

Rehabilitation and services for brain injured people.

*Who chooses what and why?
An Independent Case Manager's
perspective
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Aims:

- To look at how choices are made in relation to post acute services and to do this from an “independent” perspective
- To separate organisational and clinical need
- To provide case histories that illuminate this process
- To provide suggestions for the future

A personal reflection on what I have seen/been involved with over the years

But why is this important?

- ABI can be devastating, resource intensive, has wider impact for the non-brain injured community and families and is often invisible and hidden
- Health, criminal justice system, homeless services costs etc are dramatic and the person with the ABI is interfacing with non-specialist services poorly equipped to deal with the cognitive, executive, behavioural and emotional sequelae of ABI (*Oddy et al TBP, McMillan et al 2006 and 2011*)

Hwang research in Toronto in 2007 recorded that 58% of homeless shelter residents reported having had an ABI

BIRT and Oddy looked at this in UK, in Leeds and their research, due hopefully for publication in Brain Injury, recorded that 60% of homeless people interviewed reported having had an ABI and, importantly, 88% of them reported having had the ABI prior to becoming homeless.

McMillan's work is perhaps even more shocking, following a cohort that had an ABI in one year in Glasgow. This is a one year, 5 to 7 year and 12 to 14 year follow up. Not all has been published yet but the 5 to 7 year study has been published in the Journal of Neurology, Neurosurgery and Neuropsychiatry 2006 Of 475 survivors studied at one year, 115 (24%) had died by seven years. In survivors at 5–7 years, disability remained frequent (53%); and the rate, similar to that found at one year (57%). Sixty three participants (29%) had improved but 55 (25%) deteriorated.

The persistence of disability and its development after previous recovery each showed stronger associations with indices of depression, anxiety, and low self-esteem than with initial severity of injury or persisting cognitive impairment.

Conclusions: Admission to hospital after head injury is followed 5–7 years later by disability in a high proportion of survivors. Persistence of disability and development of new disability are strongly associated with psychosocial factors that may be open to remediation, even late after injury.

The 13 year study, as reported same journal 2011, was worse. The severity of head injury was not associated with survival outcome beyond the first year after injury. Even when head injury was classified as mild by the Glasgow Coma Scale, death rate was more than twice as high as in community controls.

Admission to hospital for injury (or factors associated with admission) contributed to a poorer survival outcome. Poorer survival outcome after head injury was related to factors associated with lifestyle prior to the injury (physical limitations, habitual alcohol excess and living alone) and to a history of mental health problems, as also reported elsewhere.

The particularly high rate of death in younger adults is important. Thirteen years after injury the death rate in those aged 15 to 54 years was more than six times higher than in community controls and this was not an artefact of gender or deprivation.

Beyond the early period of up to 1 year after injury, the death rate in those aged over 54 years did not exceed that found in community controls. The reason for greater vulnerability in younger adults is unclear but requires further consideration, especially given the particularly high risk of head injury in younger adults

And.....

- Frequently we are working with people and families with low trust of services, in a state of shock, denial, helplessness, lacking in insight, angry etc. (*Boss: Ambiguous Loss*)
- Sometimes we need to work in areas of conflict and with issues of capacity/safeguarding
- Is it cost effective to set rehabilitation up to fail?
- If a life is worth saving then it should be worth living perhaps?

Pauline Boss identifies the notion of living with this complex ambiguity of a person who is present but absent, having changed. I am certain that there is no person in this room who works with people with ABI who has not experienced the complexity of the emotional response of family members. Angry, depressed, delusional etc etc. Normal responses to an abnormal situation

Do you know your client and their family?

- If the answer is no, then how do you know their expectations, understand their communication, support them to define their role and their input?
- People, often in extreme distress, are not likely to work with you on what may be a lifetime of need, if you do not form this relationship. *(Prigatano and Kreutzer 2011 BIRT conference)*

Rehabilitation, bearing in mind we are talking about people regaining/relearning/adapting/adjusting is a process that involves a very strong emotional component. What would your response be to being removed from your life and placed away from home with strangers who are odd?

We are not purchasing hip replacements, company cars or establishing an IT contract. We are taking highly damaged family systems, with a huge number of unknowns and squeezing them in to services that will be more successful if they feel a part of, if they are allowed to develop relationships with.

Do you know the services?

- How? Hopefully not via promotional material alone.
- Have you visited? Are you up to date?
- Are you knowledgeable enough about ABI to recognise the differences in approach that are required for clients who present differently?
- Why are you going inpatient anyway?
Organisational decision? Experience shows that some very complex clients are better catered for outside of an institutional setting, particularly where they are confronted by others with an ABI.

Resources change. Bearing in mind what we know about how key the relationships between therapists and client/family it would be illogical to not expect that units would change in their effectiveness as key staff join/leave.

In the last eleven years I know of one unit that has gone from Nursing home with bells on top to good neuro rehab (physical emphasis but with behavioural interaction) back to being a nursing home. The name has not changed in this time and nor has what they state they can provide

We have two clients, one spent 11 years as inpatient, one spent 13, now both in the community, functioning far better, less medication.

Sometimes individuals and families need a period of community exposure to develop insight/increased understanding of need for rehab and input. How hard is it to access these services once discharged from the NHS system?

How can you establish clinical need?

- What process do you use to create this formulation? Has this assessment included post ABI experience of real life functioning, incorporating views and evidence of family and wide range of neuro-specialists?
- So what services does someone actually need, does the provider provide that, how can they evidence that and how will they work across disciplines and in preparation for change.
- What are the realistic expectations, what do you mean by post acute rehab, slow stream rehab, long term placement etc?

Bearing in mind people need to function, need to utilise what they have meaningfully, then a bland statement of 4 hours physio per week, 3 hours OT etc is meaningless. This is about organisational commissioning and not need. If for instance the goal is community reintegration then the physio/OT/Psychologist might need to be in the supermarket rather than the unit with the client

Experience shows that gains are slow, take work to sustain and are environmentally mediated. Client who has made more executive gains/learning in years 13 to 15 post ABI than the previous 13.

Funding.....

- Clinical need should form a significant part of establishing what resources are available to provide the requisite services (not vice-versa)
- Who is paying? What are their expectations? How “hands on” are they?
- How genuinely knowledgeable is your commissioner/funder?
- Is funding and the process of funding interfering with clinical need?

But it's much more complex than that.....

- It takes work to get people to rehabilitation/into services
- It takes work to keep them there
- It takes work to incorporate family/others in to this process
- The hardest part is transferring skills/structures to the next setting (no point in providing the service unless this is done, the unit cannot and will not do this alone)
- The wrong unit fails the client and therefore wider society and pins the blame for failure on the client; it's very easy to "prove" that it's the client that is wrong

And.....

- There actually is very little choice when it comes to units/services
- Experience leads me to believe that placements fail/are less effective without adequate bridging between settings. This is after all a complex, lifetime condition where poor insight/executive functioning is the norm.

So, some personal rules of thumb....

- The model of provision for learning disabled people is, generally speaking, wholly inappropriate for this client group.
- EMI units serve older people with dementia
- The less knowledgeable a unit the more likely they are to accept complex clients without question with inevitable consequences
- If you are being offered a cheap service for a complex person then it's the wrong service

LD staff interview poorly and do not pick up how to manage choices, failure of executive functioning/the interrelationship with emotion

Better to have bright staff without experience who can be trained and learn

UNIT tried to take behavioural client with no dialogue, no previous experience, no working experience of Neuropsychology/Neuropsychiatry but they had hoists in every room

Horror stories and happier outcomes

- “John”
- Yo-yo’ing between services as the underlying assessment was inaccurate and geography and finances took precedence
- Haliperidol, (*Fleminger BMJ 2003*) no specialist input, no maintenance of structures, no behavioural recordings, no medication recordings, no therapy staff, no understanding of impact of environment
- Basic health care needs not being met
- Going backwards. Unit chosen by geography. Working with family enabled them to understand clinical need trumped geography. With them on board, just the funders to convince.....

13 years of history.....

Using the law when appropriate...

- “Jane”
- A declaration of Best Interests sought from COP. SSD suggesting PD and LD units
- Statutory services arguing over geography. Initially refusing to accept responsibility, then arguing over diagnosis/need then failing to see that behavioural improvement requires input to maintain, client is environmentally “managed”

The wrong assessment is actively dangerous....

- “Bob”
- Lacking capacity to manage own health needs
- Ignored by statutory services for 4 years
- Very behaviourally difficult to manage. 2 x dangerous health conditions PLUS highly alcohol dependent
- After capacity issue was accepted, SSD offered LD unit that had no ABI experience and none of the health care provision that was essential for maintaining his life. It was closer to his family but they knew he required specialist ABI input

The good news is:

- That is is complicated, so our frequent communal failure is explicable.
- That we fail when we work alone, we achieve more when working with all parties, especially the client and their family. Not everyone wants to work with you, don't give them the choice.
- The brain injury is not going away so cohesive and joined up planning is more clinically and cost effective. Independent organisation of services can demonstrate that complex scenarios can be managed over the longer term and in the client's best interests.

But

- Decisions need to be based upon a detailed and skilled assessment of need.
- To do this you must know brain injury, must know the services, must know the client, must know their family and must be prepared to work with them AND the unit to make it work.
- We build in failure, frequently blaming the client/their family, if we do not do all of this.

So what can we do?

- Mix and meet, promote learning and sharing of knowledge.
- Collate information, research, lobby and raise the profile. The wider public will believe it is wrong to place people inappropriately.
- Recognise that our structures may be the greatest barrier to success. If we separate out clinical/organisational matters we can see the wood for the trees
- Form partnerships with the client/family, build in success, work to sustain positive changes and understand that it is the very condition that necessitates this.

A big role for Headway and organisations like this.

2 clients picked up 24 hours post injury. Reasonable outcomes (very cheap now), 11 years input, bridged all settings, worked with family at all points never a cross word. A sample of two, not good enough to extrapolate perhaps but.....