The background is an abstract painting with vibrant, textured colors including yellow, orange, red, blue, green, and purple. A large, white-outlined blue speech bubble is the central focus, containing the main text. The text is arranged in four lines: the first two lines are in yellow, and the last two are in black.

**SURVIVING
IS ONE THING
LIVING QUITE
ANOTHER**

Support that makes
life worth living for
people affected by
traumatic brain injury

Marsaili Cameron
and Sheila Marsh

The Ajahma Charitable Trust

The Ajahma Trust is a registered charity established in 1977 (Charity no 273823). The Trust funds work in the fields of international development and issues around age and gender in the London area. It also has a longstanding interest in funding local groups' work on traumatic brain injury. While its purpose is grant giving, it seeks recipients for its own priorities rather than accepting unsolicited applications.

PublicServiceWorks Associates

PublicServiceWorks researched and authored this publication. It is an established consultancy whose directors have a long track record of working with partners to support development in public service arenas where the ethos of public service is central. The company focuses on:

- supporting new ways of thinking and doing in difficult times, working especially on research, policy and strategy, service development
- organisational and partnership development and evaluation
- innovative public engagement that creates genuine involvement and collaboration in pursuit of sustainable solutions to a wide range of public challenges.

www.publicserviceworks.com

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Foreword

I am delighted and proud to recommend this comprehensive and very topical review of Traumatic Brain Injury (TBI) from three different perspectives.

Firstly, as a member of a Nottinghamshire NHS Clinical Commissioning Group, I am very aware that neurological conditions in general, and TBI in particular, present a challenging area for commissioners. This publication provides a comprehensive review of recent research, best practice and patient/service user input that both ‘demystifies’ and provides an invaluable reference point. What strikes me most is how the emphasis needs to move from generic medical pathway models to personalised care based on the needs of the individual and the family. Much has been achieved for vulnerable people with multiple long-term conditions with proven care models involving public and voluntary sector agencies working in integrated teams – this review makes the case for a similar co-ordinated model for TBI.

Secondly, as chair of a leading charity providing long-term care for people with neurological conditions (including Acquired Brain Injury), I have experienced the need to champion the individual in a system that can feel like a series of barriers. There is clear evidence in this document of the importance of long-term social and community support for survivors of TBI and their families to combat the isolation they experience and the resulting negative impact on their lives. This makes sense on a compassionate individual level but also in terms of public finances as the costs of illness, unemployment or family breakdown far outweigh the costs of successful rehabilitation and recovery.

Finally, as a trustee of the Ajahma Trust (who have funded this inquiry and publication), I am very proud that our charity is providing clear evidence of potential solutions to other funders and commissioners. It is clear that TBI is an area where a little funding for voluntary sector organisations and peer support groups can go a long way.

Thank you for your interest in this publication. I hope you enjoy reading it as much as I have.

Roger Paffard

Trustee of Ajahma, Chair of Sue Ryder,
Vice-Chair of Newark & Sherwood NHS Clinical Commissioning Group

Preface

Among the fundamental functions of the human brain – perhaps alongside creativity and tool use – is that our brains enable us to be successful social beings. We form and sustain relationships, we navigate these relationships and hopefully enjoy our lives in our communities. An injury to the brain disrupts many facets of life: and, not surprisingly, when things go wrong, the impact is on the individual, their family and their wider social community.

Among the many challenges after brain injury, it is especially distressing that there is poor recognition of the social, emotional and cognitive consequences, sometimes referred to as ‘hidden’ neuropsychological disabilities. This makes it difficult for people to identify their needs. Injured individuals may be isolated and are often least able to advocate effectively for the help they need. It is very difficult to understand the variety of resources and agencies that may be able to help. There is much complexity to be faced, including enormous variability of activity and ability to participate. There is a need for support and compassion potentially for years beyond the initial injury. At the same time, people experiencing these problems may be exposed to systems that lack compassion, in the way identified by the Francis report.

This excellent document presents research findings, analysis and guidance. The authors provide a cogent analysis of the way things are right now in our communities. There is an urgent need for things to improve as advancements in acute care mean many more brain-injured people attempt to thrive, not just survive, in their communities – and who will otherwise remain marginalised, vulnerable and fail to fulfil their potential.

For health and social care professionals, the commonly used image is ‘pathways’. In this report, the authors point out that if the elements that are needed don’t join up, ‘it’s not a pathway, it’s an obstacle course.’ The different professionals involved may also not be in the habit of taking a wider perspective on their part in the overall pathway of care, resulting in people falling through the cracks. A critically important paving stone in this picture is the need for shared language and understanding. Services from different sectors may be disjointed partly because they haven’t agreed a common language. Achieving a shared understanding and language between clients, families and services is, for me, often a hard-sought rehabilitation outcome. Right now it is the systems around clients and their families that can, with support and positive commissioning, improve in their understanding.

By engaging with the content, and the questions posed, in this report, I believe you will gain insights that may help solve some of these big problems. This will improve the quality of the services provided and the lived experience of people who find themselves in need of your expertise.

Andrew Bateman PhD

Clinical Lead for NeuroRehabilitation, Oliver Zangwill Centre for Neuropsychological Rehabilitation, Cambridgeshire Community Services NHS Trust

*Acknowledgement:
Dr Bateman is
supported by the
Department of
Psychiatry, University
of Cambridge.*

Publication at a glance

What is it for?

Brain injury is unlike many other injuries. The effects, especially on your behaviour, relationships and thinking, may be hidden, mistaken for something else, or slowly emerge many years after the injury. Survivors of brain injury, along with their families, often find that leaving hospital feels like being abandoned to long years of fear, loneliness, self-doubt.

The focus of this publication is on **traumatic brain injury (TBI)**, an injury to the brain caused by trauma of some sort, such as a road traffic accident, a fall or an assault. In clinical terms, TBI is a sub-category of acquired brain injury (ABI), a term that refers to any brain injury that has occurred since birth, including stroke, haemorrhage, oxygen starvation and other causes (RIPFA, 2007, p1). Many of the statistics cited in this publication apply to this wider population of people with ABI; and many of the issues discussed and views expressed are shared across all types of brain injury.

This publication aims to make a constructive contribution to the debate about **how to think about, plan for and provide rehabilitation and long term support that meets mental, emotional and social needs as well as the physical**. Healthcare-related rehabilitation services are discussed; but the added-value of this contribution lies in a focus on what is needed to support longer term quality of life – an issue generally not addressed within the early healthcare dominated rehabilitation stages. In particular, the publication aims to:

- identify the opportunities and outcomes associated with providing appropriate community support to those affected by traumatic brain injury
- identify the risks of failing to provide support of this kind
- point to good practice in this area and encourage action.

The publication is not a comprehensive review of the evidence base, nor an in-depth analysis of the evidence. It is rather a quick guide to the main features of the landscape, guided by the voices of brain injury survivors and others in identifying important areas of common purpose that can be acted on by those commissioning and providing services. It aims to help all involved work together.

Where did it come from?

The Ajahma Charitable Trust commissioned the publication as a result of their long-standing interest in brain injury and in supporting local groups working with people affected by TBI. Working closely with Sheila Marsh, Marsaili Cameron and Roma Iskander from PublicServiceWorks Associates, the Trust designed an inquiry project (see [Annex](#) – for more about the inquiry method) that explored the experience and views of people with a brain injury, and those working with them locally in England, Scotland, Wales and Northern Ireland. The brief for the project highlighted the fundamental question that exercises many funders and grant recipients: how can we create the maximum positive difference to the lives of the beneficiaries of the charity through grant-making? And in the current context: how can we do this in a difficult economic climate?

Those involved in the first phase of the inquiry had survived brain injury, were their carers or worked with people affected by TBI, both volunteers and paid staff. A second phase of the inquiry involved communications, including interviews, with a number of allied health professionals and specialist researchers engaged in finding approaches to rehabilitation capable of making the kinds of difference that are most important to people with TBI and their families.

Who is it for?

Much of the material that follows is relevant to people living and working across the UK. However, some of the discussion regarding commissioning principally reflects arrangements in England following the Health and Social Care Act 2012.

The publication will be of particular interest to:

- Commissioners/funders of all relevant acute and community-based services/activities, including clinical commissioning groups and local authorities, grant-making bodies and trusts
- Organisations in the voluntary and community sector offering support, whether or not contracted by statutory bodies to provide services
- Service providers in acute health settings (e.g. trauma context) and specialist inpatient rehabilitation services
- Providers of community-based services in health and social care
- People with TBI, their families and supporters.

The audience is broad, but much of the material is of common interest. If people with TBI are to live well, then an integrated effort is needed from commissioners and providers of support and services. And successful integration depends on people understanding who needs to collaborate with whom, and why. In a highly fragmented field, there is need for a common base of understanding.

How can you use it?

- To understand the needs of people affected by TBI
- To create dialogue across clinical and non-clinical groups about what people with TBI and their families need, especially in the longer term
- To develop evidence-based support in the community for people affected by TBI
- To make a case for funding.

The material is suitable for use by:

- Individuals – for example, as a briefing guide and to find out sources of further information
- Individuals and teams within departments – for example, for briefings, agenda setting, planning and review
- Individuals, teams and groups from different organisations, partnerships and networks – for example, to help identify areas of common purpose and work out the practicalities of shared approaches.

Acknowledgements

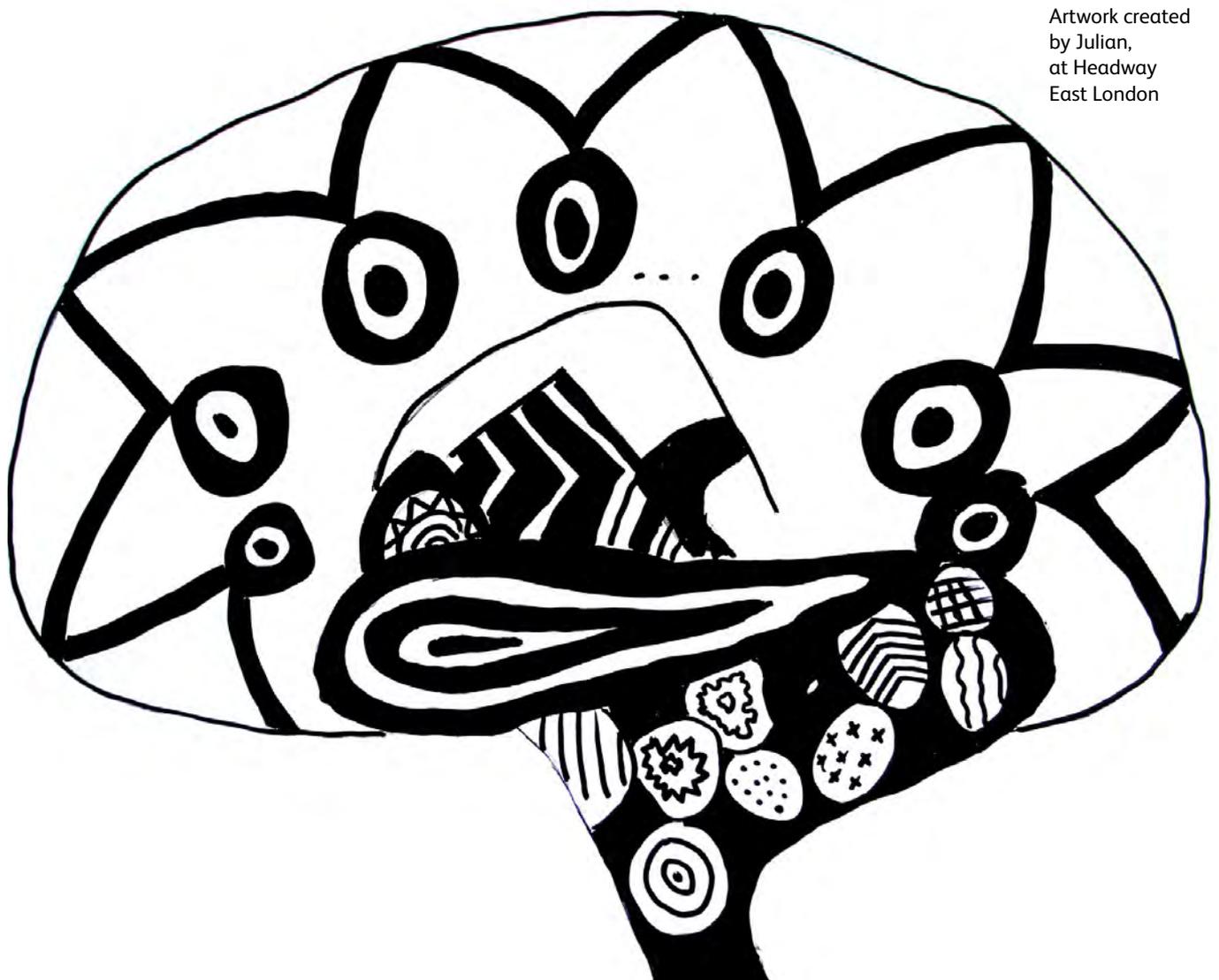
Grateful thanks are due to all who gave their time to be interviewed or respond to our e-questions or take part in a discussion group. Special thanks from the PublicServiceWorks team for the care taken in organising and supporting discussion groups by Headway group staff in Dumfries & Galloway, East Lothian, London, Nottingham and Preston & Chorley; for the willing support of the Oliver Zangwill Centre and the ABI Families e-network; and, importantly, to our critical readers for their insights: Deborah Harding, Joint Faculty of Health, Social Care and Education, Kingston and St George's, University of London; Roma Iskander of PublicServiceWorks; Dr Petra Makela, Darzi Fellow at King's College Hospital, London.

As is the case with many local groups supporting people with brain injury, the walls of Headway East London are covered with vivid pictures produced by people attending the centre. Thank you to all involved for permission to reproduce some of these pictures in this publication. Individual credits appear beside the pictures.

We are grateful to Taylor & Francis for permission to reproduce in Section 2 a quotation from Wilson, B.A., Winegardner, J. and Ashworth, F. (2014) *Life after brain injury: survivors' stories*. Hove: Psychology Press.

Traumatic brain injury (TBI) is an injury to the brain caused by trauma of some sort, such as a road traffic accident, a fall or an assault. In clinical terms, TBI is a sub-category of acquired brain injury (ABI), an encompassing term that refers to any brain injury that has occurred since birth, including stroke, haemorrhage, oxygen starvation and other causes.

(RIPFA, 2007, p1)



Artwork created
by Julian,
at Headway
East London

Section 1

Making the most of life with TBI: the brief guide to seriously good community support

Section 2 Leaving hospital is when problems begin...

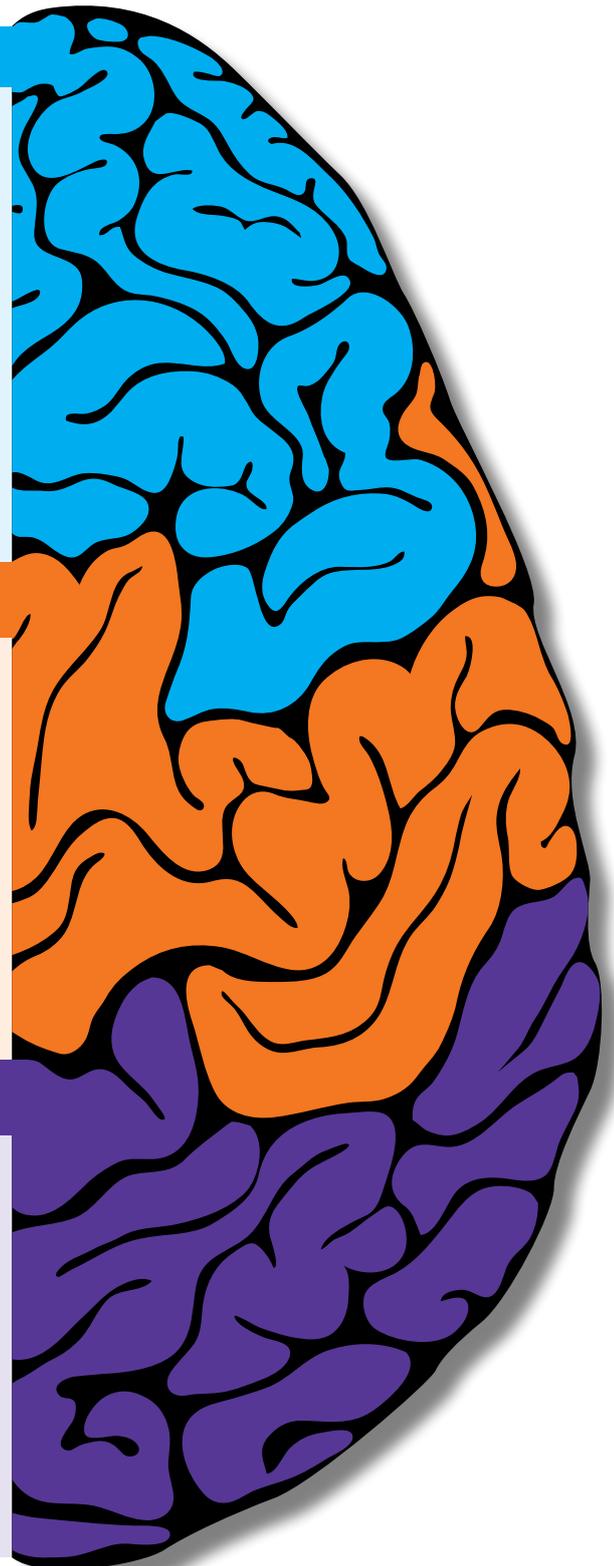
- Many people affected by TBI are young, so the social and economic costs are considerable
- The effects of TBI are felt long after the injury, take a variety of forms, and may be hard to recognise
- People with brain injury, and their families, often feel isolated and abandoned
- Organisations from third sector can help navigate complex pathways
- Access needed to specialist rehabilitation and to community-based activity
- Support from local voluntary groups makes a huge difference to quality of life
- Options for community support need not be high cost and high tech
- The most effective support is person-centred, reducing dependency and increasing self-management
- Planning head injury related services at local level needs to be based on local incidence figures

Section 3 Effective support for living well – what does it look like, and what good does it do?

- Success depends on true collaborative efforts among professionals, volunteers and family members
- People with brain injury want to re-connect with community, society and, where possible, work
- For favourable outcomes, brain injury survivors need to be involved from the outset in commissioning and designing support
- Support group liaison workers can facilitate transition between models of care
- Emotional and psychological support is as important as more visible rehabilitation
- Community and peer support is invaluable, but it is extremely difficult to get sustainable funding

Section 4 Securing widespread access to effective social support and rehabilitation

- The need for short and long-term support in the community is becoming more pressing
- Tangible outcomes for individuals with brain injury need to be combined with nurturing a sense of community
- Community and voluntary groups need to hold on to their values while responding to business demands
- Ensuring support is there when needed requires a willingness to confront complex issues
- Commissioners need to develop a full understanding of the complex needs and aspirations
- Providers of services need to take into account current policy directions in their planning



Section 2

Leaving hospital is when problems begin...

This section presents an overview of the situation confronting people with TBI and their families in the UK in 2014, with particular focus on what happens once people leave hospital to return to their families and communities and what support they need. Information is given on the distribution and numbers of people affected by TBI but many of the statistics cited in this section apply to the wider population of people with ABI; many of the issues discussed and views expressed are shared across all types of brain injury. Relevant national policies and frameworks are outlined, along with the real-life tensions and challenges associated with them.



Artwork created
by Witman Layrea,
at Headway
East London

What faces people with traumatic brain injury?

In a book that usefully brings together the personal accounts of people who have survived injury to the brain along with professional therapists' reports of their progress through rehabilitation, Wilson, Winegardner and Ashworth (2014, pp101-102) include the following vivid account of someone re-awakening to a changed world after an attack of herpes simplex encephalitis. The illness left her with a number of cognitive problems, the most severe of which was prosopagnosia, an inability to recognise faces.

'Here I was, being told that I was somebody I knew nothing about. That this man 'Ed' was my husband, and that these four children were ours. I knew nothing about any of them and couldn't recognise anybody. I had no understanding of my life, where I lived, worked, or who I shared it with. Words can't describe just how lost and confused I felt. My family were strangers to me, whatever it must have been like for them I can't imagine. It was very hard for me to accept that these strangers were my family. [...]

In hospital I had been able to relax and was supported in understanding and managing life little by little, but when I was discharged and at home it was completely different. It felt as though I had crash-landed into somebody else's life, one where I was meant to fit in but I felt so lost and separated from the whole thing. I came home to a house I couldn't find my way around and, although I wanted to do the usual household tasks which I had always done, I didn't have a clue where to start. [...]

I didn't know myself or anyone else. I couldn't recognise animals/birds either. I had no concept of gender, initially, and had to re-learn ways to appreciate this, and also skin colouring confused me too. I get startled by mirrors and don't even recognise myself in them. Going into department stores in the city centre was, and still is, hard as I struggle to realise that the dressed up models aren't real people. I jump out of my skin and feel very wary in that environment.'



Artwork created by Gary H, at Headway East London

What survivors, families and professionals say about life after hospital

Stories such as this were heard not infrequently in the PublicServiceWorks inquiry that forms the core of this publication. Many people spoke movingly of the disastrous consequences for their lives of failure to recognise in the early days how their injury might affect them. For example:

'I went back to work too fast, I didn't understand there was anything wrong with me'¹

'I was sent to live with this family, I didn't know who they were, gradually I came to know they were my wife and children.'

'I knew I wasn't right, but I wasn't heard, they said I had nothing wrong with me, it took 4 years before I got help for TBI, that was too late, the job went to pot.'

A kind of cascade effect seems to operate, where a general societal lack of understanding of brain injury percolates into the practice of professional groups and results, finally, in those with a brain injury, and their families and friends, being stranded on a very lonely shore in their communities. As the comments below show, support from a local voluntary group (in this case Headway) made a huge difference, but such groups themselves struggle:

'Before I came to Headway I was a bird in a cage that I couldn't get out of, in the cage for 20 years'.

'My son was injured 25 years ago but it's only in the last couple of years, since being involved with Headway that I understand what happened to him.'

'It's quite a challenge to find rehab activities that people are able to do, physically and cognitively – but that take into account that these are adults who don't want to be patronised.' (local group worker)

'There are people wanting to come to a group, but waiting for the money – from the council or whoever. They're just sitting at home waiting for the call. The money could be used to support them for a year to come to a group. Parents need this support too; they're so frustrated looking after them and waiting.' (local group worker)

¹ Unless otherwise stated, all quotations come from people with brain injury, and those caring for them, who took part in the discussion groups or interviews at the heart of the PublicServiceWorks inquiry, November 2012 – April 2013 – see Annex

The severity of these situations illustrates how important it is for professionals working in the community to understand and communicate clearly. Many local voluntary group workers speak of the mountain facing them. For example:

'I must repeat myself virtually every day, giving the facts, telling the story, highlighting the big issues. It's largely about training people in the statutory sector, whether health or care professionals. We've got fantastic acute services; but it all falls apart when the person is discharged.'

There is often a problem with getting the right material to the right audiences at the right time. As one worker put it, *'Our carer stuff is great. But by the time I can get it into the hands of the carer, the really important moments have gone. They've struggled alone.'*

Potentially lifelong support needs...

Wilson et al (2014, p1) describe the implications of the unique nature of the brain:

'Unlike damage to a limb or indeed even another organ, damage to the brain can be debilitating to an extent that those injured remain dependent on others for the rest of their lives. Except in rare circumstances a brain cannot be substituted by an artificial device or treated back to its original form or capacity, so brain injured people have to learn how to live their lives with handicaps that are not going to disappear over time.'

What might this mean in practice? There is a very wide spectrum of need, with **great variation in the effects of brain injury** on behaviour, relationships and thinking. Some survivors of brain injury return to live independent lives in their communities. Some people will regain independence soon after injury but when attempting to carry on with their life may face setbacks as a result of under-acknowledged 'hidden disabilities', such as much reduced tolerance to stress. Others will be discharged from a rehabilitation setting, but may have on-going support needs that may or may not be met in the community. Some require support to live in their communities; for example, they may depend on support workers or rely on help from family members or look for companionship to regular meetings of a local group supporting survivors of brain injury. Others need residential care, either temporarily or indefinitely, due to serious disorders of consciousness and profound physical problems. In all these different situations, the **families of those affected by brain injury will have their own needs for support** – needs which at present are often ignored, with the result that families commonly suffer from feelings of isolation.

While in hospital immediately after an injury, all these individual variations are treated, mostly in physical terms. It is often only later, after discharge, that further **longer term effects** on emotions and mental processes become evident. When people suffer from disrupted social cognition/cognitive communication skills, a strain is almost inevitably put on social networks. Some family members and friends are likely to distance themselves from the survivor, unable to cope with the social awkwardness involved. Sometimes the awkwardness is difficult to pinpoint, but this makes it no easier to deal with – in fact, in many cases, rather less so. Where behaviour and insight problems are hard to detect, they are also hard to support. Here lies the challenge of working with people with brain injury and their families and with different organisations to create appropriate kinds of support.

It is of key importance to achieve a good match between the needs, capabilities and aspirations of individuals and the type of rehabilitation offered. In short, no one size fits all, as far as rehabilitation is concerned – which presents a significant challenge to commissioners and providers of services and support to brain injury survivors.

...and inevitably involving more people

For some people, the effects of a brain injury can be dramatically reduced and, in some cases, almost eliminated. Thrombolytic medication, for example, can make a significant difference to some stroke patients. But while preventative action can be taken in relation to traumatic head injury – for example, promoting the wearing of cycle helmets – the level of risk tends to remain pretty much unchanged. It can be argued too that in a society where we glamorise adrenalin-seeking behaviours, the risk of brain injury is unlikely to recede soon. In reality, anyone can be affected by brain injury, in a wide range of different situations as simple as falling downstairs or falling off a ladder, and often with catastrophic results. Perversely perhaps, medical advances mean that more people are living with traumatic brain injury because we have become so adept at care in the acute stage. So the numbers of people (and their families) living with this challenging condition are growing (see page 18).

Paradoxically, while as a society we have been investing in acute care, we have paid little attention to the longer-term impact of the injury and identifying the kind of support that might be needed to live a meaningful life.

...but rehabilitation and support can be effective

The focus of this section is on clarifying the nature of the challenge facing those affected by brain injury, those caring for them and those working with them. Wilson et al (2014) comment that there is much misunderstanding about the nature and consequences of brain injury, even among health professionals and managers. It is not the case, as many believe, that once a person can walk out of a hospital, nothing else needs to be done.

Psychologist and brain injury specialist, Keith Cicerone, described rehabilitation in the following terms:

'The goal of rehabilitation, to assist people to live meaningful, fulfilling lives, is a tremendous undertaking, one that cannot be accomplished without a true collaborative effort.' (Foreword to Wilson et al, 2009)

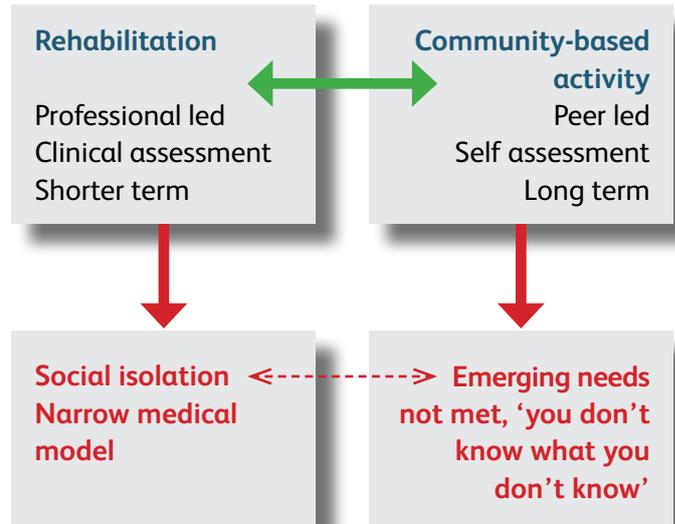
This publication aims to shed light on the 'tremendous undertaking' of rehabilitation, and to offer some insight into the nature of the 'true collaborative effort' needed to make it possible. More detail, examples, and an annotated list of resources are provided in later sections. It is, however, worth making the key point at this early stage that **rehabilitation is not the same thing as recovery**. This realisation has proved helpful to many brain injury survivors. For example, the survivor quoted on page 13 went on to say, *'That [realisation] turned a huge corner for me. [...] I was able to tell myself that we have one life, and that we must live it, and here I was being given all the support and strategies to manage the complications in mine, giving me the ability to help myself to live it happily.'* (Wilson et al, 2014, p103).

Those working in the field of neurorehabilitation (e.g. clinical and neuropsychologists, occupational therapists, speech and language therapists, specialist doctors) have built up a deep understanding of the results of injury to the brain. They have also pioneered ways of analysing and diagnosing difficulties faced by brain injured people; and they have developed scientifically supported methods of treatment (Wilson et al, 2014). Comprehensive neuropsychological rehabilitation has been shown to be effective in both clinical and economic terms. Indeed, given the fact that many people affected by TBI are young with a relatively normal life expectancy, the costs of not offering opportunities for rehabilitation are formidable.

It is not always appropriate or possible to offer specialist clinical rehabilitation of the type described above – and often not for long enough. However, as this publication will show, **there are considerable benefits associated with what might be called 'social rehabilitation', involving long-term peer and community support**. This is hardly a surprise: many people create, and benefit from, their own version of peer and community support. But, as many social care professionals are well aware, the difference for people with a brain injury is that their

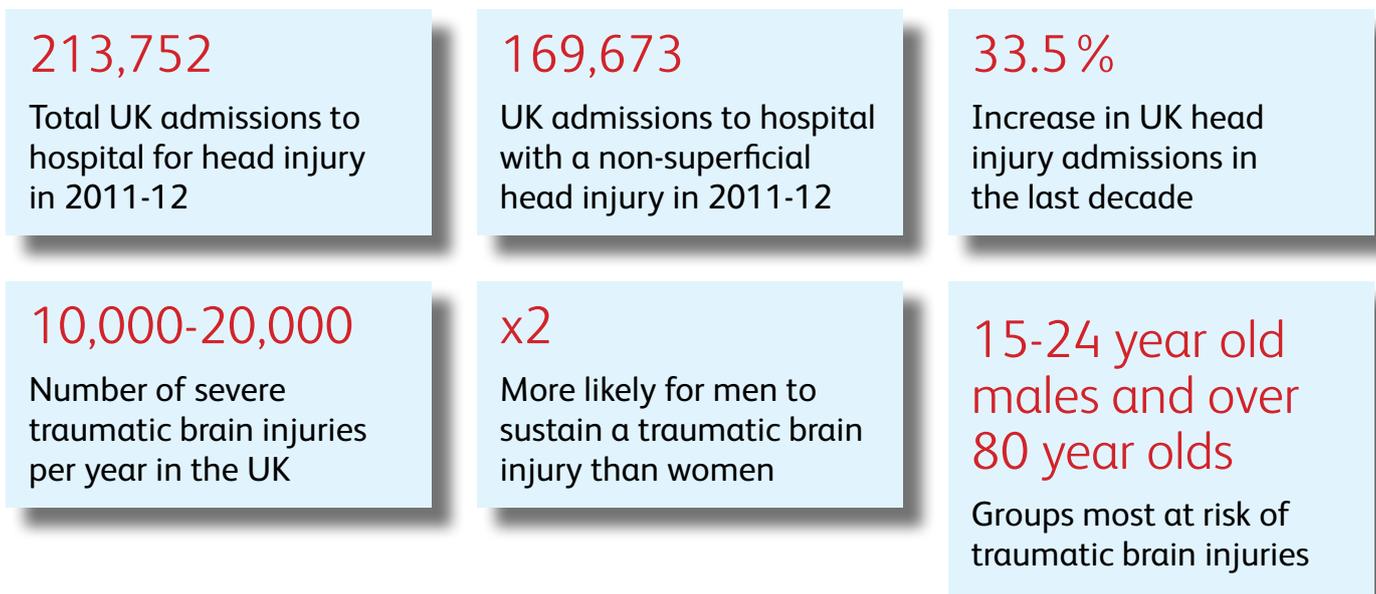
condition often erodes their ability to seek company and friends, leaving them isolated and lonely. While specialist skills in neurorehabilitation will necessarily remain the preserve of a few – and are important for uncovering hidden effects of TBI – the *social skills* needed to engage, support and encourage vulnerable people and support their families are much more widespread. What is clear is that **both** are required. Without attention to both sets of skills, the danger is that people with TBI experience major problems – as shown in red in the diagram opposite.

A core aim of this publication is to indicate ways in which skills of both kinds can be put to use for the benefit of people with TBI and their families.



How many people are affected by TBI?

Approximately 700,000 people per year in England and Wales attend an emergency department for head injury. About 1 in 5 of these people (150,000) is admitted to hospital for further assessment and treatment². Overall numbers and distribution are given by Headway UK³ as:



These figures do not, of course, include the many people who are the families and carers of people with brain injury; they are also profoundly affected by TBI and live with the consequences of the condition over the long term.

The evidence reviewed emphasises the importance of supporting them. For example, Turner-Stokes et al (2013) point out that gaps in ongoing community rehabilitation and social support are associated with excess care burden and costs to the family. However, to date resources are very thin on the ground, with voluntary sector groups such as Headway offering them most help.

² Figures from NICE www.evidence.nhs.uk/topic/head-injury?q=head+injuries accessed 15/10/2013

³ See www.headway.org.uk/key-facts-and-statistics.aspx accessed 2/10/2013

Local figures are not easily available but one study (Tennant 2005) found a hospitalised incidence rate for England of 229 per 100,000 in the population over 2001/2 and 2002/3. Head injury incidence in England, however, was found to vary by a factor of 4.6 across health authorities and primary care trusts. Socio-economic factors were found to account for a high proportion of the variance in incidence in different parts of England, as the table⁴ shows:

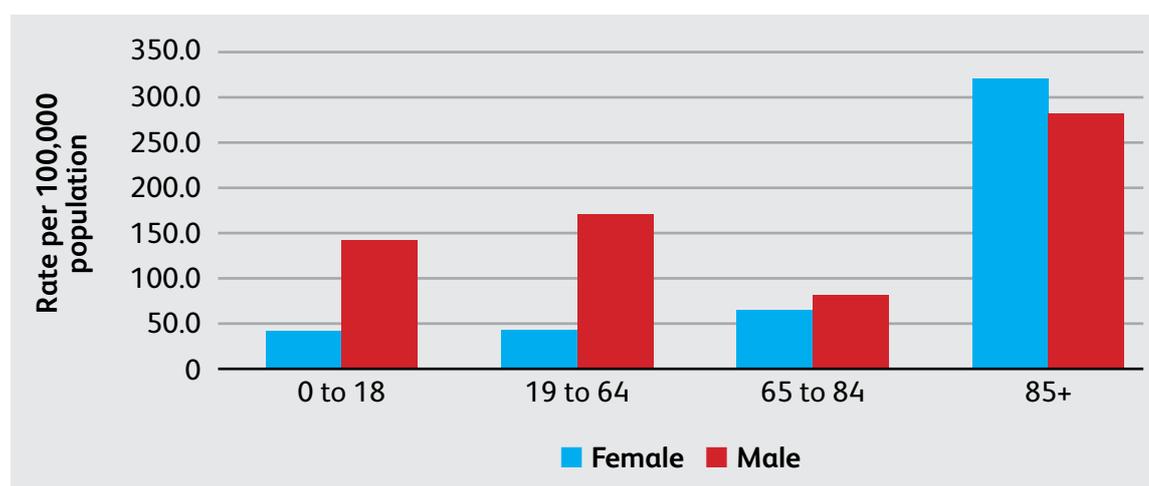
Cluster analysis of socio-economic indicators associated with head injury in England

| Characteristic | Cluster | | | |
|-----------------------------------|---------|-------|-------------|---------|
| | London | Shire | Other Urban | England |
| Admission Rate – all ages | 176 | 206 | 288 | 229 |
| % Born out of UK | 26.7 | 5.7 | 4.8 | 9.2 |
| % of working age permanently sick | 4.5 | 4.2 | 7.6 | 5.7 |
| % age 16–24 unemployed | 5.5 | 4.6 | 7.4 | 5.9 |
| % without qualifications | 22.4 | 26.7 | 35.1 | 29.7 |
| % qualified at level 5+ | 33.2 | 19.6 | 14.8 | 19.3 |
| % using private transport to work | 35.2 | 67.0 | 65.3 | 62.2 |
| % using public transport to work | 43.8 | 8.9 | 14.2 | 15.6 |
| % households without a car | 38.3 | 20.1 | 32.3 | 27.6 |
| % owning (or buying) own home | 55.8 | 74.0 | 66.5 | 68.6 |
| % Lone parent household | 10.9 | 8.2 | 10.9 | 9.4 |
| % living in overcrowded homes | 18.0 | 5.1 | 5.7 | 7.0 |
| Average Townsend Index | 5.5 | -2.7 | 1.2 | 0.0 |

These findings are potentially very significant for those commissioning and providing services. Planning head injury related services at the local level may need to be based on local incidence figures rather than regional or national estimates.

Some local examples can be found via public health observatories for regions. For example, the following table shows the rate and distribution of admissions for acquired brain injury in the north-east of England in 2010/2011⁵.

Rate of admissions in the NE region for ABI by age band per 100,000 population (2010/2011)



⁴ Source: Tennant 2005 p4 <http://eprints.whiterose.ac.uk/922/1/tennanta2.pdf>

⁵ Source: www.nepho.org.uk/search.php?q=brain+injury

What policies and frameworks are in place, and how effective are they?

Because the social and economic costs of brain injury are so considerable, both national governments and international organisations have seen the value of trying to create integrated patterns of care and support. Considerable tension remains, however, between the desire to move in this direction and the reality of forging links across different disciplines and domains – the kind of links that are essential to ensuring quality of life for people with TBI and their families.

Government concern

The effects of long-term disability represent a huge portion of the cost of trauma on the UK economy, estimated in 2009 at £3.3- £3.7bn per year⁶. Improved rehabilitation is seen as playing an important role in reducing this societal cost significantly. Government has pursued this concern in two ways:

- 1. The National Service Framework for Long-term Neurological Conditions** (NSF, 2005) recognised the need for an integrated approach to service delivery. An independent review of its impact, however, concluded that access to services is frequently compromised by restrictive eligibility criteria, ill-defined pathways and a lack of availability or capacity locally⁷: that is, services are thinly stretched and patchy. Also, since the NSF did not come with resources, it has been put into practice only where local initiatives have secured funding and networks. There is also a need to link with other related initiatives, such as trauma networks (see below) and the new strategic clinical networks covering neurological conditions.
- 2. The establishment of major trauma networks** aimed to improve quality of care and of intensive rehabilitation in hospitals to help recovery (Department of Health, 2009) since it was clear that rehabilitation was the worst performing part of the acute pathway. After the introduction of the intensive Traumatic Brain Injury Programme, delivered through the major trauma networks, NHS organisations demonstrated an improvement in quality and productivity as measured by shorter length of stay, higher cognitive outcomes at discharge, and higher rates of discharge to home, along with high levels of return to work and independence of locomotion sustained after 6 months (DH, 2009).

Given these approaches, the role of groups such as Headway remains vital as a constant resource within the community, regardless of a person's stage of rehabilitation. Importantly, when the statutory services determine that they have 'completed' their input, these provide (albeit limited) support for individual and family for their ongoing and still changing needs. Of course not every area has easy access to such a group and not all groups

⁶ Rehabilitation of major trauma patients 2009 Department of Health QIPP report at www.evidence.nhs.uk/qualityandproductivity

⁷ See <http://php.york.ac.uk/inst/spru/research/summs/ltnc.php>

offer the same range of support, activities or services. The person's GP is often required to function as the underpinning coordinator of individuals' needs but may not be aware of how to meet these or to how to access support required – often the discharging healthcare service does not provide information. The need for support to GPs is therefore highlighted – and picked up by Headway in 2013 as 'Resources for GPs' webpages⁸.

Around broad government initiatives, then, remains substantial local variation in available, accessible support and services across all stages of the person's journey post-injury, since these have evolved haphazardly in statutory and voluntary sectors. This picture is increasingly complicated by service cuts and the continuing segregation of health and social care funding.

New challenges after Health and Social Care Act 2012

The reorganisation of the health service in England from April 2013, following the Health and Social Care Act 2012, has resulted in new challenges for all those concerned with survivors of brain injuries – commissioners and providers of services, as well as organisations and groups lobbying on behalf of service users. The following comment, written from the point of view of health charities, stresses the resulting increased need to gather, analyse and present data on local populations.

'Many decisions about local health priorities will now be taken by the 211 new clinical commissioning groups and 152 health and wellbeing boards which bring together local authorities and health commissioners. Strategies and commissioning plans will be informed by evidence about local population needs. That means charities now have to gather, analyse and present data on local populations to influence the development of these plans.'

To continue to be successful influencers, we will need to ensure we can provide robust, reliable, [condition-specific] data on local population need, as well as evidence about what service solutions are cost effective and how they deliver improved health outcomes.'

In the current economic climate, the gold standard evidence for commissioners is anything that delivers downstream savings – for example, by reducing unplanned hospital admissions or in-patient bed days.' (Bouverie, 2013)

With their characteristically long-term and complex needs, there seems a real danger that people with TBI and their families will be caught between two growing trends. On the one hand, there are likely to be reduced resources available for community support (resources that were very constrained in the first place). On the other hand, the specialist commissioning arm responsible for funding much rehabilitation is very

⁸ See www.headway.org.uk/gp.aspx

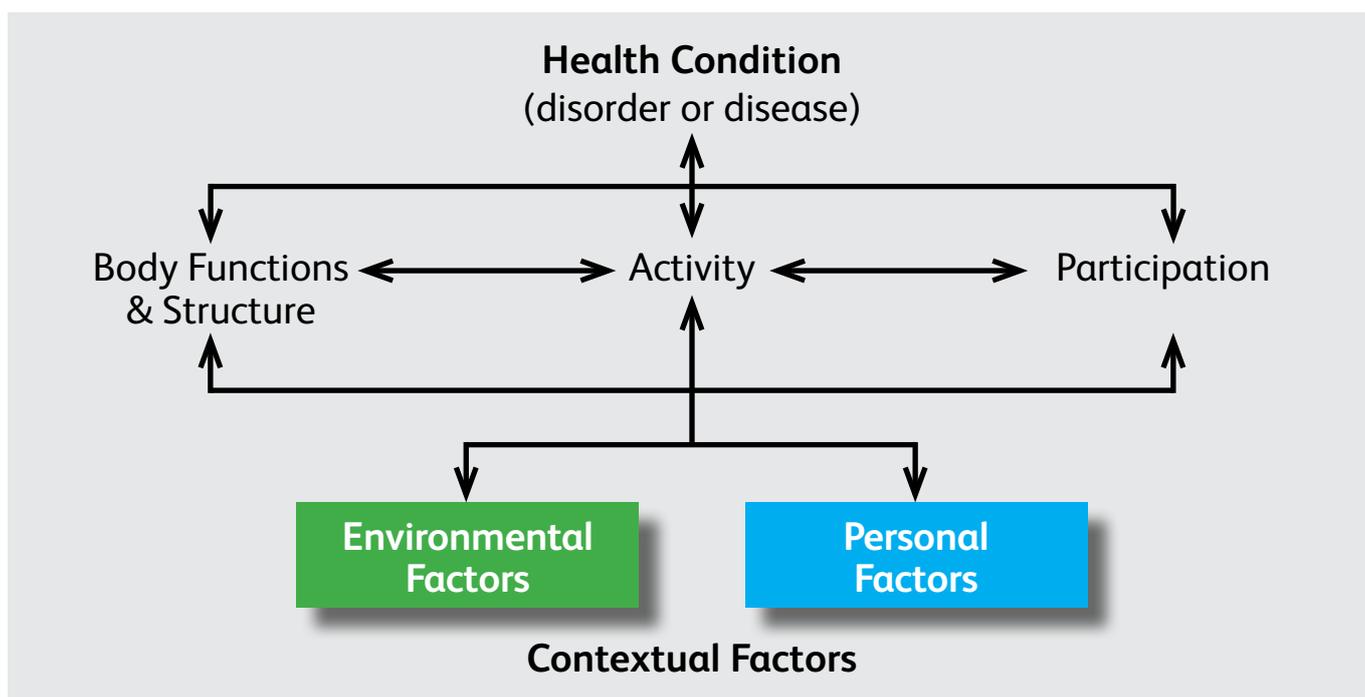
much orientated to the acute hospital sector and arguably subscribing predominantly to the medical model of health. For those with more severe brain injury, the disjointed nature of services encountered within their journey following injury is likely to be compounded by pathways crossing commissioning boundaries – from specialist (NHS England’s responsibility) to non-specialist (CCGs’ responsibility) settings to social care needs (local authority responsibility).

Nonetheless, there are **opportunities** from the recent changes in a greater emphasis on partnership working. Closer cooperation envisaged between health and social care, including new arrangements for integrated funds, might be an opportunity – voluntary sector organisations and local commissioners will need to be alert to the possibilities.

Seeking a common language

The framework, *Towards a common language for functioning, disability and health*, usually known as the ICF Framework (World Health Organisation, 2002) is useful for both providers and commissioners of services for people affected by TBI. Offering an international classification, this framework is widely used across disciplines in continental Europe, and offers a basis for speaking a common language about the effects of brain injury. The concepts prioritised are patient goals, self-determination, framing own identity. A resource/facilitation model is encouraged – where experts support patients in achieving their own goals.

In the UK at present, a common language across health, social care and voluntary organisations is noticeably lacking – to the detriment of people affected by TBI and their families.



Moves towards a common language are likely to be particularly helpful for commissioners of services, whether they have a health or social care remit. With increasingly wide-ranging responsibilities, commissioners are unlikely to have expertise in brain injury and may not have access to appropriate specialists to advise them. The divide between providers and commissioners over recent years has accentuated the gap in experience and knowledge; and moves to bridge that gap would benefit all concerned. In addition, part of the language barrier is between health and social care. A common language would help draw in those commissioning social care, rather than only health commissioners, and meet the concern to develop longer term support.

But debate continues on what language to use

Although the ICF framework is an accepted model for rehabilitation management, it is not without its critics. For example, Wade and Halligan (2003) argue that the framework does not capture dynamic processes over time, and does not take into account personal values and a person's own evaluation of their quality of life. Others suggest that the framework is associated with a particular understanding of what rehabilitation is – that the underlying assumption is that the person with brain injury is 'being rehabilitated from' brain injury rather than 'living as well as possible with' the condition. (As [Section 3](#) will show, there is continued, wide-ranging and impassioned debate about what 'rehabilitation' means.) An alternative approach has been suggested to finding a common language, which conceptualises using a human rights model, in order to shift the emphasis of values (Siegert et al, 2010).

There are perhaps two key messages in this discussion:

- **It is far better for partner professionals and organisations to agree to explore differences in underlying assumptions, through the medium of conceptual frameworks, rather than ignore differences in understanding and go on to act them out, with negative consequences for the lives of vulnerable people and their families.**
- **Organisations from the third sector are in an excellent position to provide advice grounded in people's actual needs.**

Continuing dilemmas for the health and care system

Saving money now vs. spending more later

The cost-effectiveness picture is complex. There is, of course, huge pressure on budgets in this time of austerity. But saving money on treatment this year may well lead to very expensive consequences years down the line. The maladaptive consequences of brain injury commonly take forms that are very expensive for the taxpayer: prison; helplessness and total dependency on care; suicide; alcohol/drug misuse; family breakdown; and unemployment.

Balancing economic and ethical considerations

Policy decisions have both ethical and economic dimensions. What ethical frameworks are used in decision making, and what is the place of compassion in influencing decisions? How well do policy decisions take account of the impact on families as well as issues for the person with TBI?

Joining policy aspirations to operational realities

An integrated approach to delivering services, including initiatives like pooled budgets, involves people from different disciplines and backgrounds making substantial culture shifts. How can they make these shifts when they are under severe 'home' pressure to reduce spending?

Keeping focus but widening reach

If people affected by TBI and their families are not in touch with a case manager or rehabilitation centre, they are unlikely to know much, if anything, about resources that are available for them. Funding needs to be found to make these resources visible to those outside the system as soon as they are affected – for example, through increased literature and guidance in GP surgeries, hospitals, libraries, community cafes, colleges/ universities and faith venues.



Group discussion held during the PublicServiceWorks inquiry.

The challenges for commissioners and providers

No simple pathway

'First establish a pathway' – this is often the starting point for commissioning services for groups within a population.

But the research literature shows that there is no possible simple rehabilitation pathway for people affected by TBI.

Pathways, and stepping stones along them, include:

- emergency health care
- regional acute trauma centres
- further hospital treatment (e.g. for further neurosurgery or other surgery, for epilepsy treatment)
- different forms of post-acute residential treatment (e.g. inpatient neuro-rehabilitation, neuropsychiatric or neuro-behavioural treatment)
- transitional living units
- intensive outpatient treatment
- community neuro-rehabilitation
- support groups for people with TBI and for families/carers.

The differences in the routes taken through these elements depend on the severity of injury, and what is available within reach of someone's home.

Commissioners need to :

- **involve service users and their families** in planning and design of services and longer term support
- recognise **what might already be working well** from the user's viewpoint
- **not** just commission to health dominated pathways
- **not overlook the small organisations** who may be excluded from competitive tendering processes in the changing environment,

At the same time providers both large and small need to demonstrate outcomes, value for money, and how they might work in partnership to create a more coherent experience for brain injured people and their families.



Artwork created by Theresa, at Headway East London

Frequent lack of early diagnosis

Often, when people are first discharged from hospital, there is no diagnosis, therefore no onward referral. For example, in a multi-trauma context, the focus may have been on bone fractures rather than potential brain injury. Limited spaces in local groups make finding support difficult; and, when a person is discharged from hospital, families tend to cover impairments by overcompensating for the injuries that are visible. In a 2007 literature review by the National Collaborating Centre for Acute Care, 394 studies were identified that attempted to use a wide range of variables and tests to predict a range of longer-term outcome measures.

No robust clinical decision tools have successfully been derived and validated to identify patients at the time of injury who could be considered for follow-up because of the higher risk of long-term consequences. This suggests that longer term attention in the community is vital for people with TBI.

Best outcomes associated with person-centred treatment

Because of the very individual patterns of experience associated with brain injury, it is highly desirable to have a person-centred approach to treatment and rehabilitation. Where practical, there should be an eye to reducing dependency and increasing the focus on self-management. This will often require a shift in commissioning focus from medical and/or health needs to social and wellbeing issues, building on people's strengths and supporting them to find new identities. Third sector organisations can often offer learning to statutory organisations on this shift of emphasis, as can other health and social care resource groups working in mental health, learning disability or maternity services.

Local groups, such as Headway, offer a range of valuable support both to people affected by TBI and their families. The web-based National Brain Injury Service Directory (www.brainnav.info) also helps people find individual pathways for living with their condition. This service makes another valuable contribution through providing some assurance of consistency for commissioners.



So what? Make your mark

1. Which of the issues and dilemmas outlined in this section are familiar to you, and which unfamiliar?
2. Are there any gaps in knowledge or understanding that you would particularly like to fill?
3. Which of the issues are important for your role/ local area?
4. Are there experiences or insights that you think it would be useful to share with others?

Section 3

Effective support for living well – what does it look like, and what good does it do?

This section explores the purposes of social support for brain injury survivors, including rehabilitation, and reviews different expectations and approaches. Tentative answers are given to outstanding questions about the nature of support and rehabilitation, the tensions involved in collaborative effort, and the kind of outcomes that people with brain injury and their families might be looking for.



Artwork created by Headway East London Collaborative

Aims of support and rehabilitation

When able to express their views, people with brain injury describe what is important to them in life in very much the same terms used by those who have no brain injury. They want to be recognised as themselves. They want to feel that their life is of value – both to themselves and to others. They want to make the most of the strengths, abilities and talents that they have. They want to know that there are people in their life with whom they can share laughter as well as darker moments. They want to live as well as they can.

What is known as ‘rehabilitation’ covers a spectrum of activity and intervention that can often make a valuable contribution to the goal of living well. But it is worth repeating here the words of the brain injury survivor on her realisation of the significance of the fact that **rehabilitation is not synonymous with recovery.**

That [realisation] turned a huge corner for me. [...] I was able to tell myself that we have one life, and that we must live it, and here I was being given all the support and strategies to manage the complications in mine, giving me the ability to help myself to live it happily.’ (Wilson et al, 2014, p103)

At the heart of this insight is the desire for genuine empowerment, where what matters is not what external agencies believe that they are doing and achieving, but what the individual person finds to be enabling and life-affirming. And what is most life-affirming may involve helping to run a photography club rather than (or as well as) taking part in mainstream ‘rehabilitation’.

So, what is rehabilitation for, what are the people engaged in this activity trying to achieve, and what might count as good social rehabilitation? The literature over the last twenty years or so presents an extraordinarily varied picture of what people understand by rehabilitation, moving dizzily across structure, process and outcome. The illustration below offers a snapshot derived from definitions from 20 different sources⁹.



⁹ Taken from teaching material by Deborah Harding – personal correspondence

Amidst such complexity, it's worth looking again at the helpful statement by Keith Cicerone:

'The goal of rehabilitation, to assist people to live meaningful, fulfilling lives, is a tremendous undertaking, one that cannot be accomplished without a true collaborative effort.' (Foreword to Wilson et al, 2009)

In individual cases, what is meant by that goal, 'to assist people to live meaningful, fulfilling lives'? The ICF framework, as described in the previous section, can prove helpful in finding answers to questions about the exact role of rehabilitation. The 'true collaborative effort' underpinning successful rehabilitation benefits hugely from a common language being available to all the different people involved – professionals, volunteers and family members.

Within the 'tremendous undertaking' of rehabilitation, psychologists, occupational therapists and speech and language therapists are likely to prioritise the neuropsychological aspects – working to address deficits in social cognition, often subtle, that lead to people not being able to understand others' perspectives or emotions, or indeed their own emotions, and the effect this has on their ability to participate in social activities. Wilson et al (2014, pp2-3) summarise evidence showing the clinical effectiveness of comprehensive neuropsychological rehabilitation.

There is less research evidence on the contribution of **community and peer support** to the rehabilitation of those affected by TBI – what might be called *social and community-based rehabilitation*. Rehabilitation groups of this kind are often volunteer-led, or may be led by a social worker, case manager or nurse. The inquiry by PublicServiceWorks revealed the extent of appreciation among people affected by TBI for this kind of contact, and what kind of difference these interactions made to their lives. The following quotations are taken from group sessions hosted by Headway groups, which had a mix of people with a brain injury, carers/family members, volunteers and staff¹⁰.



A group collage: how we see Headway

'My picture is of balloons taking off. Arriving here at Headway it took off. The guitar group, the writing class, it really took off.'

'We're a community here. We're different, but looking to achieve the same thing.'
(staff)

'We're all on a long journey. ABI is for life. You may not need Headway all the time, but it's there when you need it; you can always come back when you need it.' (carer)

'As soon as you walk in, you can feel the support that people have for each other. Out there in the community, that support doesn't exist. In here it's different. All are accepted.'

'Like a family – everyone works as a team, we help each other with what we need. Everyone can take part, and do what they can do. People are accepted for who they are.' (carer)

'This calm sea says something about the calm of Headway, in contrast to the rest of the world around us'

'Headway is a bridge, not knowing where we are going but it shows a way forward' (carer)

¹⁰ For more information about the inquiry, see [Annex](#)

The atmosphere and sense of community reflected here that people felt they gained was striking – community is not just the setting but is created through this type of work in voluntary organisations in ways that are very hard for statutory services to achieve.

There was also much discussion about **the possibilities and the future**, following real losses as a result of injury, especially loss of work. People wanted things to look forward to and a chance to regain some of what they had lost, to **re-connect with community, society and work**:

'The word is disabled but I see a lot of potential here. I see disabled but there are a lot of possibilities. The thing is we all may seem fine but we have problems in our head. One person got hurt in his head and lost an arm, I've lost my balance, there are never ever two injuries the same.'

'My past life, before the crash I could have been a footballer, after I was with the Inland Revenue but they chucked me out. Then came to Headway and closed the door on my previous life.'

'People encourage each other here – to reach out, do as much as you can.'

'I've been coming here for a year – now I can go out at night if someone goes with me. Not being able to go out in the dark used to make life very difficult. And I'm more confident. I wouldn't have spoken like this a year ago.'

How does work fit in?

People with TBI usually have a normal life span, and therefore want to work, to contribute as much as they are able. No one wants to be identified as 'sick' for the whole of their life (it is worth noting here that the PublicServiceWorks inquiry involved people who were reasonably able cognitively). Work and the income it brings are crucial to brain injured people being able to overcome the challenge of accessing leisure activities and achieve social integration. Being pressured into unsuitable work, of course, would not contribute to living well; rather the reverse. Work may be within the community or may take place in a sheltered context where, for example, woodworking or craft skills may be developed and lead to enterprise initiatives in local groups where artefacts are sold.

The academic research backs up this emphasis on work. Stergiou-Kita et al (2012) found people they worked with prioritised the following issues: meaning of work; process of return to work and reconciling new identities; opportunities to try versus risks of failure; significance of supports. They concluded that clients' post-injury work goals, interests and motivations must be reviewed, as the meaning of work can

change following traumatic brain injury. People need opportunities for experimentation with work activities, to help develop self-awareness and new self-identities, as well as practical and emotional support for challenges that may arise during return to work.

However, it is not as simple as supporting and preparing the brain-injured person to work. It is very hard for people to access work as a result of:

- The misunderstanding of employers – who, like other members of the public, are largely unaware of the impact of ABI
- The difficulty in making ‘reasonable adjustments’ (required by law) which account for unpredictable behaviours/impaired insight and hidden disabilities.
- The same issues being present on gateway or access schemes run by government. It is tough for unemployed brain injured people to access government schemes and do well on them. There is no clear record of how many may lose their benefits if they cannot keep up with such programmes, where their disabilities may not be understood.

Some answers to the question, ‘What would help?’

In the PublicServiceWorks inquiry, people with brain injury, and those who work with them, were full of ideas about what would help:

- **Help for people to re-enter their community/society**, including work-related support, enterprise skills and volunteering in the community.
- **Hardship grants for local groups** to help support those who are deemed ineligible for statutory funding under the new system. *‘We will need to provide preventative services for these individuals and their carers.’*
- **Transport** for people to access support was emphasised time and again.
- A **broader range of activities** to attract younger brain-injured people.
- **Ways for local groups to keep in touch with people/offer something before their assessment by statutory agencies.** There may be a considerable time lag before people with TBI are assessed for rehabilitation. This is seen as a very hard time for people to be left on their own, given they have no funding at this point and often very little information or support.
- **Fund key functions** such as mentoring, counselling, therapies, Return to Work preparation programmes, out of hours support.
- **More activities** for people with brain injury and carers, e.g. classes, leisure, trips.
- A **‘comfort pack’ for families in early days in hospital**, especially for poor families who can’t afford hospital cafes.

There is perhaps an overarching message here: the pressing need for brain injury survivors to be involved from the outset in the commissioning and design of services and practical support intended for their benefit.

Good support for living well: the big Qs and As

A review of the research on long term support for people with brain injury highlighted some important questions, themes and tensions. A summary of this material was presented to a number of experienced professionals working in the field of rehabilitation; and they offered feedback based on what they had learned from years of ‘true collaborative effort’. The following questions and tentative answers emerge from this interaction between theory and practice.

What can be done to achieve continuity of care?

Research has identified **continuity of care** as being of key importance to the wellbeing of those affected by TBI. The common experience of excellent, specialist care in hospital followed by an almost complete lack of attention once back at home and in the community does nothing for anyone’s wellbeing. Care may have to stretch over time as well as space. For example, 20 or 30 years after the injury, people may continue to struggle in life, but services and attention are rarely available to them.

The current pressure on health and social care services presents huge challenges to the continuity of care of people with TBI. One respondent described a situation where a socially isolated and vulnerable elderly man still suffering from the effects of TBI inflicted some 50 years previously was deemed ineligible for help from either social services or mental health services. ‘My mistake’, commented the professional dryly, ‘was to answer Yes to the question, “Can he wash and dress himself?” and No to the question, “Does he have hallucinations?”.’

Many people would see the kind of social isolation involved here as being related to a broader lack of compassion within today’s society. On the other hand, others would cite the work of local voluntary groups and charities as evidence that practical caring is not confined to families or professional groups. It is worth noting too the vital importance of local groups in acting as advocates for people who may not have family or friends who can take on this role.

How can you navigate tensions between medical and social models of disability?

The research literature highlights the gap between interventions based on the **‘medical model’ of disability vs those based on the ‘social model’**.

One respondent commented:

‘There is a perceived divide; but in reality it’s often not as great as might be assumed from reading the literature. In real life, you sit and talk with people. So it would help for people to use the same language.’

Big gaps between different kinds of approach make for inconsistent care and shortfalls – usually in the social arena. A consequence is that people with TBI may be missed or may be diagnosed with mental health issues as opposed to the injuries that they really have. More centres and support in the community would help to try to normalise things and support people in adopting coping strategies.

There are other kinds of gap – situations of co-morbidity, for example. People sometimes fall between services, when they are considered ineligible for neurorehabilitation due to psychiatric problems, or ineligible for psychological interventions due to the presence of neurological damage. Gaps of this kind need to be anticipated and forestalled; they are unnecessary and harmful.

Different models of care are appropriate for different stages of the person’s journey after their traumatic brain injury – for example neurosurgeons operate a medical model and Headway a social model. However, neither of these models is appropriate across the whole care journey, which needs to operate a flexible bio-psycho-social model, moving from a more medical model in emergency care, a more educational/psychological model in rehabilitation to a more social model for long-term care in the community. So the role of professionals evolves from that of an expert assessor/ advisor in assessment, to a trainer/ educator/coach in active rehabilitation, to that of a mentor or facilitator in long-term personal and family adjustment.

Given the sharp demarcations among different professions and disciplines, there is at present no seamless transition from one model of working to another. The goal has to be to achieve individual-based tailoring and interweaving of the different elements of care. Since this interweaving around holistic needs is generally done poorly by healthcare-rehabilitation services, there is potentially a key role here for input from support group liaison workers who can keep in close touch with individuals, families and health and social care professionals.

The challenges of coordinating care for people with complex chronic conditions are by no means confined to the field of TBI. A recent helpful publication from the King's Fund discusses how best to apply (and combine), in practice, various strategies and approaches to care co-ordination (Goodwin et al, 2013).

What is the contribution of community and peer support?

Local groups for people with brain injury are often extremely good, and also support family members, but are limited in geographical coverage – so more such groups are needed. The evidence on the **role of groups for people with brain injury** is basically that the more you belong to, the better. (Although since groups may not suit everyone, there is also a need to develop more options for activities and to signpost these clearly.) Respondents' experience is that peer support for clients with brain injury and their relatives is of great value in helping **both** groups to:

- attribute their difficulties to brain injury (rather than to themselves)
- share practical coping strategies
- provide on-going peer feedback, support and light relief
- learn that others share at least some of their concerns and that they are not alone with their difficulties.

It is not unusual for clients and relatives to exchange contact details in order to follow up with additional mutual support. The relationships built up in this way can be very helpful in developing a sustainable pattern of support. While peer support helps individuals, more support is needed to help families understand their situations. For example, sexuality is far too rarely talked about, and staff can be ill-equipped to attend to this domain.

Community groups also set up user groups and create roles for former clients and families that can provide vital experience, normalise difficulties and provide a new and valued social context. For example, users and family members go on to be successful, committed volunteers or committee members and/or take up paid roles in community based groups. That said, many people with brain injury lack the confidence, unsupported, to join a community group; so there is a vital role for 'buddy' schemes that support them in taking the first steps in joining these groups.

Of growing interest for many community groups is the concept of 'timebanking', a means of exchange where time is the currency (see www.timebanking.org). For every hour participants 'deposit' in a timebank, perhaps by giving practical help and support to others, they are able to 'withdraw' equivalent support in time when they themselves are in need. In each case the participant decides what they can offer and everyone's hour is seen as equal.

Although community and peer support is invaluable, the experience on the ground is that it is extremely difficult to get sustainable funding for this kind of support – or for its evaluation, in order to make a case for such funding.

How do you ensure that people can engage with rehabilitation?

Research suggests that if rehabilitation is to be effective, **people need to feel ready to engage** in the process. The associated concept of ‘rehabilitation readiness’ is less simple than it may at first seem.

Some people working in the field argue that where there are only modest gains following neurorehabilitation, the reasons are likely to include differences between patients’ needs and aspirations, the nature of patient-clinician interactions, and patients’ rehabilitation readiness (van den Broek, 2005). An example of less than helpful patient-clinician interaction would be a situation where, from the client’s point of view, staff are providing the wrong information at the wrong time. To avoid this impasse, it is suggested that the clinician helps the client to think about the sources of motivation for them at the moment, and how they feel about change. In some cases, because a TBI can itself directly affect motivation, a quite different therapeutic approach may be required.

Some respondents took a more sceptical view, seeing the concept of rehabilitation readiness as ‘a professional notion, not necessarily a genuine phenomenon.’ According to this view, ‘readiness’ or lack of it may reflect the match/mismatch between a given sort of provision and the needs and aspirations of service users.

Why is it important to carry out further research and evaluation?

‘Need to know more’ questions are frequently identified in the research literature. These include:

- How cost-effective are different types and levels of rehabilitation?
- What are the best timings and settings for ‘slow-to-recover’ candidates?
- Is it realistic to try to establish consistent approaches to treatment linked to some predictable outcomes?
- Which interventions in which settings optimise recovery for which groups?
- Which approaches are most effective in supporting a return to work?

There are two important broad areas where research is signally lacking, and where a deeper understanding would bring significant benefits.

1. Evaluation of family education/interventions and neuro-psychotherapeutic interventions to facilitate long-term adjustment.

This would involve exploring in depth questions like, ‘What is the effectiveness and cost-effectiveness of including the family and community within neuro-rehabilitation for people with TBI?’

Research should focus attention on partners, children, relatives and friends, whose needs are mostly not taken into account at present – but whose wellbeing and understanding of TBI is likely to have an impact on the TBI survivor.

2. The current lack of research on community rehabilitation and support is a major issue – the implications are that this approach does not become widespread and the benefits do not become known.

Associated research is needed to evaluate existing examples of good practice. More needs to be known about how initiatives:

- improve community outcomes and quality of life for people with TBI and their relatives
- achieve cost-effectiveness in terms of improved outcomes (e.g. independence, return to work, quality of life) and prevention (e.g. reduced re-admissions to hospital or admissions to residential care)
- reduce risk of physical or psychological harm to person or others
- reduce relationship or family breakdown.

There are constant time pressures in routine clinical work that make it difficult to put together funding proposals. One thing that would help would be funded research facilitators to work with clinicians to enable this kind of work to be systematically investigated. A specific research call to investigate community rehabilitation and support would also be beneficial. It is also important to attend to the right scale of research as UK studies on TBI are mainly very small scale, rather than European-scale research as happens with other conditions.

Good support for living well – the principles

Make sure that activities have purpose

Like everybody else, most people with brain injury want to feel that their lives are rich, and that they are constantly developing in one way or another. No one wants to feel that they are stagnating. Some local voluntary groups have tackled **tracking outcomes thoroughly, with clear assessment/planning processes and good reviews** involving users and carers; others are just at the beginning of recognising this issue as important. Most voluntary groups make real efforts to work with people with brain injury to get their view of what they find most worthwhile and to try to provide it.

Don't withdraw support without checking other help is there

A complex pathway only counts as a pathway if the different elements join up. Otherwise it's an obstacle course. Much can be done to bring together acute, statutory and community services for people with TBI and their families. For example, over a period of years, one local group carried out pioneering awareness-raising work with statutory services, with the result that the group is now treated as a full partner in the provision of services to people with ABI. Another locality formed a cross agency Brain Injury Strategy Group which became a BI Service Network, operating through a BI Rehabilitation Protocol/Operational Policy. The network was cited as an evaluated example of good practice for Quality Requirement 11 of the National Service Framework for Long-term (Neurological) Conditions. Different models and approaches across the care pathway can be integrated too through service network meetings and professional training events.

There is also an integrative role for the regional rehabilitation service, which has the ability to interface across acute, rehabilitation, community and follow up settings and form links with patient support groups. At present, however, there is huge variation in this activity across the country.

Pay as much attention to mental, emotional and social needs as to the physical

In the course of the PublicServiceWorks inquiry, local groups emphasised the importance of emotional and psychological support, as well as more visible rehabilitation. A member of staff commented: 'We never used to talk about this and it's so important.' Peer and community support have a significant role to play. In one specialist rehabilitation centre, for example, prospective clients are encouraged to spend time with current clients from the very outset. The rehabilitation programme offers scheduled events to promote peer and community support – for instance, a daily community meeting, a weekly peer support group, scheduled opportunities to meet former clients, family days at key points in the programme, a regular service user group. Clients also frequently socialise outside the rehabilitation setting.

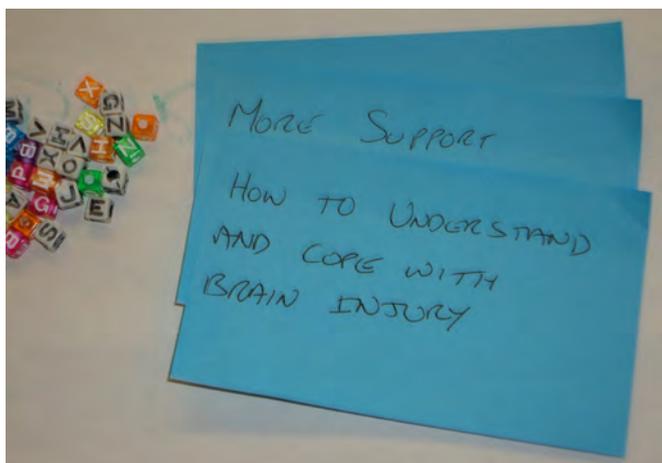


So what? Make your mark

1. In your experience, what example of support and rehabilitation would you pick out as involving 'true collaborative effort'? How might this example be built on?
2. In your area of responsibility, what opportunities are there for introducing constructive work-related activities into support and rehabilitation?
3. What practical action might you take in relation to the three areas highlighted under the heading, 'Good support for living well – the principles'? How would you judge whether these steps are effective?
4. What steps can you take to ensure that current and potential service users help to identify what is important to them, and build on this in a creative way?



Group discussion held during the PublicServiceWorks inquiry.



Priorities from group discussions in PublicServiceWorks inquiry.

Section 4

Securing widespread access to effective social support and rehabilitation

This section outlines the threats and opportunities associated with securing effective social support and rehabilitation for TBI survivors. Some key tensions are explored and discussed, including the potential re-direction of resources to achieve effective rehabilitation. If a 'true collaborative effort' is to be achieved, different agencies and organisations need to play linking roles: the nature of these roles is examined in practical terms for commissioners and for service providers, including community and voluntary organisations.



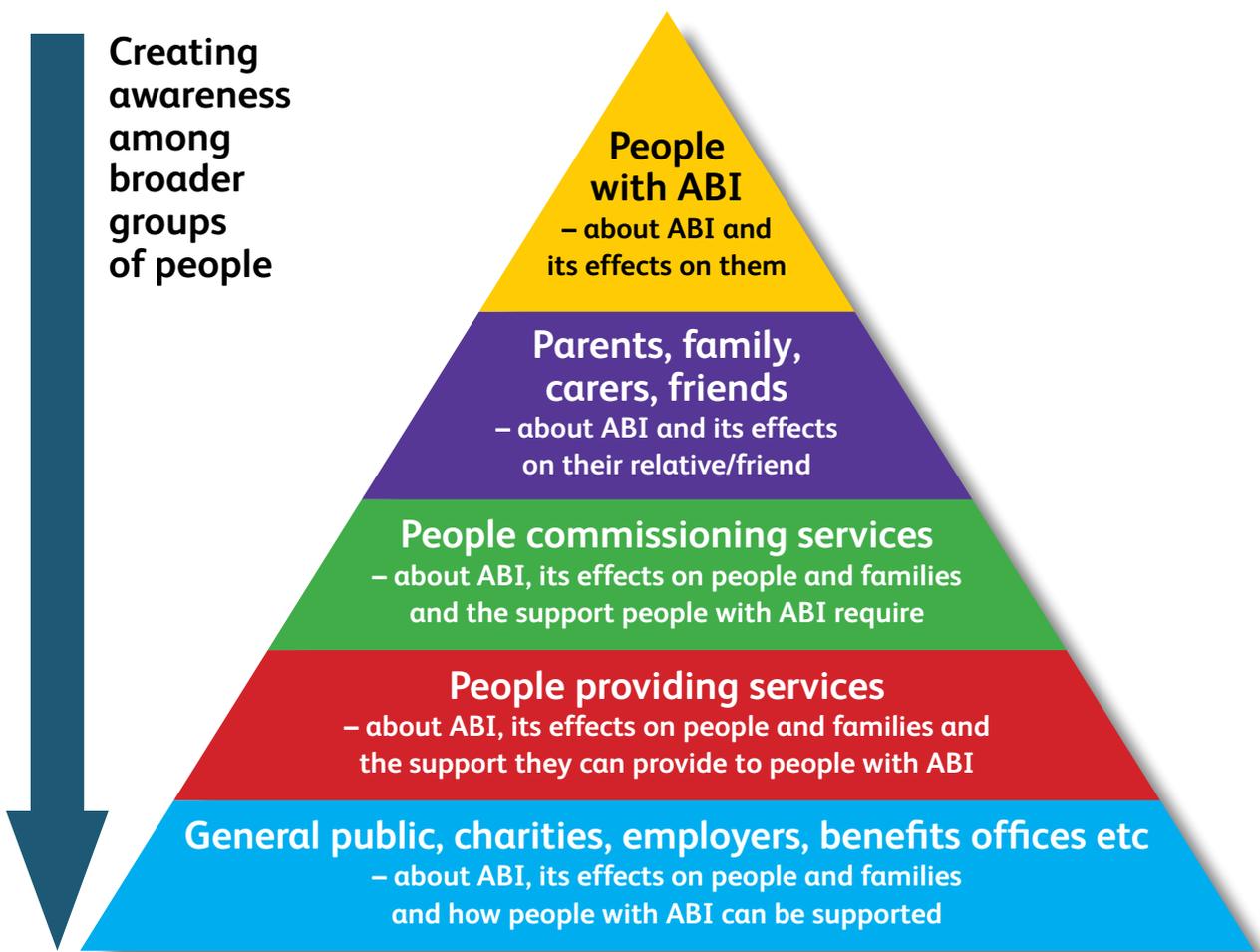
Artwork created by Vicky, at Headway East London

Identifying threats and opportunities

Section 2 outlined broad trends in the care of people with TBI, and pointed to some of the potential implications of these trends. In particular, it was noted that, as the length of time people spend in acute care is reduced, so the need for short and long-term support in the community becomes more pressing. It is a sombre fact that, as this need becomes more and more obvious, the climate of austerity in the public sector becomes, if anything, more pronounced; and systems of care become increasingly fragmented.

Section 3 looked at how active and imaginative collaboration across professional and other boundaries can build up a network of support that will enable people with brain injury to live well, and contribute to the wellbeing of their families. Collaboration of this kind, of course, requires funding, and one of the topics of this section is the potential re-direction of resources to better achieve the core aims.

A basic threat identified by respondents and interviewees of all backgrounds, and touched on in previous sections, is the **widespread lack of awareness of brain injury and its effects**. Health and care professionals, it seems, are often as unaware as the general public in this respect. The following diagram summarises the need for awareness raising among different groups.



In discussion with local voluntary groups, there was overwhelming support for the idea of a national publicity drive that shed light on the nature and effects of brain injury and also created awareness of the value and professionalism of voluntary sector responses to this condition. There was a parallel concern to gather evidence and build it into a recognisable 'model' of care/support for those with brain injury. This latter concern meshes readily with the desire, reflected in earlier sections, to find a common language in which to talk about rehabilitation for people with TBI. The ICF framework perhaps offers a useful starting point for this endeavour.

Reflecting on threats and opportunities in the external environment can usefully direct the attention of organisations and individuals to relevant strengths and weaknesses that they identify in themselves. The interaction between external and internal is often experienced as tensions and dilemmas. As with much research, the PublicServiceWorks inquiry highlighted a series of tensions that are visible in how people view their situations – and that therefore must be managed for success.



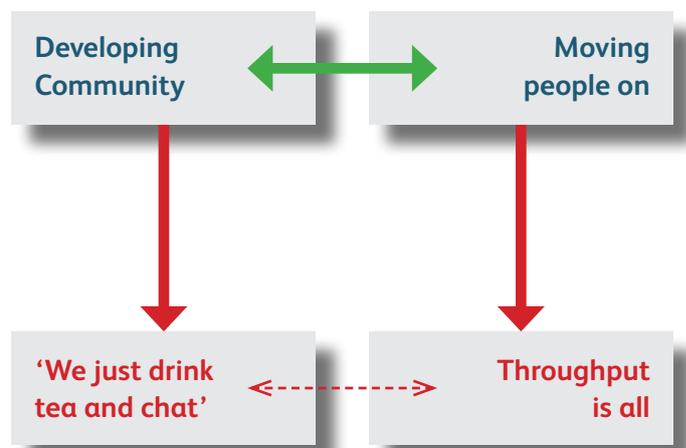
Artwork created by Brian Searle, at Headway East London

Confronting issues and dilemmas

The tensions identified in the inquiry are *paradoxes* i.e. **they are not choices, but both elements must be addressed** in a thorough-going way – tackling one or the other skews the situation and can lead to severe negative effects.

Developing community vs. moving people on

The local groups participating in the research were clear that the overall objectives are about rehabilitation and ‘moving people on’, helping them rejoin the community. Similarly, commissioners of services stress the need to achieve tangible outcomes for individual clients. At the same time, what people with brain injury value most about local groups is the sense of community, often in stark contrast to their experience of the ‘outside world’, and local groups do a great job of nurturing this. However, both elements are needed or things can degenerate as shown in the red areas of the figure opposite.



The following quotations give vivid expression to some of these tensions:

‘I’ve heard from social services about my son. Is he improving? Isn’t he improving? If he’s not improving, we’ll stop his money.’ (parent)

‘We need to track users’ progress and measure the impact of interventions and activities. Unless you have evidence-based practice, you’re not going to get the support of funders. We need to move much more in this direction. People don’t see the benefits sometimes – we meet, we have tea, there’s a speaker; and it doesn’t seem like much.’ (staff member)

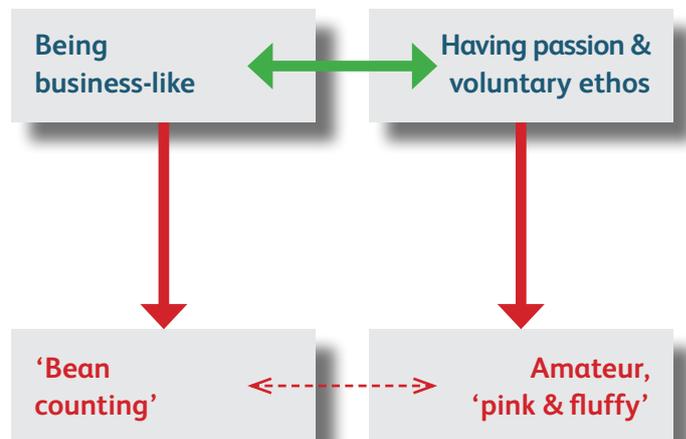
From the client’s point of view, the priorities are often: memory; other people don’t understand; can’t organise my life or solve problems. A specialist commented, ‘When individuals start to accept that they have a problem and want to move forward, that is the time to start encouraging them more but I personally start when I meet them by telling them that things change on a daily basis and that, with support, they can take control of their future’. Another stressed the importance of systematic assessment of all elements of the person’s life and situation by working with them and their family. But the same person also stressed the need to keep connected to people even if they don’t engage at first:

‘If we know in advance that someone is reluctant to engage with our service, we may telephone them or invite them for an informal visit or visit them at home to explain our services. If someone attends for assessment but is then reluctant to engage we are likely to adopt a light touch approach with limited assessments/interventions, gradually increasing input in line with increasing engagement. If someone does not engage initially we will maintain contact with them and/or leave the door open for them to engage later, as and when they are ready.’

Being business-like vs. having passion and a voluntary ethos

The changes in the external environment are driving charities and other voluntary organisations into an ever more business-like or ‘professional’ approach, compared with the passion and voluntary sector ethos many start(ed) with. Again, both elements are vital, and the question remains what will help people stay on the top line of the figure opposite and avoid the negative forms of the tension.

Developing the kind of community-based, long-term support discussed in section 3 requires community and voluntary groups/organisations to take this tension seriously: to appreciate and work to the business demands of those who commission them and take deliberate steps not to lose the passion for the clients that motivates them in the first place.



Making a positive difference

The PublicServiceWorks inquiry had at its heart the fundamental question that exercises many funders and grant recipients: ***how can we create the maximum positive difference to the lives of people with TBI? And in the current context: how can we do this in a difficult economic climate?***

The different agencies and organisations involved in creating the system surrounding people with TBI and their families all have different, but linking, roles to play in ensuring that support is there when it is needed. All these roles call for willingness to confront complex issues in an open-minded way, and to engage in ‘true collaborative effort’. Taking this requirement seriously will make a huge difference.

The role of commissioners and funders of services

The PSW inquiry found a widespread belief among workers in local voluntary groups that commissioners of services are largely unaware of the needs of people with TBI and their families. For example:

‘Disability charities are at the bottom of what funders will fund, ABI is at the bottom of that because it’s not generally understood’

‘ABI is such a tiny part of the commissioning world’

What is probably less well understood is **the complexity for commissioners of thinking through the implications of planning care for high cost, low volume populations with heterogeneous needs**, such as people with brain injury. Health and welfare economics need to be considered as well as person-centredness and choice. A clear overarching challenge for commissioners lies in the cost of meeting the needs of this small group of high need individuals when budgets are being squeezed ever tighter. Commissioners must be able to evidence that they are getting value for money and justify what appears to be a huge cost when measured against other services.

How can these challenges be met? Two issues stand out:

- Commissioners need to develop a full understanding of the complex needs and aspirations of people with TBI
- Providers of services need to plan and present their offers with great care.

Tackling these two issues effectively involves identifying the more specific challenges underpinning them and pursuing these, working in partnership wherever possible, at different levels, from national to local. Challenges of this kind are outlined below.

Who are the commissioners?

Both commissioners and providers of services have identified problems caused by complexity and fragmentation in the system. For example, in some areas, services can be commissioned by a plethora of clinical commissioning groups, city councils, county councils and borough councils, plus region-wide specialist commissioning – with no consistency in the way in which these commissioning structures are organised. Providers have to get to know how responsibility/ funding are split between different agencies in their areas – and keep up to date with the shifting portfolios of commissioners. Building connections with them can also benefit the commissioners themselves, since they are often commissioning across a large swathe of services and many are in new roles following the changes in April 2013 in England.

What do commissioners want – for people with TBI and themselves?

Earlier sections have discussed the substantial costs likely to be involved in not providing rehabilitation opportunities to people with TBI. To achieve best value for money, however, it is essential to think carefully about the goal of rehabilitation and beyond, with a clear eye on what those involved are trying to achieve. As was indicated earlier, there is no one simple pathway for this condition, but there are real opportunities to devise integrated plans to meet physical, mental, emotional and social needs. Systems and processes need to look after the whole person. In particular, they need to:

- Include the social model – especially as regards participation, in order to avoid a gap between impairment-based treatment and participation-based activities.
- Be set up round client goals, self-determination, and the person framing their own identity. In most circumstances, a resource/ facilitation model is useful – where experts support patients in achieving their own goals.
- Aim for continuity of care: along with integrated plans of the kind described above, this can only be achieved if consistent approaches are taken to case management and there is genuine integration of budgets – ensuring, for example, funding for assessors who have experience of hidden injury.

How best to make the case for a small group of people with wide-ranging needs?

Partly because of the hidden nature of much brain injury, along with the gradual emergence of subtle effects over time, it is difficult to get a true picture of the numbers of those directly affected. Those indirectly though significantly affected, like family and friends, remain largely uncounted. As the time spent in acute care diminishes because of clinical advances in treating TBI in the immediate aftermath of the injury, the need for medium and long-term support within the family and community is increasing. The community and voluntary sector (see below) has an important role to play in advocacy and campaigning for social and community support. For their part, commissioners are willing to offer guidance on how to lobby effectively in the current challenging context, with respondents suggesting:

'Make sure you are addressing the user group the commissioner is concerned with; refer to the evidence base for what you are offering.'

'Help us to understand how the service can support an integrated pathway with other providers.'

'Use local contacts to gain an understanding of current pathways so any approach has a realistic suggestion of how the service would improve on the current offer.'

'Be aware that additional investment means a reduction in investment elsewhere, so improved efficiency or cost-saving e.g. through a preventative approach is a necessity for any proposal.'

What about specialist commissioning?

Specialist commissioning exists to meet the needs of what is, in this case, a comparatively small group of people. These individuals have a high impact on services if something goes wrong – for example, problems with unemployment and alcohol and drug misuse where there are unmet needs for mental, emotional and social support. It is important therefore that Specialist and Primary Care Commissioning Leads work closely with agencies and organisations who, between them, offer a range of possible sources of support.

The role of providers of services, including support groups

As many providers of services are aware, and as discussed above, there is now a pressing need to take into account the requirements of commissioners of services, as well as those for whose benefit the services are being commissioned. That said, the words of one experienced local community worker are worth heeding: *'Why on earth would anyone want to pay good money for services that are neither needed nor wanted?'* In many cases, the needs of commissioners and of service users are not nearly as far apart as is sometimes suggested.

Providers of services may find it useful to review their offering in light of current policy directions. For example, 'on-going rehabilitation' might be re-framed as 'self-management of a long-term condition.'

Providers of services can also usefully collaborate over 'stepped' provision for TBI survivors. The goal is to assess and work together to meet the needs of TBI survivors across the spectrum, from those at one end who are fairly able and those at the other end who are left with severe deficits. This approach can be very effective. It is worth noting, however, that the complexity of conditions in this field can result in some significant symptoms being missed by those without specialist training. For example, people may be prevented from participating in group activities because of a subtle deficit of cognition that could benefit from specialist input. For this reason, **the closer the collaboration between different kinds of provider, the better the outcome is likely to be for the client.**

What other actions and strategies by providers could help to achieve continuity of care? Highly recommended is **the combination of proactive GP monitoring and a TBI care coordinator** whose role is to monitor the on-going progress of each person treated at a regional trauma centre, with regular audits of the pathways followed. One area has a Brain Injury Specialist Community Practitioner post that provides a vital link between community brain injury service and acute hospital services, the in-patient rehabilitation unit and nursing/residential care homes.

As indicated above, **voluntary organisations and local support groups** – representing the third sector – have an important advocacy/campaigning role as well as a delivery one. They are in an excellent position to use their experiences, perhaps re-framed as **case studies that illustrate the impact of lower cost/'low tech' solutions on wider health and social well-being.** For example, they might want to demonstrate how access to a community cafe where someone can be themselves 'unconditionally' might reduce trips to the GP. It would be good to see this sort of evidence from a consortium of third sector organisations representing a range of health and social care groups to illustrate the common ground and draw on best practice from a range of settings.

The PublicServiceWorks inquiry found that local groups were keen to share and develop learning, especially in relation to **communicating about what works and to innovating in raising awareness of TBI and developing services for TBI survivors**. They also expressed the desire to explore together how to make progress in:

- Funding what we do in difficult times
- Supporting people and helping them ‘move on’
- Working out how we know (and demonstrate) what difference we make.

What about other, non-statutory funders?

Of course for many providers, especially in the community and voluntary sector, the role of grant-making trusts, large and small, is crucial. Such trusts could usefully focus their funding criteria in this arena on any of the priorities and issues discussed in this section. It may be especially helpful to consider funding **solid evaluative work focused on community-based rehabilitation/support**, or to enable local groups to **fund work to track and measure outcomes** themselves. But it is equally valid for such funders to focus on offering support for activities and opportunities that the statutory sector may not be able to fund. These may include a **focus on enterprise and work, out of hours contact, more therapeutic services, meeting transport needs**. In many areas, the contraction of statutory funds also means other funders may need to consider core funding for groups simply to be able to continue – in the arena of TBI, keeping **continuity and connection** with this isolated group is critical.



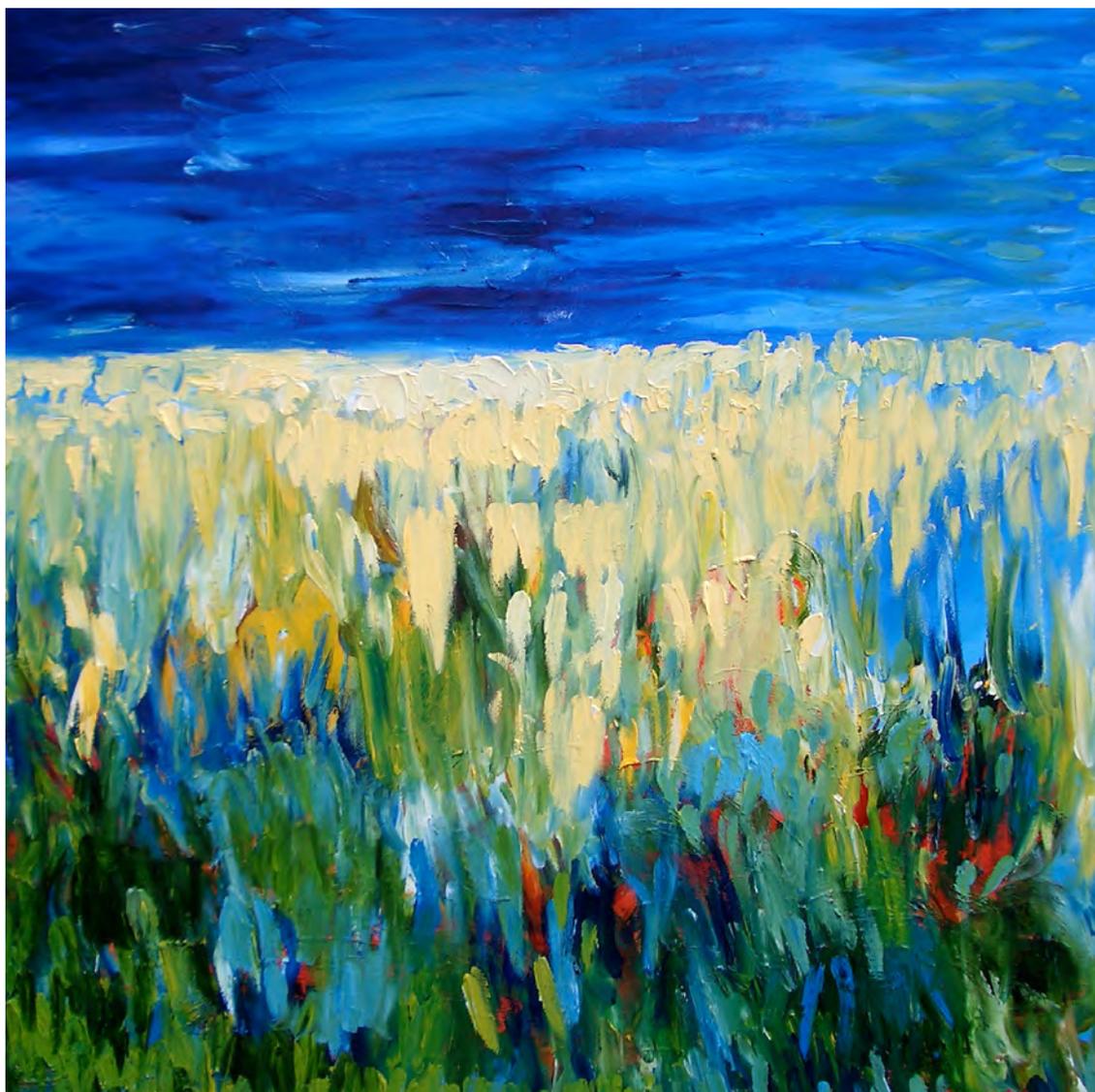
So what? Make your mark

1. Which of the issues discussed in this section have most resonance for you, and why? How might you manage the tensions more effectively?
2. Have you come across, or expect to come across, cases where care has been interrupted by clashes between different sources of funding? Who needs to be involved in preventing such clashes in the future?
3. How might you and your organisation further develop collaborative effort to enable effective rehabilitation and support for TBI survivors and for the wellbeing of their families? What immediate steps could you usefully take?

Section 5

Further sources of information

This section aims to provide a quick link to core material and sources of information as well as an introduction to key elements of the evidence base. It is organised into: **useful websites; relevant publicly accessible reports/publications; academic research articles.**



Artwork created
by Michelle,
at Headway
East London

Useful websites

Acquired Brain Injury Ireland

www.abiireland.ie

Acquired Brain Injury Ireland [formerly The Peter Bradley Foundation] is Ireland's leading provider of flexible and tailor-made services for people with an Acquired Brain Injury (ABI).

Brain-nav

www.brainnav.info

This website has been created to assist people with brain injury to find the right service at the right time on their journey through rehabilitation and beyond. At present this is a directory for brain injury services in England.

Buckinghamshire Brain Injury Network

[www.buckshealthcare.nhs.uk/Our clinical services/A to Z of clinical services/chis.htm](http://www.buckshealthcare.nhs.uk/Our%20clinical%20services/A%20to%20Z%20of%20clinical%20services/chis.htm)

The setting up of the brain injury service network was supported by a brain injury professional training programme, as well as quarterly network meetings. Community Head Injury Service Steering Group is now expanded to address interfaces with other services through inclusion of representatives from relevant health, social & voluntary services, as well as client and family representatives. The network, along with client/family representatives on steering group, an individual goal planning system and annual client/family feedback exercises, helps to maintain a person and family centred approach.

Headway: the brain injury association

www.headway.org.uk

Through a range of frontline services run from its Nottingham base and via a network of more than 100 groups and branches across the UK, Headway provides support, services and information to brain injury survivors, their families and carers, as well as to professionals in the health and legal fields. The website offers information, publications and statistics about brain injury.

The following Headway groups contributed to the research in this publication by hosting discussions with people with TBI, families/carers, staff and volunteers:

- **Headway Dumfries & Galloway** www.headwaydg.org
'Headway is the only specialist service for people with acquired brain injury across the whole of Dumfries & Galloway, and offers a variety of services to adults and children who have sustained a brain injury, their families and carers.'
- **Headway East London** www.headwayeastlondon.org
'Headway East London specialises in creating personalised support services and programmes for people with an acquired brain injury. We are a person-centred organisation, so instead of telling our members what to do, we ask what's important to them and work from there.'

- **Headway East Lothian** www.headway.org.uk/branches/east-lothian.aspx
'Headway East Lothian aims to support and improve quality of life for people in East Lothian with Acquired Brain Injuries, their families and carers.'
- **Headway Nottingham** www.headway.org.uk/branches/nottingham.aspx
'Headway House in Nottingham was founded in 1996 by carers and people with brain injuries. The centre provides a diverse range of social, leisure and educational activities. The outreach service offers practical support to families, supporting people to come to terms with the change in lifestyle following brain injury.'
- **Headway Preston & Chorley** www.headwayprestonandchorley.com
'We aim to provide a wide range of support to meet the individual needs of people with an acquired brain injury, their families and carers and promote awareness of acquired brain injury by means of information, advice and training throughout our local community.'

North Wales Brain Injury Service (NWBIS) www.wales.nhs.uk/sitesplus/861/page/51758

The NWBIS is a community-based, multi-disciplinary team, providing outpatient rehabilitation for persons with acquired brain injury. It forms part of Specialist Services within the Mental Health and Learning Disability Clinical Programme Group of Betsi Cadwaladr University Health Board. The NWBIS provides assessment and longer-term, low intensity rehabilitation and review within the community.

Oliver Zangwill Centre for Neuropsychological Rehabilitation (OZC) www.ozc.nhs.uk

The Centre is part of Cambridgeshire Community Services NHS Trust. 'We provide high quality rehabilitation for the individual cognitive, social, emotional and physical needs of people with acquired brain injury. The Centre offers a unique (to the UK) holistic and intensive assessment and therapy programme'.

Scottish Acquired Brain Injury Network www.sabin.scot.nhs.uk

The National Managed Clinical Network (NMCN) for Acquired Brain Injury (ABI) is a Scottish National Network established by the National Services Division (NSD) in 2007. Its aim is to improve access to and the quality of services for children and adults with Acquired Brain Injury (ABI).

Society for Research in Rehabilitation www.srr.org.uk

A multidisciplinary society of about 500 members, the society is the major rehabilitation research society in the UK. Its aim is to advance education and research into all aspects of the rehabilitation of people with disability and to disseminate the useful results of such research for public benefit.

St Andrew's Healthcare Charity, Northampton **www.stah.org**

St Andrew's brain injury service comprises the National Brain Injury Centre housed at the Kemsley unit and Berkeley Close, a step-down community-based facility providing safe longer term care. Developments have included Berkeley Lodge, which opened in Spring 2009, which provides the link between care and independent living. In addition, a Brain Injury Service for Young People opened in early 2011. The Charity caters specifically for service users who present highly challenging behaviour as a result of their injury and focuses on their self-management and ownership of the condition.

UK Acquired Brain Injury Forum **www.ukabif.org.uk**

United Kingdom Acquired Brain Injury Forum – 'giving a voice to ABI' – aims to promote understanding of all aspects of acquired brain injury (ABI). 'Our priorities are to educate, inform and provide networking opportunities for professionals, service providers, planners and policy makers and to raise the profile of ABI and campaign for better services in the UK. Our website works as an information and signposting resource.'

www.scoop.it/t/neurorehabilitation-and-outcome-measurement

A blog site curated by a leading professional in the field from the Oliver Zangwill Centre.

www.healthtalkonline.org/Disabilityandimpairment/experiences_of_life-changing_injuries

An online information and story sharing resource for survivors of traumatic injuries in London, including TBI. It is multimedia and includes text, audio and video components, all generated by qualitative research methodologies.

Relevant publicly accessible reports/ publications

Bernard, S., Aspinall, F., Gridley, K. and Parker, G. 2010 *Integrated Services for People with Long-term Neurological Conditions: Evaluation of the impact of the National Service Framework, Final Report, SPRU Working Paper No. SDO 2399*. York: University of York, Social Policy Research Unit. Available at <http://php.york.ac.uk/inst/spru/research/summs/ltnc.php>

The National Service Framework (see below) was evaluated in 2010 by the team at SPRU in York focusing on continuity of care as a proxy for concept of integration which the NSF aspired to create. The research concluded that:

- **‘day opportunities’** i.e. peer support, social and leisure opportunities, as well as access to meaningful activity and/or learning and employment opportunities were a best practice model that provide a focal point for care coordination as well as supporting people to build confidence and enjoy social activities. ‘For many people, these services were key to maintaining quality of life and feeling like a valued, valuable member of society.’
- **care co-ordination** is central to continuity of care.
- specialist expertise in long-term neurological conditions was common to those services valued most by people using them.
- **voluntary sector organisations**, particularly those with a focus on specific neurological conditions, were central to the delivery of continuity of care in the best practice models they found.
- **timely access** to valued services, intervention and support was central to the experience of continuity of care but ‘was frequently compromised in a number of ways, including a lack of local availability or capacity of services, restrictive eligibility criteria, referral anomalies and pathways that were ill-defined and unclear to people with LTNCs and professionals.’ Many PCTs had not got proper plans to implement the framework thus limiting access.

Department of Health 2009 Rehabilitation of major trauma patients DH QIPP report www.evidence.nhs.uk/qualityandproductivity accessed 15/10/2013

This report outlines the impact of a project to improve rehabilitation efforts in hospitals for trauma patients including those with TBI.

Department of Health 2005 National Service Framework for Long-term Neurological Conditions. Available from www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-term-conditions

This aimed for integration of services but did not provide for resources to support this. It specifically set quality requirements for longer term rehabilitation:

- People with long-term neurological conditions living at home are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish.
- People with long-term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support, to enable them to find, regain or remain in work and access other occupational and educational opportunities.

ERABI Canada 2012 *Evidence-Based Review of Moderate to Severe Acquired Brain Injury Exec Summary*. December available from www.abiebr.com

This group, established for 8+ years, aims to synthesise evidence on ABI rehabilitation. For this latest summary 772 articles were carefully analyzed and summarized, 30,000 titles reviewed over the 8 years. Of the 772, 178 were Randomised Control Trials specific to rehabilitation. The paper uses accepted scientific methods of reviewing and rating research material. It offers a large range of evidence on different interventions and some wide ranging conclusions e.g.

- insufficient evidence to draw any conclusions regarding the ideal structure of a complete model of ABI care
- some evidence for the positive effects of community-based rehabilitation programs that use a peer or supported relationship model
- structured multidisciplinary rehabilitation in community setting can improve social functioning
- rehabilitation issues regarding communication and employment are present years post rehabilitation

Gridley, K., Brooks, J. and Glendinning, C. 2012 *Good support for people with complex needs: What does it look like and where is the evidence? Research findings*. NIHR School for Social Care Research. York University available at <http://php.york.ac.uk/inst/spru/pubs/2225>

This summary reports on research that included a literature review from 1997 on the UK and consulting experts in the field. They concluded that people with complex needs value person-centred support, typified by the availability of time to get to know a person and flexibility to manage changes in circumstance – but no robust evidence was found in support of any particular approach. In general there is a dearth of evidence about the outcomes and costs of models of social care considered good practice for people with complex needs. The most robust evidence of effectiveness related to four different models of organising services: a multidisciplinary specialist team; intensive case management; specialist social work; and inter-professional training. Experts also argued strongly for on-going contact with a key worker or case manager with specialist knowledge. SPRU recommends urgent rigorous evaluation of models of support for people with severe and complex needs, with comparison groups and clear reporting of costs and outcomes.

National Collaborating Centre for Acute Care 2007 *Head injury: Triage, assessment, investigation and early management of head injury in infants, children and adults*. NICE guideline 56 available at www.nice.org.uk/cg56

While the guidance does not address the rehabilitation or long-term care of patients with a head injury, it does explore possible criteria for the early identification of patients who require rehabilitation and recommends patients are given information on community support services on discharge e.g. on advice cards.

O'Connell, B. 2010 *Community Rehabilitation for People with Acquired Brain Injury – An Irish Model: Innovative, Collaborative and Value for money*. Acquired Brain Injury Ireland (formerly Peter Bradley Foundation) Presentation to National Disability Association Conference Eire October. Available at www.nda.ie/website/nda/cntmgmtnew.nsf/0/9BD10A7EEBC8080F802577D8003B61F8?OpenDocument

ABI Ireland has 15 clinically supervised accredited Home and Community Outreach Services in four geographical regions specialising in services for people with ABI. The presentation concludes:

‘The challenge today in times of very scarce resources is to look at new and innovative ways to respond, to move from segregated wrap around service delivery to integrated and collaborative working maximising all available supports to meet the individual needs in a person centred approach. Using one point of contact to bridge the fragmented care pathways which exist within our health service. The model used by Acquired Brain Injury Ireland has many transferable components to services for people with other disabilities. Above all we have to measure outcomes to prove efficiency and effectiveness and value for money.’

RIPFA 2007 *Evidence cluster’ paper on Acquired Brain Injury Dartington, Devon.* Available at www.ripfa.org.uk/resources

RIPFA (Research in Practice for Adults) promotes the use of evidence-informed policy and practice in adult social care. Its papers draw on published research to sum up the evidence for practitioners. This paper comments that evidence for TBI is ‘a somewhat murky picture. The majority of the literature is medically based, with very little focus on social care interventions’. The lack was especially marked in relation to people with TBI themselves commenting, to issues of return to work and to being supported in your home. The following conclusions are drawn:

- lack of consensus about appropriate treatment
- little evidence with regards to intensity of intervention, however, there is nothing to suggest that there is a ceiling effect
- clear evidence is available identifying family needs for: information, effective communication, emotional support, respite, maintenance of hope
- little is known from the perspective of the person with ABI but evidence to suggest they experience difficulties with self-awareness; as a consequence services may need to be pro-active in building relationships
- employment that is meaningful and productive can lead to many benefits and enhance recovery
- some evidence that it is possible for people with even the most complex ABI to live in their own home given support

Wilson, B. A., Winegardner, J. and Ashworth, F. 2014 *Life after brain injury: survivors’ stories.* Hove: Psychology Press.

The authors present an up-to-date compilation of stories from people with TBI, a unique resource. They say: ‘There is plenty of evidence to show that comprehensive neuropsychological rehabilitation is clinically effective. ... for example, ... such programmes can improve community integration, functional independence and productivity, even for patients who are many years post injury’ (p3)

World Health Organization 2002 *Towards a Common Language for Functioning, Disability and Health: ICF The International Classification of Functioning, Disability and Health* Geneva: WHO www.who.int/classifications/icf/training/icfbeginnersguide.pdf accessed 15/10/2013

This offers a helpful model of disability that integrates health and wellbeing to provide a common framework for professionals and others working with people with TBI.

Academic research articles

Boschen, K., Gargaro, J., Gan, C., Gerber, G. and Brandys, C. (2007) 'Family interventions after acquired brain injury and other chronic conditions: A critical appraisal of the quality of the evidence' *NeuroRehabilitation*, 22, 19-41

This Canadian review comments on the lack of 'strong research evidence supporting any specific intervention method for family caregivers of individuals with ABI ..., although an abundance of anecdotal, descriptive, and quasi-experimental support exists. Authors call for 'rigorous evaluations of caregiver intervention effectiveness'.

Brown, D., Lyons, E. and Rose, D. (2006) 'Recovery from brain injury: Finding the missing bits of the puzzle' *Brain Injury*, Vol 20(9): 937-946

These researchers interviewed 24 individuals with brain injuries and identified three themes relating to how participants constructed their experience of brain injury: finding the bits of the puzzle; filling the holes of memory; and redefining the self.

Cattelani, R., Zettin, M. and Zoccolotti, P. (2010) 'Rehabilitation Treatments for Adults with Behavioral and Psychosocial Disorders Following Acquired Brain Injury: A Systematic Review 2010' *Neuropsychology Review*, 20: 52-85

Reviewed 63 studies and concluded that comprehensive-holistic rehabilitation programs offer the greatest overall improvement in psychosocial functioning. They comment too that the huge heterogeneity of patients and symptoms make overall conclusions hard to make across a range of studies with different groups involved. They call for more work that tackles behavioural issues post injury as this would have big impact on people with TBI and families.

Cicerone, K.D., Langenbahn, D.M., Braden, C., Malec, J.F., Kalmar, K., Fraas, M., Felicetti, T., Laatsch, L., Harley, J.P., Bergquist, J.T., Azulay, J. and Ashman, T. (2011) 'Evidence-based cognitive rehabilitation: updated review of the literature 2003 through 2008' *Archives of Physical Medicine and Rehabilitation*, 92(4): 519-30

This review identified 'substantial evidence to support interventions for attention, memory, social communication skills ...after TBI'. They reviewed 370 pieces of research including 65 randomised control trial type studies classed as high quality evidence. The researchers conclude 'there is now sufficient information to support evidence-based protocols and implement empirically-supported treatments for cognitive disability after TBI and stroke.'

Coetzer, R. and Rushe, R. (2005) 'Post-acute rehabilitation following traumatic brain injury: are both early and later improved outcomes possible?' *International Journal of Rehabilitation Research*, 2005, 28, (4):361-3

Coetzer, R. (2008) 'Holistic neuro-rehabilitation in the community: Is identity a key issue?' *Neuropsychological Rehabilitation iFirst*, 1-18

Coetzer, R. (2013) 'Traumatic brain injury: loss and long-term psychological adjustment' *Neuro-Disability & Psychotherapy*, 1(1): 96-107

These three studies stem from a body of work in the North Wales Brain Injury Service (NWBIS) 'focused on long-term slow stream community-based rehabilitation'. This is a multidisciplinary outpatient brain injury rehabilitation service with input from clinical neuropsychology, neurology, occupational therapy, social work, neuropsychiatry, physiotherapy, speech and language therapy, and rehabilitation assistants. The articles explore key themes for community-based rehabilitation with the following points emphasised:

- service users continue to report psychosocial improvements more than 2 years post injury, whereas their carers mostly do not
- long-term change, especially as regards identity and adjustment, is slow. So careful and less intense input over time may be more sensible, even in a rural area where much time is inevitably spent travelling to places in the community, including people's homes – they conclude this is a price worth paying.
- focus on the emotional impact of disability and lack of capacity including notions of grief and bereavement and the importance of a notion of 'post-traumatic growth'.

Foster, A., Jonathan Armstrong, J., Buckley, A., Sherry, J., Young, T., Foliaki, S., James-Hohaia, T.M., Theadom, A. and McPherson, K.M. (2012) 'Encouraging family engagement in the rehabilitation process: a rehabilitation provider's development of support strategies for family members of people with traumatic brain injury' *Disability & Rehabilitation*, 34(22): 1855–1862

This New Zealand study focuses on families and carers and concludes family support should include: (i) early engagement, (ii) meeting cultural needs, (iii) keeping families together, (iv) actively listening, (v) active involvement, (vi) education, (vii) skills training, and (viii) support for community re-integration.

Hibbard, M., Cantor, J., Charatz, H., Rosenthal, R., Ashman, T., Gundersen, N., Ireland-Knight, L., Gordon, W., Avner, J. and Gartner, A. (2002) 'Peer Support in the Community: Initial Findings of a Mentoring Program for Individuals with Traumatic Brain Injury and Their Families' *Journal of Head Trauma Rehabilitation*, 17(2):112–131

This USA study concludes that areas of greatest reported impact for mentoring were in increasing participants' knowledge of TBI and in helping them cope with the consequences of TBI, such as overall ability to cope with TBI, quality of life, their general outlook, and their ability to cope with depression and sadness. Most participants stated that the program had little impact on increasing the social support they received from family, friends, and community. 'In this study, select aspects of empowerment (i.e. ability to cope) seemed to be more likely to be impacted by peer support than by others (i.e. control over one's life). These findings highlight the fact that the term "empowerment" may reflect a rather heterogeneous and multifaceted set of experiences.'

Rohling, M., Faust, M. Beverly, B. and Demakis, G. (2009) 'Effectiveness of Cognitive Rehabilitation Following Acquired Brain Injury: A Meta-Analytic Re-Examination of Cicerone et al.'s (2000, 2005) Systematic Reviews' *Neuropsychology*, 23(1): 20–39

This argues that 'future research should move beyond the simple question of whether cognitive rehabilitation is effective, and examine the therapy factors and patient characteristics that optimize the clinical outcomes of cognitive rehabilitation' (p. 1681).

Stergiou-Kita, M., Rappolt, S. and Dawson, D. (2012) 'Towards developing a guideline for vocational evaluation following traumatic brain injury: the qualitative synthesis of clients' perspectives' *Disability & Rehabilitation*, 34(3): 179–188

A study from Canada that focuses on return to work strategies for people with TBI. People they worked with prioritised the following issues: meaning of work; process of return to work and reconciling new identities; opportunities to try versus risks of failure; significance of supports. Key implications of their study are:

- incorporating clients' perspectives within vocational evaluation makes them partners in the process.
- clients' post-injury work goals, interests and motivations must be reviewed, as the meaning of work can change following traumatic brain injury.

- opportunities for experimentation with work activities, to facilitate clients' development of self-awareness and new self-identities are key.
- instrumental and emotional supports available to clients must be identified, to mediate challenges that may arise during return to work

Turner-Stokes, L., Disler, P., Nair, A. and Wade, D. (2005) *Multi-disciplinary rehabilitation for acquired brain injury in adults of working age (Cochrane Review)*. The Cochrane Library, Issue 3, 2005 (Reprint)

This review of evidence concluded that there was strong evidence that a group of patients with moderate to severe brain injury would benefit from high level intervention but there was a risk that they would not present themselves for rehabilitation without routine follow up. So for rehabilitation to reach those most in need, teams may need to be proactive in identifying appropriate candidates rather than expecting those with ABI to be sufficiently self aware. Also they comment 'there was no evidence of a ceiling effect in therapeutic intensity' (p11) in any of the studies they reviewed i.e. suggesting that specific hours/time limits for rehabilitation may be arbitrary.

Wehman, P., Targett, P., West, M. and Kregel, J. (2005) 'Productive work and employment for persons with traumatic brain injury: What have we learned after twenty years?' *Journal of Head Trauma Rehabilitation*. 20:2, 115-127

Wehman et al suggest that 'meaningful and productive employment can enhance recovery'. They identified two key factors influencing success: self-awareness and a job 'worth keeping'. They state that "it does appear that self-awareness and acceptance of disability clearly have an impact on employment outcomes" (p116). A job that was 'worth keeping' meant the availability of health insurance, opportunity for progression, social interaction and level of support. They also call for further longitudinal research into vocational rehabilitation to enable predictors of success to be identified, and for more research on employment outcomes for people with disabilities from minority ethnic groups, especially in relation to brain injury.

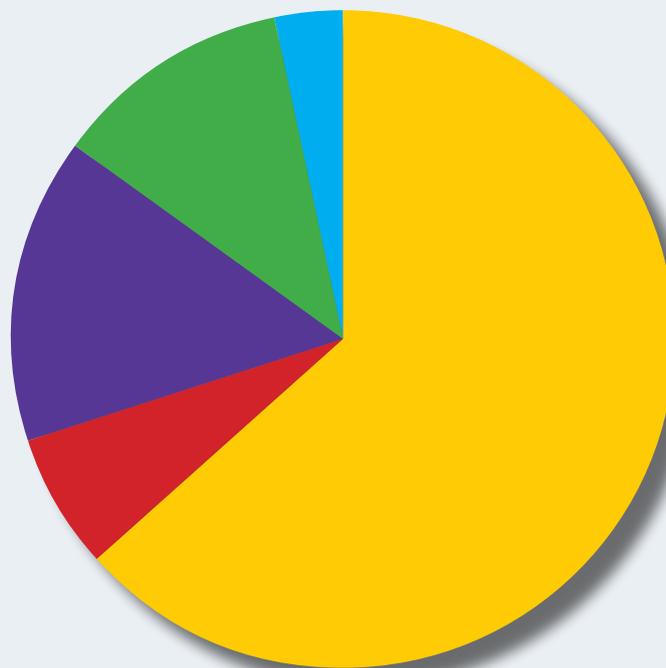
Annex: the approach to the inquiry by PublicServiceWorks for the Ajahma Charitable Trust

The PublicServiceWorks team worked in 3 phases on the inquiry:

- They carried out 17 interviews with the help of Headway UK and local Headway groups in different parts of the UK. Interviewees included with Headway staff, managers, volunteers and service users, and also key stakeholders from other organisations, such as commissioners and other charities.
- They took the themes from this work into discussion groups with people with TBI, carers/ family members, volunteers and local workers. Headway groups in Dumfries & Galloway, East London, Nottingham and Preston & Chorley kindly hosted sessions that involved 55 people in total. The chart shows a breakdown of who they were (NB several people combined two roles e.g. volunteer/person with a brain injury).

Group participant breakdown

- people with a brain injury (38)
- family members/carers (4)
- volunteers (9)
- paid staff (7)
- trustees/committee members (2)



- The emerging analysis was then developed through a literature review and the contribution of 10 experts in the field, from centres of excellence and/or practitioners in rehabilitation, through e-discussion and a mini 'Delphi' study.

Finally the text of this publication was reviewed by two critical readers from this group of experts.

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