

TBI Challenge EU, Vienna, September 2015

***“I did not really know what was happening”*: Siblings experiences and needs after brain injury**

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Example at 11 yrs. Post-TBI – trauma

“Lot of people around....brother lying in the road, there was someone supporting his head, there was a lot of blood about, saw the mangled bike at the side of the road, I had a look at him but I was taken away....the ambulance came and I was taken by a friend’s Mum back to their house”

“I didn’t really know what was happening....I remember crying, I didn’t know what to do”

Sibling example – hospital visits

Neuroscience centre:

“I vaguely remember seeing him in a room still unconscious, touched his hand, he was as white as anything, distressing really, all a bit much to take in at the time.... he looked a lot worse than I thought he would, you see it on the TV.... but a lot worse..... I didn't know what was happening”

Local hospital:

“....a lot better but very annoyed, very frustrated”

Sibling example – after coming home

“Definitely wasn’t as close, parents shielded me and didn’t want me involved....his temper, very angry, he had been quite a kind person before the accident, straight after so much anger.....”

“He took it out on my Mum – his main way of getting it out. He hit me, throwing things at me, (I) just used to go to my room, (I) didn’t get involved.... (I) did want to be involved but didn’t want to annoy my parents”.

Sibling example – Ongoing effects

“It was like not having a brother for a few years, he didn’t want me around....I wasn’t welcome”

“Lost one of my friends – he didn’t want to know, friends couldn’t come around, was embarrassed, didn’t want friends to know about it”

“Stress on parents it drew me away from the family, I didn’t want to ask any favours, we didn’t do anything together....four separate people living in the house”.

“Open University (UK) funded study
**“The impact of severe head injury
on siblings – a pilot investigation.**

*“Russell A, Walmsley J, Tyerman A,
Booth J & Fraser S.*

In G Yeates. Neglected sub-systems siblings, work colleagues and community members.

In C Bowen, GN Yeates and S Palmer (eds). (2010).
A relational approach to rehabilitation: Thinking about
relationships after brain injury. P260-5 London. Karnac.

Background – 8 people with TBI

5 adult, 3 children (6M,2F)	Median	Range
Age at injury	22 yrs.	11-37
Time in intensive care	14 dys.	1-42
Post-traumatic amnesia	35 dys.	14-91
Time in hospital	10 wks	1-19
Time since on CHIS referral	2 yrs.	0-16
Time since on interview	9 yrs.	3-32

Home circumstances at time of injury

Siblings: 2 brothers, 6 sisters, at injury	n
Sibling and person both at home	4
Sibling left home, person at home,	2
Sibling at home, person left home,	1
Sibling & person both left home	1

Semi-structured interview

- Life before the head injury
- The head injury (& early hospital care)
- Return home – early months – impact on sibling
- Rehabilitation (incl. sibling perspective)
- Long-term effects
 - Ongoing difficulties for the person
 - Effect on family including sibling
 - Effect on sibling & other family relationships
- Support for siblings & families

Sibling Interviews – Themes

- Traumatic experience for siblings
- Wish for more information
- Need for involvement
- Impact on wider family relationships
- Perceptions and explanation of changes in the injured sibling in the context of ABI, and
- Need for continuing availability of support.

A traumatic experience for siblings

All siblings commented on traumatic experience:

- Of the accident a younger brother commented:
“We went into the back of a lorry and my brother hit his headand just kind of like exploded his head kind of thing.... I’ve never seen so much blood on anything in my life”
- On brother coming out of coma a sister said:
“..... it was quite frightening really because I didn’t know what to expect at all”.

Traumatic experience for siblings (2)

- On first seeing her brother in hospital a younger sister commented, *“It was awful really, because he, he wasn’t my big brother any more. He was a baby, you know he was just kinda curled up in a little ball and he was just lying on the bed and it was quite a shock...”*.
- Not just initial trauma but complex emotional impact for siblings - acute care, rehabilitation & long-term: Shock, confusion & fear > anger, frustration & sadness

Wish for more information

- Siblings want access to information at all stages – in hospital, on discharge, during rehabilitation and also late post-injury.
- Some siblings want direct explanations, not via their parents, particularly in hospital setting – when asked about this, one sister commented, “...*me personally, no, I mean sort of by proxy through my Dad and stuff, I was sort of told things but no, not directly*”.
- ? Lack of information increased the uncertainty

Need for involvement

- Siblings wanted to be involved but were often unsure of what to do. Some saw a key role in supporting parents, others in helping more directly in rehabilitation.
- A younger sister commented : *.....that was probably the turning point of my life then when he came home it was like, like now you've got to grow up and look after your brother. It wasn't a case of you go out and party with all your friends it was how I felt, I wanted to do it and I knew he needed me so. And that was probably the turning point where we got closer as well".*

Influence on family relationships

- Often major overall impact on family, sometimes bringing families closer together, with siblings taking on a role in supporting their injured sibling. However, sometimes TBI was reported to contribute to family breakdown in already difficult relationships.
- An older brother commented,
“.... it tore it (the family) to pieces ... It was the final straw ... I don't think the parents would have lasted the course anyway... ... I lost the chance to grow up with a brother that.... I'm sure we'd have been a lot closer.....”

Influence on family relationships (2)

Often complex changes in family roles and relationships:

As a result of family breakdown same brother continued:

“...I’d say it was down to that that you perhaps had another relationship with (brother) that you wouldn’t otherwise have had and that’s a father figure as well. So not only are you best mate and a big brother and a life-board, you’re fulfilling a father’s rolesI find that quite an intrusion on my life... I stepped in and became a half-parent even in those days I took on responsibilities...”.

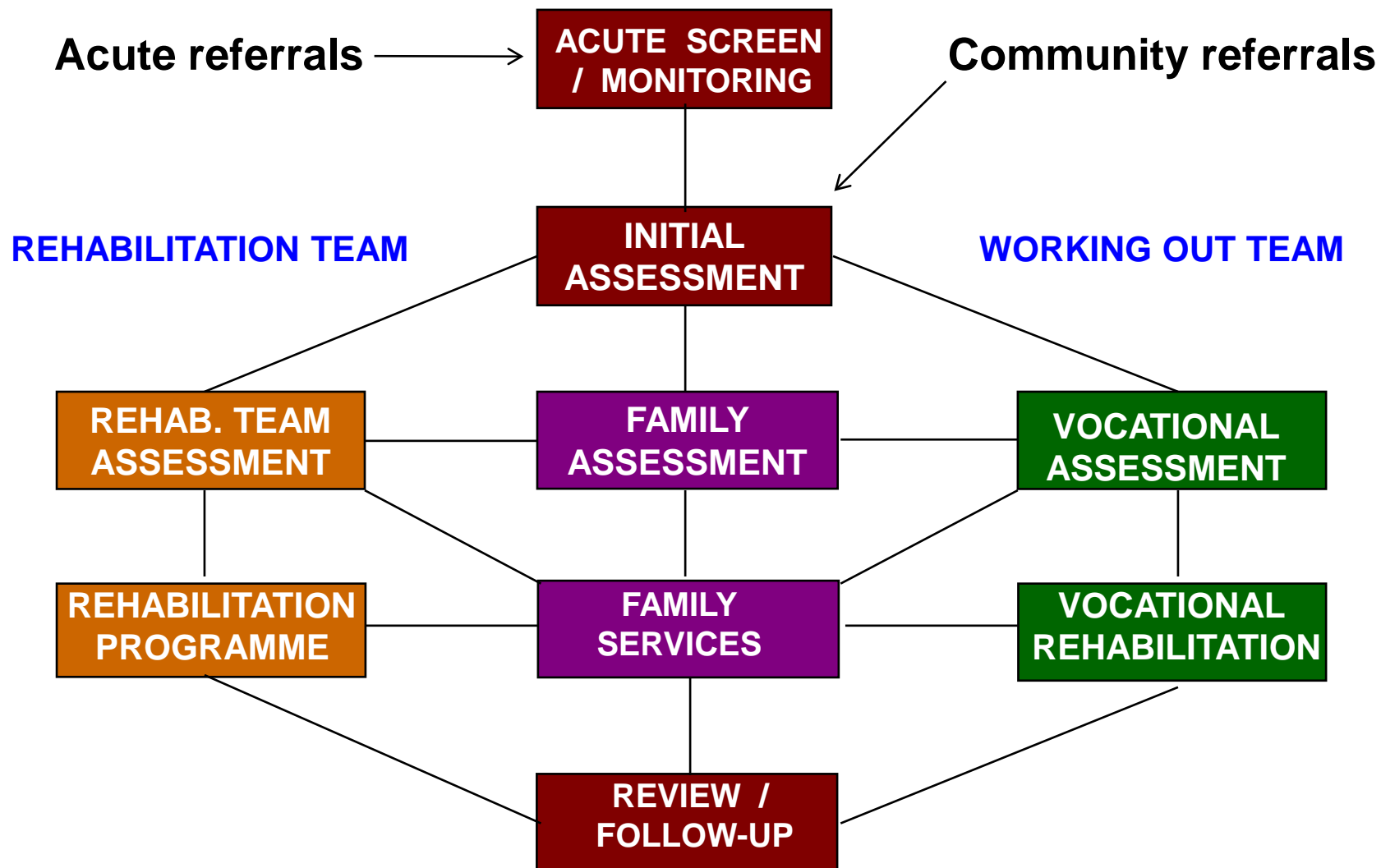
Perceptions & explanation of change

- Behavioural changes difficult to understand. Two siblings reported great release when able to attribute challenging behaviour to TBI. Whilst understanding helped to cope and support sibling, it was tinged with sadness at injured sibling lost future opportunities - a sister commented,
“To understand thatshe might never get better, back to her old self....it was the didn’t care attitude she never had before, you know that was difficult to understand and, if we would have known then, that that was all part of the head injury and it wasn’t her couldn’t be bothered.”

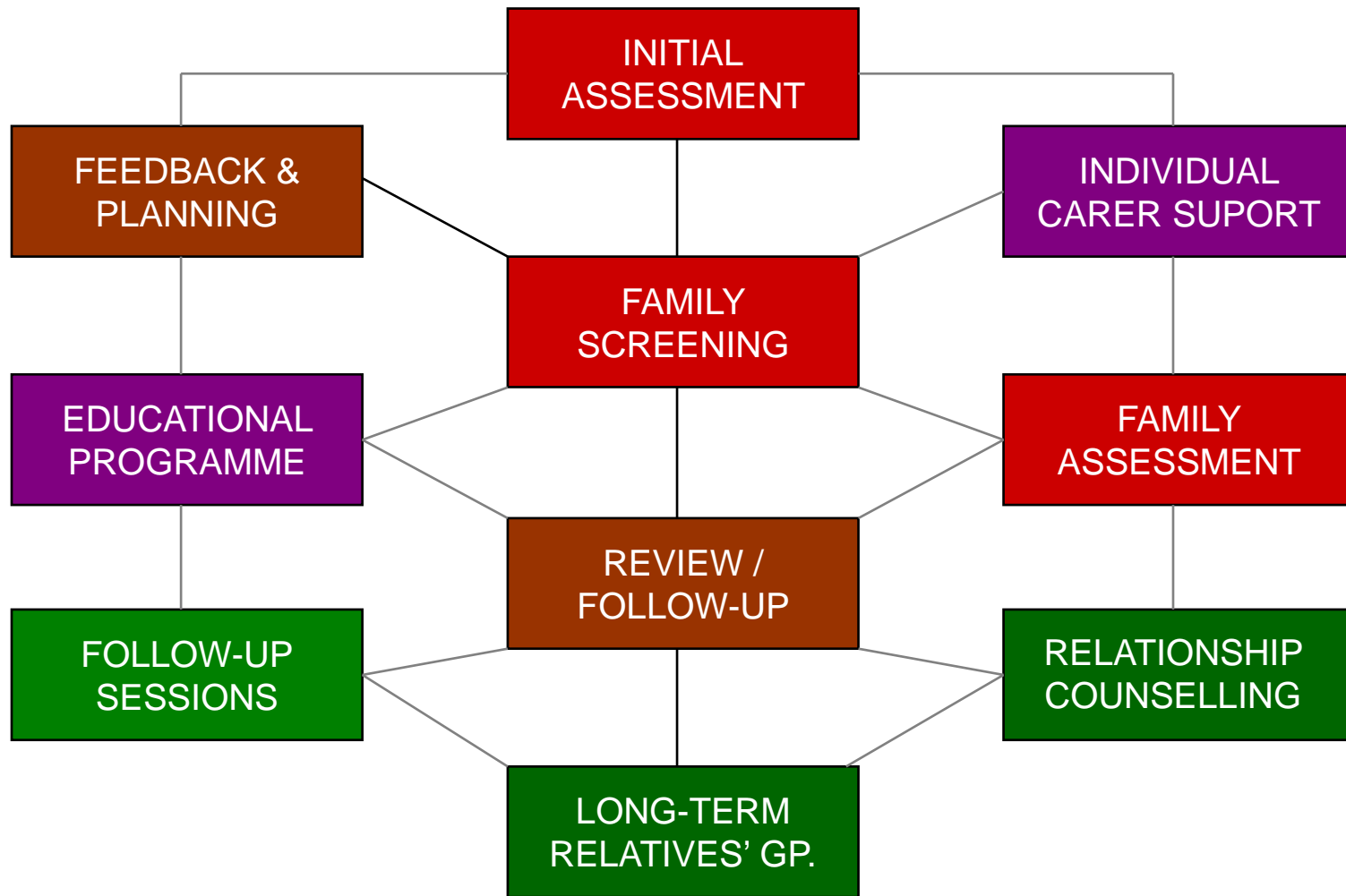
Need for continuing support

- Need for information and support to make sense of effects of TBI at any time in future - sister commented:
“It’s difficult to think, why is she saying that or why is she doing that and not have an answer on how to deal with it. To have somebody (the service) explain it, I can’t emphasise enough how much (this) helped us, I really can’t.... we can contact (the service) at any time if we’ve got any problems or worries and just knowing that, is a great relief.”
- Need identified for siblings to share their experiences

Community Head Injury Service, Aylesbury, UK



CHIS: Working with Families



CHIS Sessions for adult siblings & children

- **Aim:**

- To provide information/support & explore needs
- Four occasional sessions - wide-ranging discussions about impact of TBI on family in general and on the siblings & children, in particular.

- **Feedback:**

- Welcome opportunity to talk with others in similar position (friends find it hard to understand) - keen to hear of others' experiences in order to make more sense of their own.
- **Keen to be invited to relevant meetings and relatives' information sessions but will probably not come !**

CHIS: Support for siblings

Impressions:

- Existing relatives educational programme, family sessions and occasional discussion sessions supporting a small number of siblings but clearly not meeting wider sibling needs
- Also need to consider what we might provide for younger siblings, for which above not suitable.

Exploring the lived experience of the sibling relationship after a paediatric ABI

Emma Tyerman, Trainee Clinical Psychologist,
Lancaster University / Lancashire Care NHS Trust

Small qualitative study, primary school siblings:
Highlights the powerful impact of both the traumatic incident itself and effects on injured person, but also disruption to the whole family system including the sibling relationship.

➤ Re-energised wish to inform/support siblings

Specialist support for siblings: ABI

Holly (CHIS voluntary assistant), July 2015

Google search of 31 ABI related websites:

- 7 offered resources to support parents in supporting siblings
- 2 of these noted to provide specific resources directly to siblings after ABI:
 - Brain Injury Hub, Child Brain Injury Trust, UK
 - Brainline

Relevant on-line family resources

- Fact sheets (mainly for parents, not siblings)
- Information DVDs (as above)
- Short books for children (incl. siblings)
- Ask the expert Q&As
- Blogs to share experiences
- Support groups (e.g. Sibshops, Young Carers UK)

Conclusion: Limited information and support resources directly for siblings

Siblings after ABI - Conclusions

- Traumatic initial experience, major disruption and ongoing family and sibling relationship challenges
- Some good information (mainly for parents & children, not siblings) BUT need to publicise existing material & develop age-specific resources for siblings of all ages.
- Need to provide appropriate opportunities + welcome sibling involvement at all stages - acute care, in-patient and community rehabilitation and in long-term support.
- Need for access to flexible, ABI informed, individual counselling, family therapy and/or peer group support (as & when required) at any stage (? using modern IT).