

# Working with children affected by familial brain injury

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# Aims

- To highlight issues facing children who have brain injured relatives
- To provide information about current practice in Oxford
- To stimulate thinking about your own practice
- To provide a launch pad for innovation in your own services

# Overview

- Why focus on children?
- Working with the 'brain injured family' – where do children fit in?
- The Oxford service: what do we do & what have we learned?
- Working with child relatives – implications for social work practice
- Where can you go from here?
- Summary and conclusions

# Why focus on children?

- TBI in the family does present children (like their adult relatives) with challenges (see Urbach, 1989):
  - Understanding the changed relative
  - Separation from the relative (hospitalisation)
  - Changes in relationships, roles & responsibilities (esp. care-taking; not being looked after properly themselves)
  - Coping with difficult & conflicting feelings
  - Dealing with the reactions / emotions of others (friends & family)
  - Social consequences

# Why focus on children?

- **The challenges associated with TBI do affect children** (like their adult counterparts)
  - Growing evidence base on the psychosocial effects on children including: behavioural problems, mood disturbance, relationship difficulties, illness related fears, loss of milestones, self-blame, anger.... (Daisley, 2002; Pessar et al, 1993; Butera-Prinzi & Perlesz, 2004)
  - However – research so far has tended to emphasise the negative impact – there are positive outcomes e.g. increased responsibility, maturity, independence, spending more time with the injured relative (Smiton & Daisley, 2005 in prep., Adams, 1991) & many children are resilient & cope well

# Why focus on children?

- **Child problems do affect the family**
  - Unaddressed family issues (including children's) may reverberate around the family system affecting and being affected by the actions/reactions of other members in that system (Maitz & Sachs, 1995)
  - Adjustment problems in child relatives found to be a significant source of stress for adult relatives of people with TBI (Harris et al, 2001) - which can, in turn, affect outcome of rehabilitation (Sander et al, 2002)

# Why focus on children?

- **We are required to:**

- National Service Framework for Long Term Conditions (DoH, 2005) states (for the first time):

“children are also profoundly affected and may also need support...a whole family approach, which includes siblings and children, may be helpful” (QR 10, pg55)

- Calls for the development of a range of flexible, responsive services to provide support for children in the family (QR 10, pg58)

# What kinds of services should we be providing?

- We don't really know – scant evidence base in context of TBI but -
- Work in other areas (parental physical & mental illness; sibling illness e.g. Beardslee et al, 1992; Lobato 1991) suggests that key factors involved in good outcome are:
  - On-going, good quality & age appropriate information (esp. on cause & effects)
  - Children feeling their needs are being met – through supportive counselling & psychological therapies (individual & family based)
  - Opportunities for the child to participate in the relative's treatment and maintain relationships
  - Effective family communication

# But are TBI services undertaking this work with child relatives?

- HOC Select Committee Report on head injury (DoH, 2001) noted that there were no services in the UK that specifically address the needs of children
- Postal survey of UK rehab teams (Daisley, Holland & Garas, in prep,) – we asked – Do you work with child relatives?
  - 84% response rate
  - 74% regularly worked with adult relatives
  - 31% worked with child relatives (and rarely routinely)

# Why are children not involved?

- Webster, Daisley & Pill (2003) National Family Focused Rehabilitation Survey
  - Asked 393 rehabilitation staff (5% were social workers) if they undertook work with child relatives – and if not – why not?
  - Only 50 (13%) had carried out work with children
- Why not?
  - Lack of skills, resources & support (including supervision & backing from managers) e.g. fear of opening up a ‘can of worms’
  - Ignorance / misinformation about the impact of familial TBI on children e.g. this work is not needed – no-one has ever asked for help for their children
  - Attitude - the work would be ineffective, unrewarding, inappropriate e.g. “whose job to work with children – not my job”

# The Oxford service

- Based at the Oxford Centre for Enablement (formerly Rivermead Rehabilitation Centre)
- AD employed in 1995 (previously working as Child Clinical Psychologist / plus experience of Neuropsychology)
- Currently work 6 sessions a week – 2 of these with children and families
- Approximately 3 families referred each month
- No budget !!– but lots of enthusiasm, commitment & creativity from the rehabilitation team

# Service aims:

- To support child and family adjustment to TBI (and other types of neurological illness / injury)
  - we aimed to ‘screen’ all children coming through our service – non-stigmatising and take pro-active approach to the prevention of problems in this group
- To support the rehabilitation process
  - Important to convince some managers of the ‘added value’ of the service – seen by some as a luxury
- To raise awareness of children’s issues – locally & nationally

# Service Aims

- To influence current practice, service provision and local policy development through staff support, training and consultation
  - we acknowledged that we were never going to be able to undertake all this work ourselves
- To contribute to the evidence base through research , audit and service development
  - Research part of AD's job description
- To continue to innovate

# Typical case load

- John (aged 3) & Joe (aged 5): Mum 6 weeks post-stroke; she is confused, agitated, shouting & does not recognise the children. They are distressed, not sleeping & are bed-wetting. Dad not coping. Advice requested.
- Anna (aged 10): Brother (who is 18) is 6 months post-head injury – severe cognitive impairments but still planning to return home; has shown inappropriate behaviour to Anna; child protection concerns. AD asked to contribute to risk assessment.
- Faye (aged 16): Dad home for 6 months after lengthy rehab following TBI. Return to work failed – family under stress (emotionally & financially). Faye & dad arguing a lot – she has recently started to cut her arms. Assessment requested.

# Typical Case Load

- Jenny (aged 12) & Paul (aged 10): Dad 8 weeks post-injury; family coping well but children would like to know more about his physical and cognitive problems
- Joanna (aged 15): Mum had TBI 2 years ago; now has 24 hour care; Joanna lives with mum and the carers but her behaviour recently 'difficult' – causing the carers problems. SS involved to assess whether home is the most suitable place for Joanna to live. AD asked to obtain Joanna's views.
- Luke (aged 7) & Katie (aged) : Dad in acute ward; assessed to be in PVS; family have requested that feeding be discontinued. Children have not been told – AD is asked to advise what to tell them.

# What do we do? Key service elements

- Child-friendly culture (environment & attitude)
- Addressing on-going information & support needs of children & adults
- Providing reassurance & orientation (who we are/what we do)
- Facilitating emotional expression & coping
- Maintaining relationships
- Reducing family stress
- Enhancing family communication

# child friendly environment

- OCE 'Family Room' - play room, visiting room, treatment & therapy room – with 'home-like' appearance
- Equipped with toys, games, computer, TV – for all ages
- Suggestions box for comments
- Notice board & library of information

# Information & education – the 'frontline' interventions

- Must be age-appropriate, matched to child's developmental stage & based on child's core beliefs & issues - Corrects misconceptions, increases knowledge, addresses unrealistic hopes & fears, increases perceived control
- emotional distress can interfere with children taking information in – so pace the rate at which it is provided
- Useful to include information about your own role, causes of TBI, effects & recovery (prepare this in advance; make a leaflet – more difficult on the spot!!)

# Information & Education

- Must be done in the context of adult relatives' information needs (where do children's misconceptions come from?)
- Few good sources of published literature – we tailor make most of ours – time intensive & requires creativity. See resource pack by Webster & Daisley (2005) which contains up to date list
- See work of Carol Pratt (Icanhoe) – example of best practice in this area and McLaughlin (1992) & Webster & Daisley (1998)

# Involving children in rehabilitation

- Orientation to ward/unit, routines, staff – leaflets, videos, tours, observing therapy sessions
- Build up to active, planned & supervised involvement in relative's therapy sessions
- Opportunities to talk to & question rehabilitation staff
- Involvement in meetings that discuss rehab progress & the future – children's views actively sought (if family agree) – especially re concerns that they will have to provide care for the relative

# Teaching children skills

- Often necessary to teach children skills that will allow continuation of relationship with injured relative (e.g. using a communication aid)
- Key issues are that
  - Child is keen to be involved – it is not a ‘must’
  - Ensure child not acquiring these skills as an alternative to professional carers or adult relatives providing care – must be of primary benefit to the child

# Supportive counselling & psychological therapies

- In practice most children only need 'front line' approaches but children who
  - Have pre-existing adjustment problems
  - Present with ideas of self-harm
  - Have experienced multiple losses (both parents in accident)
  - Whose injured parent is sole carer
  - Were involved in accident themselves

MAY require specialist advice and therapy (individual or family focused).

Refer outside your service if not available

# Psychological therapy

- Issues that often arise:
  - Self-blame for accident
  - Resentment
  - Guilt
  - Fear
  - Shame
  - Desire for revenge

Few published examples of this work (see Urbach & Culbert, 1991)

# Indirect working – with adults

- Non-injured relatives
  - Supporting their own adjustment/coping/stress management
  - Increasing their competence in supporting their children & maintaining routines ('inadvertent neglect' common)
  - Frame problems in context of TBI rather than on parenting skills deficits

# Indirect working - with adults

- The injured relative
  - Management of 'symptoms' that are most problematic for children
  - Discussion of parenting issues & concerns (neglected area – more work done in mental health)
  - Increase awareness of possible effects of TBI on children (often difficult for adults with awareness difficulties)

# Indirect work – with other professionals

- Inter – not multi – disciplinary working is central to this work
- Children & adult services fragmented – provided by different people in different locations
- Often problems about whose responsibility it is to meet an identified need
- Seek the help of other key people working with children – teachers, school counsellors, educational psychologists, GPs, health visitors..

# Teaching & training

- On-going staff training in our service (on child / family issues)
- Joint-working on clinical cases allows skill sharing & provides support
- Liaison & support to others working with children locally (teachers, health visitors) – integral to establishing network of available support

# Research

- Very little published work
- Examples of research we have undertaken:
  - Children's understanding of parental brain injury (Tonin, Daisley & Wheatley, 1996)
  - Children's psychological adjustment to parental brain injury (Daisley, 2002)
  - National survey of family focused rehabilitation (Webster & Daisley, 2005, submitted)
  - Children's coping with parental brain injury (Smiton, 2005)
- We are always keen to collaborate on research or support others in developing research ideas-contact us!

# Policy development & systems level change

- 'In-house' policies – innovative practice from the 'bottom-up': protocols & policies written to reflect changing practice:-
  - Children visiting / involvement in rehabilitation sessions
  - Information provision to children
  - Use of family room
  - Child protection awareness (in conjunction with Trust guidelines)

# Policy Development & systems level change

- Urgent need to improve communication & working across adult & children's teams (NHS, SS & other sectors)
- Multi-agency 'Parents with Disabilities Reference Group' – established in 1999 – led to the development of the 'Parents with Disabilities Policy' (ratified by all local Trusts / organisations)

# Future developments

- Continued expansion of clinical service (children with parents who have progressive neurological conditions e.g. MND)
- Funded research into effectiveness of child & family focused interventions
- Development & publication of child-focused literature & staff resources
- More work on parenting issues after TBI

# What have we learned?

- That you can do a lot with not very much!
- Meeting the needs of child relatives is complex, time intensive & emotionally demanding
- Requires co-ordination of multiple services
- Work with children must be undertaken in the context of work with their adult relatives (child problems often reflect unaddressed adult problems)

# What have we learned?

- Collaborative working in the team & with families is essential to successful outcomes
- That while TBI in the family *is* a challenge for most children, it does not necessarily lead to poor outcome
- Agencies must work together and review how services are organised & policies implemented

# Implications for SW practice

- Training & experience may be predominantly adult-focused – therefore -
- Identification of children's needs/issues may be difficult (without knowledge base of child development/child adjustment & coping) – important to seek support, supervision & training
- Stigma attached to SWs involved with children can be problematic - especially when issues of risk are raised

# Implications for SW practice

- Issues re parenting capacity & competence can arise – can compromise relationships with clients
- Dilemma re whose needs to focus on (e.g. who will be caring for the adult with TBI but who will care for her children – who addresses which concern?)
- Boundaries, roles, responsibilities & confidentiality can be difficult

# What can you do next?

- Audit/document the number of adults with TBI who have children in your service (often not known – no national data)
- Normalise children's concerns & be proactive in asking about them when working with families affected by TBI (children & parents often reluctant to discuss)
- Be mindful of the issues around children as carers
- Work on improving services & support available to adults with TBI as parents (another neglected area)

# What can you do next?

- Is there a planned response/policy locally relating to disabled parents and the needs of their families?
- Challenge the way services are organised locally (so that outcomes for children and adults are not compromised)
- Establish small SPIG to steer children & family issues in the context of TBI
- Know what exists locally to support children & families (develop a resource list that can be shared among teams)

# Summary & conclusions

- Children in 'brain-injured' families have been a neglected group
- But growing evidence suggests that this has been an important oversight - many good reasons why services should focus on children
- There are pockets of innovative practice around the country & lots of interest in this group of children – but there are barriers to service development
- Start small & identify some changes that you could make to your own practice to focus more on the needs of the children of your clients

To discuss clinical cases, research, training or service development issues (or to request our staff resource pack) please contact me:

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