- If these people weren't available to you – what would you do? Do you go without and wait till the next day? What would need to happen to avoid this situation?
- What are the advantages and disadvantages of having these supports?
- Are there additional challenges that you face?
- How do you think you could overcome these?
- Are there resources within your local community which you have not accessed but might help you? What's preventing you from accessing these? What would help you overcome this?

Appendix C: Individual Interview Schedule

The following is a schedule of the questions asked in the focus group interviews…

- Can you tell me about what an ordinary week looks like for you? What do you do on a day-to-day basis?
- Who helps you in your day-to-day living? Cooking, housework, shopping, socialising?
- What kind of help do you need? Prompts: household tasks, transport, small errands etc.
- How do you feel about this help? Prompts: Burden on family members? Reluctance to ask for help when needed? Loss of identity as one who does the caring
- Did you participate in any community activities before your injury? If yes, can you still participate in these activities? Prompts to include interest/social life work etc. if required
- Does your ABI prevent you from taking part in day-to-day activities? If yes, in what way? Prompts: fatigue, epilepsy, memory loss
- Are there any extra difficulties you face following your injury? If there are, how to face/overcome them?
- Some people say that ABI is made worse because it is often quite invisible. What do you think about this?
- Memory loss is something that comes up a lot in discussing living with ABI? What is your experience of this?
- Same for fatigue
- What can be done in order to make life easier for you in terms of going about your daily activities?
- What is your understanding of independent living? What does that mean to you?

Glossary of Terms

ABI- Acquired Brain Injury

HSE- Health Service Executive

NDA- National Disability Authority

TBI- Traumatic Brain Injury

UCC- University College Cork