Considerations in developing rehabilitation services for people with acquired brain injury

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Overview of presentation

- Case vignette
- Challenges impacting service provision for people with ABI
- National policy and service delivery context
- Preliminary findings from CLAHRC research studies
- Suggestions for future service provision
- Questions
The story of Jim...a ‘hidden disability’

- Pre-injury vulnerability
- TBI at young age with ‘hidden’ cognitive and emotional issues
- Lack of service provision early post-injury
- Poor coping, increasing mental health issues, loss of social roles and family stress
- Presents to specialised service several years post injury
What can we learn from Jim?

Could certain service models/processes/tools have helped identify his needs before crises occurred?

What services could have been involved earlier in his journey?

What services are required now to support Jim and his family?
Head Injury

- Estimated 760,000 people in England live with the consequences of head injury.
- ~235 per 100,000 suffer serious head injury (resulting in hospitalisation or death) (Tagliaferri et al, 2006).
- Incidence across the UK may vary by a factor of 4.6 (range 91 – 419 per 100,000), with socio-economic factors contributing to this variation (Tennant, 2005).
- Higher incidence of head injury 15-24 years and >75 years.
- On average about 36 people per 100,000 population per year will need rehabilitation.
- Estimated costs of health and social care associated with young adults with ABI (18-25 years) range between £17,160 p.a. to £33,900 p.a.
Challenges of service provision for ABI

• Heterogeneous clinical population
  – Physical, cognitive, emotional and communication difficulties impacting activity and social participation
  – Variable trajectories of physiological, psychological and social recovery over life course of condition

• Incidence & prevalence for psychiatric conditions post TBI is complicated by lack of clear operational definitions, small sample size and study design (Kim et al 2007)
  • PTSD prevalence ranges from 3-27%
  • Aggression ~33% in adults
  • Depression and anxiety disorders common (~30%); Suicide risk elevated and increases 5-7 years post injury (Teasdale & Engberg, 2001)

• Ripple effect – person sustaining injury and wider family impacted
Service delivery context

Guidance advocates network approach, integrated pathways responsive to changing needs over time delivered by multiple agencies and services

In the context of

- Severe economic constraints
- Reorganisation of provision of public sector services incl. health & social care, DWP, benefits...
- Introduction of Mental Health clusters for commissioning
• Gladman review (2007)
  – Variability in specialist community rehab. service provision in UK
  – Healthcare delivery systems underestimating persistence of cognitive & behavioural /psychological problems after ABI
  – Those with ‘hidden’ neuropsychological disability especially poorly served
• Particular challenge accessing services for people with ABI + behavioural or affective disorders, drug/alcohol misuse
Acquired Brain Injury Stream: Core Project Schematic (May 2012)

- Those referred to OZC (START Study)
- Accepted for Assessment: characteristics of 'complex hidden disability'
- Participating in rehabilitation programme (SUJ Study)
- Immediate & longer term outcomes 3+ years post (SUJ)

- OZC service aims and characteristics
- Team design, function, processes, decision making (SUJ)
- Service user-service interactions (SUJ)
- Team climate and stress (TEAMS 1, 2)
- Service design studies

- DtGP policy analysis: Gaps and tensions in guidelines with respect to 'complex hidden disability'
- Application of system design and simulation modelling tools to rehab service design
- Model of service change and engagement
- Approaches to change: tools for understanding service and service user complexity

- Definition of complex needs post ABI
  - Optimum service structures and processes
  - Tools or processes to facilitate change

- Broader comparisons and guidance (LD/ABI, national)
- Implementation: local service outcomes, guidance and change
- Tools for service evaluation, design and change

18/05/2012 Fergus Gracey, Donna Malley
ABI is described clearly as a ‘biopsychosocial’ phenomenon
  - ‘Organic’ injury results in impairments of functioning, in turn impacting upon social participation
  - Participation changes may contribute to disrupted functioning
  - Influence of social and policy context on relative emphasis of biological, psychological and social domains

Patient choice, autonomy and control are core principles
  - Rehabilitation as collaborative endeavour

Knowledge as the dominant discourse for change:
  - Patients’ acquisition of knowledge seen as sole mechanism for achieving condition self-management
  - Psychological / cognitive or social models of change leading to self-management was lacking

“codifiable practices, which can be represented by a set of instructions, transfer more successfully than tacit knowledge-rich practices that defy decomposition into cause-and-effect relationships”

• Small number of ‘complex people’ who place disproportionate demands on limited service resources and disrupt planned service provision

• “the goal would be to find a way of selecting patients for more specialist rehabilitation services, to determine and to justify the resources allocated to an individual patient within the rehabilitation process, and to act as at least one measure of prognosis to help understand the outcome after rehabilitation” (Wade, 2011, p.393).
About the service

• Offers outpatient neuropsychological assessment and rehabilitation (individual & via comprehensive HNRP) for adults with ABI
• Small numbers of service users receive high intensity input
• Highly skilled & experienced interdisciplinary team
• Service users typically have a ‘hidden disability’ (interacting cognitive, communication, emotional and functional challenges) impacting self esteem, QoL and social participation contributing to a discrepancy in their identity
• Service users funded on a case by case basis via NHS or private sources
• Also deliver education programme, NeuroPage and undertake research

www.ozc.nhs.uk
HNR principles

Prigatano (2000)

• Principle 1: ‘the clinician must begin with the patient’s subjective or phenomenological experience to reduce their frustrations …’

Ben-Yishay (2000)

• Agitation ceases, mourning occurs, able to identify meaning in rehabilitation, sense of hope and self-worth

Wilson, Gracey, Evans and Bateman (2009)

• Shared understanding between team, client, family
• Therapeutic milieu
• Learning skills and strategies
• Psychological therapy
• Working with family and significant others
• Engaging in meaningful functional activity
The ‘Y shaped’ model

(Wilson et al, 2009; Gracey, Evans and Malley, 2009)

Social and self discrepancies
→ Self under threat
→ Safe to explore
→ Test strategies and develop skills
→ Who might I be? How might things be better?
→ Positive growth
→ Contextualised support

‘aspired to or old me’

→ Possible new me
→ Reflect
→ Predict
→ Plan
→ Do

‘feared me’

Exploring and consolidating the “new me’s”
To examine the rationale, outcomes, process and cost of a national specialised service for people with ABI with mental health and/or behavioural problems
Data collection process...

- Admissions Assessment
- Admission to Programme
- During Programme
- Outcome at 18 weeks
- Outcome at 3 & 6 month reviews
Preliminary Data Analysis (n=35)

Those referred to HNR programme were:

• 17-56 at point of referral (mean age 33 years)
• 74% male
• On average 3.4 years post injury (up to 11 years post injury)
• Diagnosis: 71% TBI, 20% Vascular, 9% other
• 68% health funded
• Range of interacting problems
• 25% of participants had a h/o substance misuse, developmental disorder (ADHD) and/or mental health disorder prior to ABI
Cluster analysis of those with ‘complex hidden disability’ post ABI: Gracey, Malley, Wagner and Clare (in prep)
**Post acute triaging**

- Low complexity rating
  - Engagement in meaningful activity/rehab possible

- High complexity rating
  - Engagement in meaningful activity/rehab challenging:
    - Extensive brain damage and high level of dependency
    - Rehab needs with DSM-IV Axis 1 disorder
    - Intellectual awareness, specific rehab needs and goals
    - Resolving problems

**Community case identification**

**Case assessment and formulation**

- Local primary health services/clinics, 3rd sector
  - Info, enablement, support and signposting, watchful waiting

- Local/specialist neuro rehab services, social care, 3rd sector
  - Specialised neuro-rehabilitation, enablement

- Specialised residential or slow stream neuro-rehabilitation
  - Social care and health

- Specialist neuro rehab &/or mental health services
  - Adapted standard psychological intervention and neuro-rehab

- Integrated neuropsych rehab
  - Focus on risk, ambivalence, self-efficacy, threat-reduction, self-awareness, self-regulation and participation

- Multi-agency coordination; specialised inpatient
  - Neuropsychiatry or neurobehav unit; AO, risk management; consultation, coordination

**Service provision**

**Post acute triaging**

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Understanding systemic complexity

Family context
- Disruption - adaptation

“Complex” service user

Rehabilitation professional
- Service context
- Disruption - adaptation

Organisational context
- Disruption - adaptation

Supervisor or manager
Understanding interaction between clinical complexity and service delivery

Service User’s health condition

Incl. Type and severity of symptoms, stability of health condition, co-morbidity, chronicity

Psychological Factors

Incl. home circumstances, finances, work situation, social support, engagement of sig. others

Social circumstances of Service User

Incl. home circumstances, finances, work situation, social support, engagement of sig. others

Service provider context

No. of service providers involved, access to and co-ordination of care, impact on practitioner (psychologically) & disruptions to planned service delivery

Previous and current mental health issues, coping, adjustment, resistance to intervention

Most Complex or most complicated - multiple perspectives across all domains increases complexity?
What does this mean for Jim?

- Previous and current mental health issues, coping, adjustment, resistance/ambivalence to intervention
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- Service User’s health condition
- Service provider context
- Social circumstances of Service User
- Psychological Factors

Incl. home circumstances, finances, work situation, social support, engagement of sig. others
Conclusions and service implications

• To meet needs of those with ‘hidden disability’:
  – More evidence required for supporting community service models to facilitate engagement in rehab, self-management and decision making
  – Develop understanding of number, nature and characteristics of most complex community ABI patients and their patterns of service use to design appropriate services
  – Develop operational definitions and appropriate tools for identifying problems and needs to facilitate decision making and rapid access to services when needed
  – Need for more co-ordinated and collaborative approach between physical and mental health and social care providers

• Integrated approach to service design required to identify, predict and minimise complexity in this population
Suggestions...

- Opportunities for integrated working across health, social care and third sector providers – pathway for people with ABI (progressive and non-progressive)
- Access to Neuropsychiatry consultation/clinics for complex cases with ABI & LTNC
- Agreement on use of measures/tools to facilitate triaging, access and evaluation of service provision
- IAPT for ABI & LTNC?
- Assistive technology solutions e.g. cCBT
- Explore different service delivery models e.g. Resource Facilitation (Trexler, 2010)
- Preventative work – improve coping skills
- Service User involvement in service design