

'I felt let down by psychology'

We hear from a brain injury survivor, researchers and a practitioner

I celebrated my 21st birthday during April 2010. I completed my undergraduate degree in psychology in May 2010 and I started my first job with a Youth Advocacy Program in June 2010. However, all of these positive and important events were overshadowed by 18 July 2010 – the day I was involved in a road traffic accident and suffered severe traumatic brain injury.

Unconscious, I was rushed to a hospital where the extent of my injuries became apparent. Brain scans revealed a fractured skull, haemorrhaging and cerebral oedema. I was transferred to another hospital in Dublin. Ten days later,

I awoke from an induced coma unable to talk, move, swallow, create short memories or remember long-term memories.

I spent the next three months in another hospital. Each of the individual services – speech and language therapy, occupational therapy, physiotherapy, nursing care and medical care – were excellent and helped me enormously while providing guidance, encouragement and support. However, during my recovery journey, I felt let down by psychology.

During these three months, I met a number of different psychologists, and I have no recollection of these individuals enquiring about my emotional state. I longed for one the psychologists to ask me 'How are you?'; 'How are you coping?'; 'Would you like to talk?' The psychologists produced a range of memory, attention and executive function neuropsychological tests without telling me the names of the tests or why it was important for me to complete the assessment. I performed these tests obediently while feeling immense frustration and confusion inside. The results of the tests were never revealed to me. Strangely, the implications of my injury were never highlighted and coping strategies were not discussed. Instead, I spent hours performing these monotonous and challenging neuropsychological tests, while trying to deal with the emotional impact of the car accident and my brain injury alone.

I remember one incident in the hospital with the psychologist using the Behavioural Assessment of the

Dysexecutive Syndrome (BADS). I was pushed in my wheelchair to the testing room and brought inside by the psychologist. The test apparatus was set up on the table. She was nice and polite, but did not explain the purpose of the test, and she did not enquire how I felt about participating in this assessment. When she finished reading the instructions out of the booklet, I remember holding back tears while she started the stopwatch. I completed the assessment, someone wheeled me upstairs to my bedroom, and I cried.

Over the next two years I made huge physical advances. However, I had become increasingly emotionally unstable, desperate and expressed strong suicidal ideation. My mother was extremely worried and reached out to local support services for help and guidance in relation to my psychological state. The request for psychological help resulted in a home visit from an assistant psychologist. The assistant psychologist, however, did not appear to have been briefed about my mental state before she arrived. She never enquired about my emotional health and instead explained that I would be performing a six-hour attention test over three days.

One month after the assessment the assistant psychologist returned with the results from the assessment. My mood had deteriorated further, but the subject of my mental health was again not mentioned. A copy of the clinical report was offered. It used technical language, medical terms and psychological definitions. When we were asked if we had any questions my mother replied: 'Niamh's mood tends to be up and down, and in the last few months, it has been very down.' I reacted very badly to this betrayal of personal information. I told my mother to 'shut up' and she began to cry, and then I did the same. The assistant psychologist left shortly after saying: 'If there are no more questions, I'll be heading, but if you think of any, don't hesitate to call.'

My three years of rehabilitation ended with me experiencing an emotional



The brain injury survivor – Niamh Lowe

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The health professional

In practice, how can we integrate neuropsychological and social psychological principles to promote a holistic approach to client care?

The ultimate goal of rehabilitation following ABI is centred around community integration (Martelli et al., 2012). Whether problems arise at the end of intervention will generally depend on whether there has been a thorough assessment of the person's strengths, needs and goals, understood within the everyday contexts and material conditions of their life. While standardised neuropsychological testing is a crucial part of neuropsychological assessment, equating testing with assessment is not likely to be helpful. Post-acute outcomes are invariably social, yet social aspects of cognition are rarely explicitly assessed during formal neuropsychological evaluations (Jackson & Hague, 2013).

There are however, some helpful signs that this may be changing, as assessment tools that are oriented towards more real-world problems are being continually developed and refined (e.g. Multiple Errands Test: Shallice & Burgess, 1991). Further, the move towards examining social aspects related to the self as vehicles of rehabilitation is to be welcomed (Gracey et al., 2014; Haslam et al., 2008).

For some people with ABI there can of course be problems with social inference, and misunderstandings with staff can occur (McDonald et al., 2014). Clients and family will often look to clinical neuropsychology services to create a narrative about what has happened to them and what may happen in the future, and then for services to do something about these issues. Occasionally, however, services may get caught up on the thorny problem of assessment and helping the person to understand the 'brain injury problem'. The idea that the multitude of neurons, neural connectivity and experiences may make up a self who develops comfort from being understood by another person can occasionally become lost in the need to provide answers to such tricky neuropsychological questions.

Reductions in social disability, and improvements in social participation, mental health and quality of life, are increasingly valued as more than just the distal outcomes of rehabilitation (Cicerone et al., 2011). Some common aspects of depression in particular can be understood to result from a loss of social connectedness and changes in social identity. Interventions that foster such (re)connectedness have been used in ABI, from the individually based, such as metaphoric identity mapping (Ylvisaker et al., 2008), dyadic interventions aiding social communication (Togher et al., 2012), through group-based interventions that promote social decision making, to broader community anti-stigma interventions delivered by people with ABI (Irwin & Fortune, 2014).

It is almost old hat to state that the biological, psychological and the social are interrelated in these complex disabilities, and that

each component must be given its due in neurorehabilitation in order to promote an environment in which people with ABI may prosper. Indeed some recent research (e.g. Miller et al., 2013) supports the conceptualisation of this interrelatedness in terms of 'enriched environments' (comprising opportunities to engage in a combination of group cognitive, physical and social rehabilitation).

Results demonstrate positive neural outcomes for clients (e.g. diminished hippocampal atrophy at 28-months follow-up).

So there are a number of substantial challenges of working within the current system, among them the complex needs of people with ABI and their families, the need for additional training, development of a viable translational social neuropsychology research and development agenda, and issues relating to commissioning and resource allocation. In order to meet the needs of people with ABI, I would advocate:

- | A more reflexive knowledge and training base for staff. The dynamic nature of the organisation, function and response to experience in the social world needs to be as prominent as the neural element in neurorehabilitation theory and practice.
- | Addressing the ever-present variability in facilities and care pathways (particularly in more rural areas), which may result in bottlenecks with delayed or inappropriate referrals. In addition, the fragmentation of services in rehabilitation, and competition between them, may not always be to the betterment of clients' experiences.
- | Moving ABI services from within general intellectual disability services. Growing evidence on the economic efficiency of post-acute neurorehabilitation (Oddy & da Silva Ramos, 2013) has been slow to translate for commissioners of services, and the current positioning may mean that complex needs are not appropriately addressed.
- | More research from those in neurorehabilitation. It is compelling that the authors of the most recent meta-analysis of psychological interventions for depression following ABI found it 'amazing' (p.1394) that the number of published studies available was so small, despite the high prevalence of depression following ABI (Stalder-Lüthy et al., 2013).



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viewpoints

breakdown and suffering severe depression with no personal feeling of hope about recovery or the future. I was referred to a psychiatric hospital where I remained an inpatient for two months. It was here that I met a psychologist who sat opposite me,

and enquired sensitively and genuinely 'How are you?' This simple question produced the suppressed emotions of the last three years.

A person is not a sum of their parts, a person is greater than their brain

functioning. In my personal experience, many of the psychologists I met failed to create a personal connection with me, and instead focused almost exclusively on assessing my brain function through neuropsychological tests.

The researchers

To mark Brain Awareness Week 2014, we joined with Acquired Brain Injury (ABI) Ireland to run an awareness campaign about head injury. We wished to create a forum where lay experiences of brain injury could be shared and heard, with particular respect given to the lived experience of ABI. Indisputably, the defining part of the day was when Niamh Lowe – a survivor of brain injury and psychology graduate – addressed the audience.

Much of what Niamh had to say exemplified in a very human way the importance of psychologists taking time to think about the impact of their work practices on those they are seeking to support. Niamh's narrative appeared to exemplify the argument that we have previously outlined (Walsh et al., 2012): that advances in neuropsychological knowledge are leading to higher-quality classification and rehabilitation technology in ABI, but often this orientation to particular deficits and the injury is interfering with a more holistic understanding of the equally important social processes that can both contribute to and detract from rehabilitation.

Neuropsychology includes a spread of intellectual traditions, but it is the cognitive approach that most often features in neuropsychological assessment (Bowen et al., 2010). Neuropsychological instruments offer considerable practical utility to rehabilitation clinicians. For example, people often experience serious cognitive deficits following closed head injuries in the absence of apparent cerebral damage on their neuroimaging. In such cases standardised neuropsychological testing can constitute the only available route for

documenting the extent and nature of cognitive disturbance impacting a person (Kolb & Whishaw, 2009).

Neuropsychological testing is, however, often predicated on an individualistic model of the person that regards all behaviour as explicable in terms of brain function. This individualistic model can give rise to constructions of individuals as 'information processors' (Yeates et al., 2007). The cognitive, information processing aspect of each person is critical to their well-being; yet, viewing the person only through this lens may lead to oversights about other social factors that influence each person.

Depersonalisation in healthcare settings is likely to be particularly significant for vulnerable clients such as those with ABI – particularly when the label of 'brain injury' may result in the client not being given the right to take an active role in their rehabilitative journey. According to Kitwood (1997), depersonalisation may lead to disempowerment (failing to allow the individual to use the abilities they retain or failing to assist them to complete actions they have initiated), infantilisation (treating and talking to people as if they are children), labelling (as the main basis for interaction and explaining behaviour) and stigmatisation (treating the person as if they are a diseased object). The label of



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'brain injury' may trump other concerns about an individual's mental health. Indeed, this may well be why mental health issues are so frequently left undiagnosed in this population. A theme in Niamh's story is the absence of her sense of feeling valued and listened to by the psychologists that she encountered – key determinants of patient trust and satisfaction (Walker et al., 1998). Perhaps this was amplified for her as she was a psychology graduate herself – she expected more. On the other hand, the role of families in supporting psychological health, is also evident. Shared social relations and the personalised care offered by families is an important health resource (Walsh et al., in press), which is too often and too routinely undervalued.

The challenge for psychology is to avoid the pitfalls of the traditional medical

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model, where the person is defined by their problem rather than being treated in a holistic way. Comorbidity associated with ABI is well-documented and the likelihood of developing depression in the wake of such a catastrophic injury is very high (Bhalerao et al., 2013). After brain injury, emotional difficulties can be the product of biological, psychological and social factors (Coetzer, 2013). Thus, biomedical models are insufficient to account for the complex disabilities often associated with chronic conditions (Main et al., 2000). In particular, Gracey et al. (2009) suggested that improved awareness might be connected to an *increase* in negative emotions as individuals cognitively engage with what has happened to them. The team tasked with Niamh's care were likely to be aware of the complexity of factors influencing Niamh's health outcomes. However, the concern about re-establishing cognitive function may have blocked a more holistic approach to Niamh's rehabilitation.

The specialisation within the system is of course one potential cause of this problem. A second troubling cause is the increased deployment of staff who are ill-prepared to deal with individual and

familial catastrophes due to limited training, experience or supervision. The over-use of assistant psychologists, particularly their use as low-paid and unpaid labour to stitch together services that are under stress, is a serious concern for the discipline. As a profession, we need to manage and govern the use of assistant psychologists carefully. In the medium and long term, the (mis)use of graduates with limited training in lieu of clinical professionals damages clients, the profession and the discipline.

Niamh's experiences within the services are, of course, a consequence of the current system. As psychology has grown and diversified, the level of specialisation has resulted in the splitting of services. There is no doubt that this specialisation results in higher-quality care and therapies that are more appropriately tailored to the clinical problem at hand. Neuropsychology has made great progress in terms of both assessment and interventions. The psychological impact of ABI and subsequent rehabilitation represents key interests for researchers at the Centre for Social Issues Research, University of Limerick. An enduring concern in our research is the apparent lack of integration

of the social psychological perspectives within clinical neuropsychology (see Walsh et al., 2012). Consistent with our aim of producing meaningful research that informs policy and praxis, we have built partnerships with local and national organisations, such as ABI Ireland. We hope that an empowered patient perspective, alongside the integration of the neuropsychological and social psychological perspective – particularly one that pays due attention to systems and structures that affect care and recovery in clinical contexts – can go some way to providing the holistic service we aspire to and that clients deserve.

Seeking more viewpoints

In this series we hear the viewpoints of those who have conducted published psychological research, those who have taken part in it and those who may put those findings into practice; or those who have come into contact with practitioner services. Contact the Associate Editor, Dr Catherine Loveday, on C.Loveday@wmin.ac.uk

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