WRITTEN RESPONSE FROM THE BRAIN INJURY REHABILITATION TRUST (BIRT)

WELSH HEALTH SPECIALISED SERVICES COMMITTEE (WHSSC): REVISED DRAFT COMMISSIONING POLICIES FOR SPECIALISED REHABILITATION

BIRT executive summary

The Brain Injury Rehabilitation Trust (BIRT) is part of national charity The Disabilities Trust, providing support and rehabilitation for people with acquired brain injury, autism and physical disabilities. BIRT delivers clinically-led, specialist neurobehavioural rehabilitation across the UK for adults with complex and challenging needs following brain injury. In Wales, services are delivered at our centre in Llanelli, Tŷ Aberdafen.

The paper is an opportunity to open up the social nature of brain injury rehabilitation and we would ask that the policy involves:

- Plans for the many currently excluded from the policy, who may form a significant number,
- Involvement of the family,
- Discharge pathways and arrangements when funding runs out,
- Stated outcome measures, which include psychosocial outcomes

Many service users in BIRT go to level 2 and level 3 treatment centres. This is **not** because the service users presented with less complex rehabilitation needs, but because of the way that service levels are defined in terms of staffing within the BSRM and UKRoC scheme.

UKRoC consider services that are not led by rehab medicine consultants lower level. This seems to be defined by the background of the staff, rather than the need of the patient. Psychology is the specialist discipline for behaviour and cognition, and these needs are recognised at level 1. Therefore, Neuropsychologists and Consultant Psychologist should be considered on par to rehab medicine consultants for individuals presenting primarily with problems of a neurobehavioural nature (including cognitive impairment and behavioural problems).

The BSRM guidelines contemplate the provision of Level 1c service for mainly ‘walking wounded patients with cognitive/behavioural disabilities’. However, the Minimum Staffing provision for specialist in-patient rehabilitation service outlined in Annexe 2 only refer to services for ‘patients with high physical dependency (a) or mixed dependency (b). Staffing levels for level 1c services should be developed in conjunction with specialist providers of rehabilitation for those primarily with cognitive impairment and/or behavioural problems.

Estimates of the incidence of aggressive behaviour in acquired brain injury vary widely (11-96%; Tateno, George & Robinson, 2003), but a study from 2006 suggests that 25% of patients discharged from rehabilitation will present with aggression at various follow-up periods (6 to 60 months; Bagueley, Cooper & Felmingham, 2006).

Lynne Turner Stokes and colleagues (2015), in a Cochrane review on the effectiveness of brain injury rehabilitation on working age adults, concluded:

> As a whole, studies suggest that patients with moderate to severe brain injury who received more intensive rehabilitation showed earlier improvement, and that earlier rehabilitation was better than delayed treatment. Strong evidence supports the provision of cognitive rehabilitation in a therapeutic 'milieu', that is, an environment in which patients receive predominantly group-based rehabilitation alongside a peer group of others who are facing similar challenges. Trial-based literature provided little evidence related to other aspects of MD rehabilitation, so the review authors recommend that additional research should be done. Rehabilitation for brain injury is such an individualised and long-term process that research studies do not necessarily facilitate general conclusions.

It should be noted that 12 out of 19 studies which informed this conclusion were rated as being of ‘high quality’.

Baguley, I. J., Cooper, J., & Felmingham, K. (2006). Aggressive behaviour following traumatic brain injury: how common is common?. The Journal of head trauma rehabilitation, 21(1), 45-56.

Chung CSY, Pollock A, Campbell T, Durward BR, Hagen S. (2013). Cognitive rehabilitation for executive dysfunction in adults with stroke or other adult non-progressive acquired brain damage. Cochrane Database of Systematic Reviews, Issue 4. Art. No.: CD008391. DOI: 10.1002/14651858.CD008391.pub2.

Turner-Stokes L, Pick A, Nair A, Disler PB, Wade DT. (2015). Multi-disciplinary rehabilitation for acquired brain injury in adults of working age. Cochrane Database of Systematic Reviews, Issue 12. Art. No.: CD004170. DOI: 10.1002/14651858.CD004170.pub3.

Overview of WHSSC proposals

- Significant redrafting of 2013 version to improve clarity and remove duplication;
- Separation of psychiatric rehab. from the integrated policy;
- On-going funding linked to continued meeting of eligibility criteria;
- Incorporation of
    - BSRM guideline, and
    - Time limited initial referral.

The background for the paper says this policy sets out:

- when patients can use these jointly commissioned specialised services,
- where these services are located,
- how patients can be referred, and
- When patients cease to be eligible for funding under this policy.

To indicate the rehabilitation need that is eligible for this level of service and the features of the services, the policy uses the definitions and standards from the British Society of Rehabilitation Medicine (BSRM), noting that this is not relevant in all its details for the neuropsychiatric service

Following this BSRM guideline, this policy commissions services for patients with Category A rehabilitation needs to be delivered in Level 1 Treatment Centres.

Access to the specialist neuropsychiatric care

To be accepted in this centre the patient must:-

1. meet the criteria for category A rehabilitation need
2. Be deemed medically fit as assessed by specialised Multi-Disciplinary Team (MDT)
3. Be considered by the centre's MDT to have specific goals for assessment and rehabilitation that can be safely met in collaboration between the patient and MDT in that treatment centre
4. Be able to tolerate or participate in an intensive rehabilitation programme.
5. Not have major investigations pending, e.g. for non-traumatic conditions
6. Not have significant pre-morbid dementia
7. normally be over 18 years of age

BIRT services across the UK feature 15 in-patient neurobehavioral rehabilitation units, and over 60 community brain injury houses, flats or homes. Over 70% of our service users would be excluded from the level 1 neuropsychiatric service outlined in the document. Yet, our specialist assessments and 25 years of combined clinical experience suggest that these individuals are referred to us because they present with the most complex needs, which are difficult for other services to manage, just as outlined in the definition of the neuropsychiatry service.

Over 70% of our service users are admitted presenting with severe memory difficulties, they often have aggressive, agitated, or disinhibited behaviour, which is out of their control and volition. Studies indicate that sleep disturbance is frequent (67%) with up to 50% meeting the diagnostic criteria for a sleep disorder (Gardani et al., 2015). All present with high risk apparent in in dysexecutive behaviour when crossing roads, managing financial affairs, or having poor insight into their own disability in order to self-care to any significant degree.

A number of service evaluations have demonstrated that the neurobehavioural approach offered in BIRT services can significantly reduce long-term care costs, reduce challenging behaviour and improve the quality of life of the persons served. These findings have been replicated in three different studies (Oddy & Ramos, 2013; Wood et al., 1999; Worthington et al, 2006) and similar results are reported year-on-year on the Brain Injury Rehabilitation Trust Annual Outcome and Research Reports (http://www.thedtgroup.org/about-us/publications/brain-injury/).

In sum, your current revision continues to exclude some of the most complex patients with ABI who present lack of insight, very poor memory and attention, impulsivity and sexual inhibition and aggression. Your neuropsychiatric admission checklist leaves the growing number of ABI patients with co-morbid history of addictions, for example, unaccounted for.

Almost **all** of our service users cannot participate in goal directed neurorehabilitation upon admission to our services, as they require help in order to orientate and attend. They need constant and consistent prompts and 'scaffolding' to help them keep track of events and support decision making. They are often display irritable and aggressive behaviour, and sitting to have a 'normal conversation', such as in a structured session, could be stressful and counter-productive.

On admission, the people we serve would simply not have the cognitive and emotional ability to 'tolerate and participate' in their therapeutic goals. It is our clinical input that gradually supports regaining orientation and self-awareness, and progressively increases the ability to engage in much needed rehabilitation. Yet, the proposed criteria would exclude them.

We do note that an individual funding request can be made for any ABI patients falling outside the proposed criteria. However, in our view, our patients are in the main stream of ABI patients. Unwieldy special arrangements should not be required to ensure their needs are met.

Indictors of eligibility for the WHSSC commissioned specialised neuropsychiatric rehabilitation services

Moving on, you assert that the criteria for admission to a Level 1 neuropsychiatric rehabilitation service is as follows:

Category A rehabilitation needs:
Patient goals for rehabilitation may include:

- Improved physical, **cognitive, social and psychological function / independence in activities in and around the home**;
- **Participation in societal roles** (e. g. work / parenting / relationships);
- **Disability management** (e. g. to maintain existing function; manage unwanted behaviours / facilitate adjustment to change)
- **Improved quality of life and living including symptom management, complex care planning, support for family and carers, including neuropalliative rehabilitation**

- Patients have complex or profound disabilities (e. g. **severe physical, cognitive communicative disabilities or challenging behaviours**).

- Patients have highly complex rehabilitation needs and require specialised facilities and a **higher level of inpu**t from more **skilled staff** than provided in the local specialised rehabilitation unit. In particular rehabilitation will usually include one or more of the following:
    - **intensive, co-ordinated interdisciplinary intervention from 4 or more therapy discipline**s, in addition to specialised rehabilitation medicine/nursing care in a **rehabilitative environment**
    - medium length to **long term rehabilitation programme** required to achieve rehabilitation goals – typically 2-4 months, but up 6 months or more, providing this can be justified by measurable outcomes
    - very **high intensity staffing ratios** (e. g. 24 hour 1:1 nurse "specialling", or individual patient therapy sessions involving 2-3 trained therapists at any one time)
    - **highest level facilities / equipment** (e. g. bespoke assistive technology / seating systems, orthotics, environmental)
    - control systems/computers or communication aids, ventilators.
    - **complex vocational rehabilitation** including inter-disciplinary assessment / multi-agency intervention to support
    - **return to work, vocational retraining, or withdrawal from work / financial planning as appropria**te

- Patients may also require:
    - Highly specialised clinical input (e. g. for tracheostomy weaning, **cognitive and/or behavioural management**, low awareness states, or **dealing with families in extreme distress**)
    - ongoing investigation / treatment of complex / unstable medical problems in the context of an acute hospital setting
    - neuro-psychiatric care including: **risk management**, treatment under sections of the Mental Health Act,
    - **support for medicolegal matters including mental capacity and consent issues**

Our point is that the criteria for our service users, with significant behavioural disturbances, social and cognitive impairment, are based on staffing and aims of rehabilitation. The **methods** to be used are not specified, to provide Wales with

leading, innovative rehabilitation services, which effectively signpost ABI patients with different needs to the most appropriate, high quality services, reporting to the government the most relevant outcomes for the population served.

When a service required for a person is defined in terms of the number and type of professional staff they have, it is reasonable to provide some idea of what that staff would be delivering.

Like a 'typical' multi-disciplinary team, BIRT delivers a range of physiotherapy, occupational therapy, speech and language and clinical psychology treatments. Alongside that, we also **insist** on the basic psychosocial approach adopted and delivered by all rehabilitation support workers (the equivalent of health care assistants or non-nursing posts). We invest heavily in training all workers in the neurobehavioral approach (McMillan & Wood, 2017; Wood, 1992). This approach allows daily social interactions to be delivered in a consistent and clear way, which supports learning and compensates for disorientation, poor memory or dysregulated social behaviour of service users. We can supply many examples demonstrating how this neurobehavioral approach is effective in rehabilitating confabulation, amnesia, disorientation and low mood.

The neurobehavioral approach is a psychosocial approach, rather than a medical approach to the rehabilitation of acquired brain injury. We are happy to deliver a presentation or provide additional research and clinical outcome reports for this rehabilitation approach, which we would ask you to consider in the Level 1 specialist services for Wales.

Lastly, we also see that the neurology and neuropsychiatry pathways **exclude** many of these ABI patients.

Patients not normally considered for admission

Patients will not normally be considered for admission if any of the following apply:-

- *'They are still in the acute post-brain injury confusional state (also known as post traumatic amnesia)'*

Around 30% of BIRT service users have sustained anoxic brain injuries which are characterised by ongoing post-brain injury confusional states. This number is growing, taken the increase in cardiac events, attempted suicides, surgical accidents and so on. To exclude this growing group might be a mistake because there are no other rehabilitation services on offer for people of their age and demographics. BIRT is currently investigating the differences between those presenting with what has traditionally been identified as post-traumatic amnesia, and more persistent severe cognitive confusion. We hope this will inform and guide the diagnosis of PTA on acute wards.

- *Suitable local services exist (i.e. Stroke Unit and Mental Health)*

Our evidence is that there is poor or non-existent knowledge and coordination of suitable local services available. This often seems to depend on the personal experience and knowledge of the doctors and managers involved in each case. In addition, the decision to exclude someone from neurorehabilitation is a life changing one, and yet, as with other aspects of this paper, the clinical detail is absent, which would allow managers and politicians to assess the effectiveness of the policy.

There is no mention of outcome measures for such aspects of the policy (for those it leaves behind). The outcome measures mentioned are the ones from UKRoC, and these measures are insensitive for a section of ABI patients with cognitive behavioural problems, often resulting in clinical presentations that are difficult for other services to manage.

- *They have declining neurological condition for which rehabilitative gains would not be expected (i.e. Huntington's, Multiple Sclerosis and other degenerative conditions)*

Dr Sue Copstick, one of the authors of this paper, was both an advisor on the current NICE ABI guidelines, and was also on the group which developed the current SIGN guidelines on Epilepsy. She reviewed the literature on the cognitive rehabilitation of epilepsy, for example, and it is not fair to leave such groups out of this guideline altogether. The mood and cognitive problems of those with epilepsy are often some of the most disabling.

Again, there is a literature on cognitive rehabilitation for those with MS (O'Brien et al., 2008), which discusses several sub-types, some of whom respond well to MDT rehabilitation (taken so many with relapsing and remitting MS or HD have marked psychological changes, including fatigue, which affect life, in this young group).

- *They have brain conditions that are attributable to alcohol or drug abuse e.g. Korsakoff's Syndrome*

A growing number of ABI are related to falls occurring when people have been inebriated relating to a history of alcoholism or alcohol misuse. We suggest that none of these individuals should be excluded from neuropsychiatric rehabilitation. The conditions are all part of the same person, and it is the person which we have to treat, not just the ABI symptoms. The decision to offer rehabilitation be guided by rehabilitation potential, as assessed by an experienced clinician, and not solely the basis of the classification of the needs presented.

- *They have functional neurological disorders, movement disorders and tic disorders including Tourette's Syndrome*

Again, if the pathway does not allow the treatment of functional symptoms, where, which is relatively local, would such patients go?

- *They have stroke-related cognitive impairment*

- *They have neurodevelopmental conditions such as Autism or ADHD; or if they acquired their brain injuries in childhood e.g. cerebral palsy or childhood*

traumatic (or other acquired) brain injury, such that they are likely not to benefit from neuropsychiatric rehabilitation

We find it difficult to understand why injuries in childhood are excluded from rehabilitation (taken that cases are assessed on an individual case basis). Our 25-year database suggests that those that had ABI's before the age of 12 have the most enduring psychological/cognitive challenges. If the problem is discovered in adulthood, why exclude neuropsychological or neurobehavioral rehabilitation? We could present you with some informative case studies.

- *They have psychiatric and medical manifestations of medical disorders such as Systemic Lupus Erythematosus (SLE), HIV, neuropsychiatric inherited metabolic disorders, and cardiac disease*

- *They have dementia, conversion and dissociative disorders including non-epileptic seizures and other somatoform disorders*

In all, this long and extensive list of exclusions, which may be addressed by assessors applying for individual exceptional funding arrangements, results in access criteria to neuropsychiatric rehabilitation so exclusive that there may be a large number of cases waiting for funding approval.

Conclusion

BIRT suggests Wales looks at the person, their particular barrier to participating in their community life, as much as the medical diagnosis and whether the unit has so many consultants in rehabilitation medicine, or this or that therapist or nurse available. Long term re-integration into community home life depends on discharge processes and liaison with ongoing support, ensuring there is family involvement, education and support as well as what is in the paper.

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