

Creating Community Connections for People with traumatic brain injury (TBI)

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LiDs Annual Roundtable, 1 Nov 2017

Overview

- A definition (of sorts)...
- Social connections for people with TBI
 - Self and social connection
 - Creating a bridge between self and society
- Developing a multi-component community connection program
 - Components of the program
 - Program logic
- Knowing the evidence
 - INCOG Guidelines (2014)
 - Efficacy of community-based, leisure/social activity programs (Tate et al., 2014)
- Applying the evidence to maximise community connection
 - Michael (and Samantha)

A definition (of sorts) to consider...

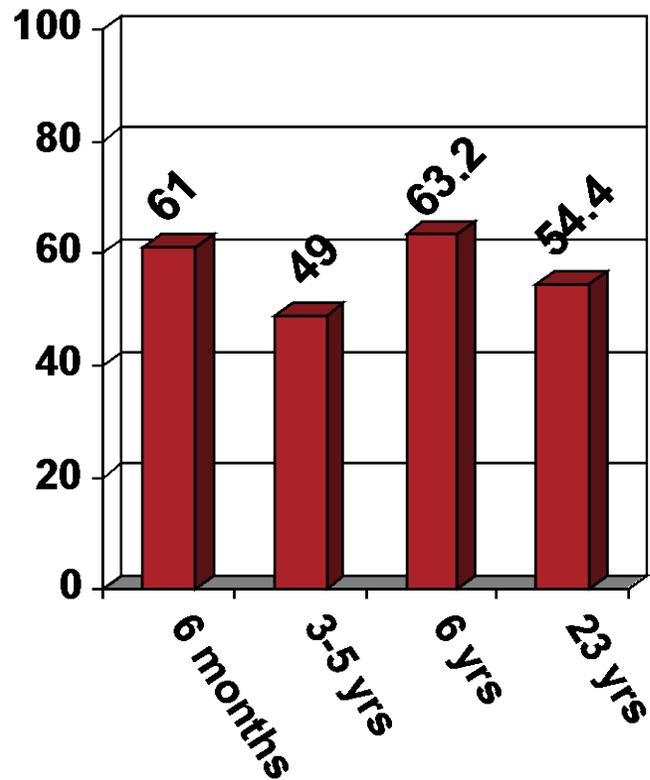
“A man’s (sic) *Social Self* is the recognition which he gets from his mates. We are not only gregarious animals, liking to be in sight of our fellows, but we have an innate propensity to get ourselves noticed, and noticed favorably, by our kind. **No more fiendish punishment could be devised**, were such a thing physically possible, than that one should be turned loose in society and remain absolutely unnoticed by all the members thereof. **If no one turned round when we entered, answered when we spoke, or minded what we did, but if every person we met ‘cut us dead,’ and acted as if we were non-existing things**, a kind of rage and **impotent despair** would ere long well up in us, from which the cruelest bodily tortures would be a relief; for these would make us feel that, however bad might be our plight, we had not sunk to such a depth as to be unworthy of attention at all.” (James 1890, Vol 1, *Principles of Psychology*, p. 294)

(Douglas, Drummond, Knox & Mealings, 2015)

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Social connections for people with TBI

TBI and social outcome: the figures



6 months (Wade et al., 1998) (n=314)

- Social disability (RHFUQ, Rivermead Head injury Follow Up Questionnaire)
- UK

3-5 years (Dikman et al., 2003) (n=210)

- ↓ Social integration (FSE, Functional Status Examination)
- USA

6 years (Tate et al., 1989) (n=100)

- Restricted relationships (SPRS, Sydney Psychosocial Reintegration Scale)
- Aus

23 years (Tate et al., 2006)

- Restricted relationships (SPRS)
- Aus

TBI and social outcome: the feelings

Rachel (22 yrs of age, 2.9 yrs after injury):

I only see mum in the afternoons when she comes home from work or on the weekend. So I just get a bit lonely sometimes in the house or sometimes when I'm at [university], sometimes a loneliness sort of washes over me and I just want somebody to talk to.

Chris (24 yrs of age, 4.2 yrs after injury)

So that's the way it is for me - always being left out.

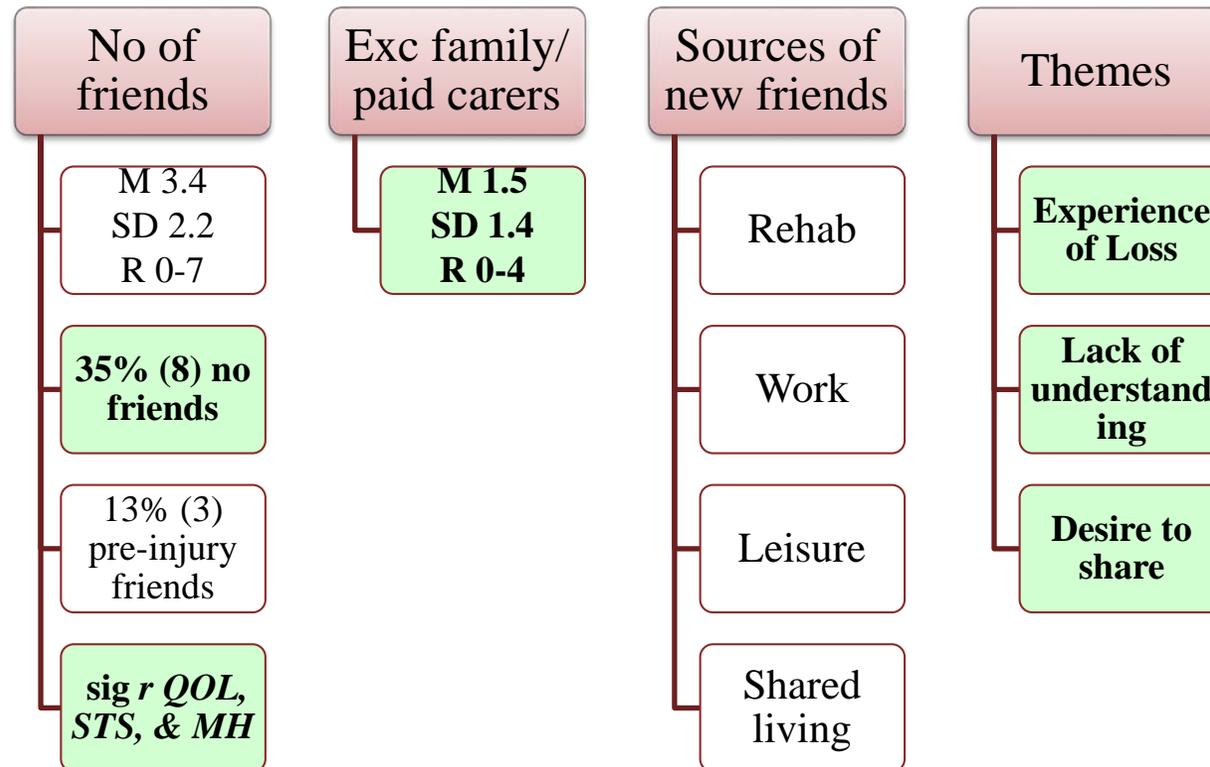
Dave (30 yrs of age, 15 yrs after injury)

I'm very much a one off sort of, or, whereas there's a big group here and a big group there and I'm sort of in the middle, sort of one on my own.

(Douglas, 2015)

TBI and social outcome: friends

- 23 adults with severe TBI (20 men)
- On average 10 years since injury (Range 2-20)
- Majority between 25 and 45 years old (Range 19-55)
- All living in the community



(Douglas, in prep)

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Self and social connection

Defining Self

Multidimensional, internal representation of the individual (Morf, 2005)

A dynamic knowledge structure (Stein & Markus, 1996)

- shapes our behaviour
- affects the way we process information about ourselves
- influences our choice of goals and motivation
- affects how we relate to others
- provides existential meaning

The unique product of the individual's own specific walk through life (Shaddon et al., 2008)

Aims

To gain some understanding of:

- the way/s in which adults who have sustained severe-very severe TBI conceptualise themselves several years after injury
- **the way/s in which they have developed and maintained a sense of connection between self and society several years after injury**

(Douglas, 2013)

Participants

- 16 men and 4 women
- Severe-extremely severe TBI
- 35.2 years (SD 9.1, R 21-54)
- 10.4 years (SD 4.2, 5-20)
- Living in the community with family &/or paid carer support
 - Alone 6 participants
 - With spouse 2 participants
 - With family 9 participants
 - Shared & supervised 3 participants

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Creating a bridge between self and society

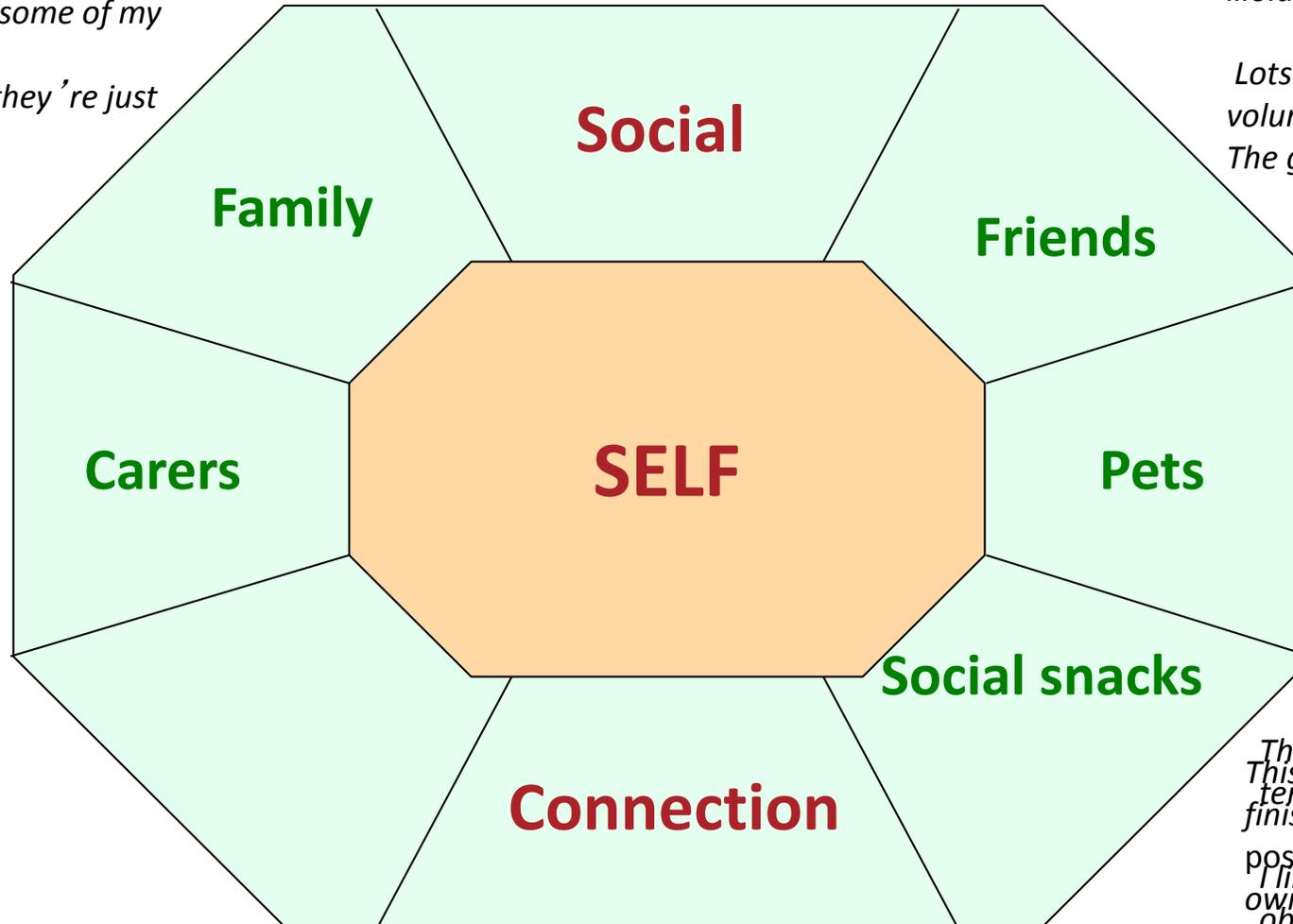
Staying Connected

*...visits with my brother and some of my brother's friends.
Family, the way they are ... they're just here.*

*...friends I had since before the accident
...old group of guys from rehab*

*Lots of friends at the farm where I volunteer.
The girls at the bakery.*

*...a close group of friends that I see often
I'm never lonely because I have Bless (dog)
...I can't by phone makes me and everyone who visits laugh.
Emailing friends from rehab - you know we met at xxx*



*I have no friends anymore only my family
I look forward to the Friends no, only wife and family, weekends because I go out with carers.
Having carers come over*

I get along with my carers...

I do lots of walking with my carers.

*The lady down the street has a This (photo) is of all of us when we terrier too....
finished.*

postcard from: old friend, who has I like the people at xxxx dog own family now, but keeps in touch. obedience.

Social Snacks (Gardner et al., 2005)

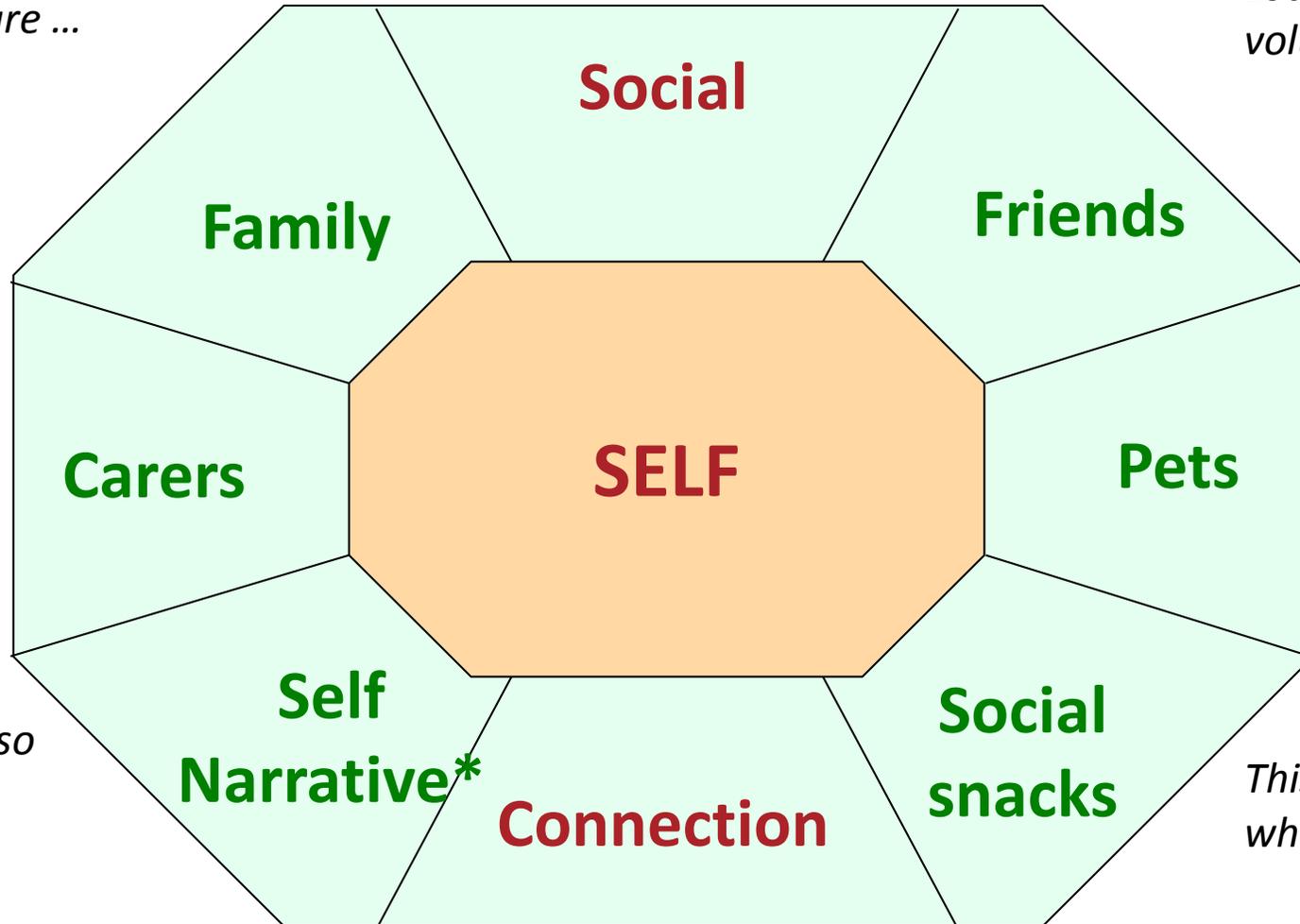
Indirect social strategies to satisfy belonging needs

- symbolic social behaviours
 - rereading cards, letters, emails
- tangible symbols
 - photos, mementos, certificates, awards
- intangible representations
 - memories and daydreams
- useful reminders of social bonds
- reaffirm and replenish a subjective sense of connection
- act as social reserves when direct social interaction is not possible
- shield one from the stings of isolation or rejection

Staying Connected

Family, the way they are ... they're just here.

Lots of friends at the farm where I volunteer.



I look forward to the weekends because I go out with carers.

I'm never lonely because I have Bess (dog).

I have my own website, so that I can tell people my story.

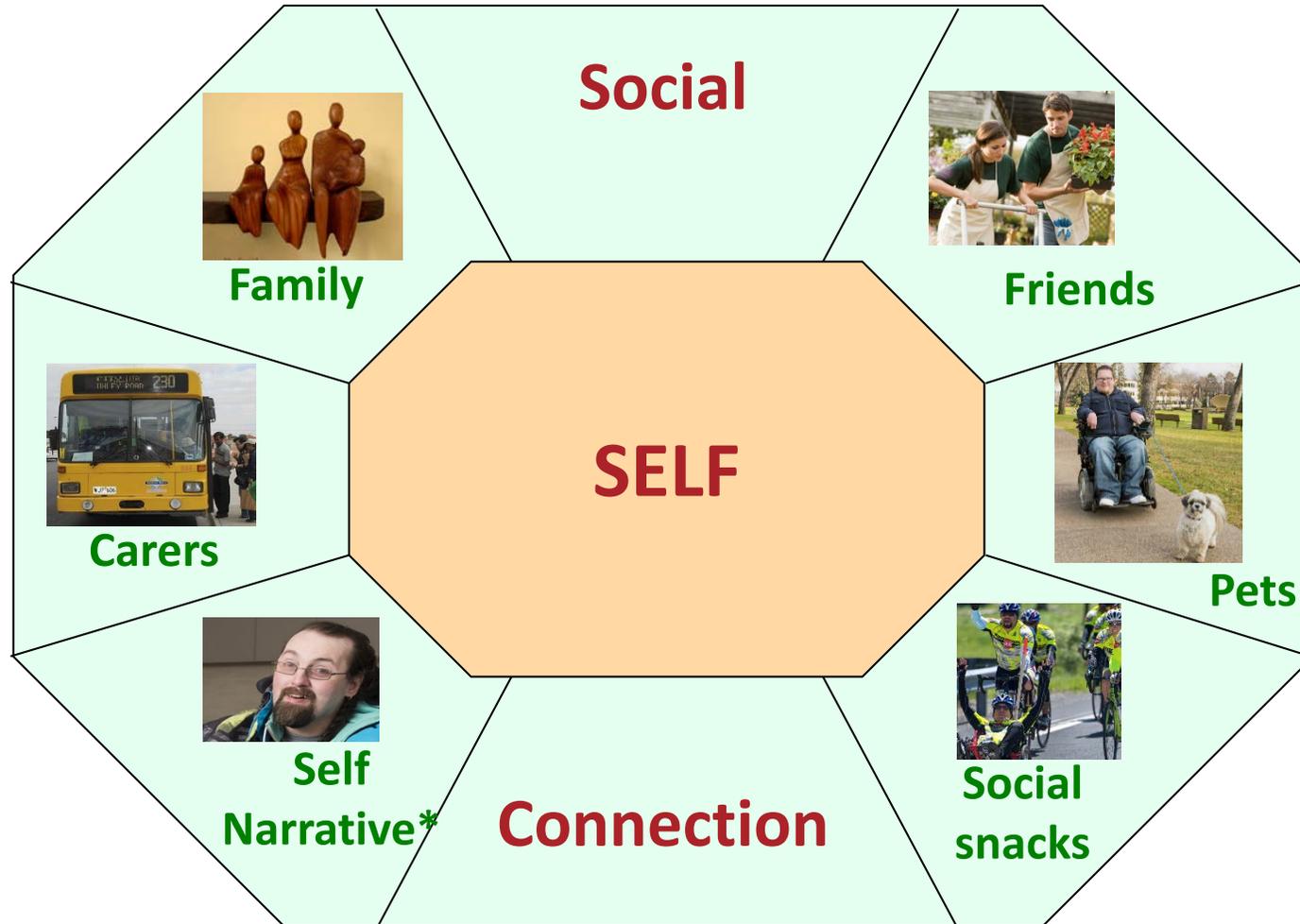
This (photo) is of all of us when we finished.

* <https://www.summerfoundation.org.au/documents/digital-stories/bilys-story/>

Self Narrative

- is shaped continuously through the ordinary and exceptional experiences of life
- allows the individual to go on with life after disruption
 - takes into account the changes associated with disruptive events
 - facilitates the meaning-making process
 - supports goal setting
- **facilitates connection with society as a unique individual**
- **is developed and validated through social interactions with others**

Staying Connected



* <https://www.summerfoundation.org.au/documents/digital-stories/bilys-story/>



Developing and evaluating a multi-component community connection program: project in progress

Douglas, Bigby, Iacono, Knox, Winkler & Callaway



Aim

- To implement and evaluate the efficacy of a multi-component community connection program (M-ComConnect) for people with severe TBI living in a variety of accommodation settings in the community
 - Living at home with family with paid support
 - Living alone with paid support
 - Living in a group home with shared support

Components of the program

- M-ComConnect is designed around 3 domains:
 - functioning in the community (skills and behaviours)
 - developing and maintaining relationships (family, friends and members of the community)
 - being involved in the community (activities and services)

Focus of the program

- Implements intervention principles, strategies and practices that have been shown to promote social connection and community inclusion
- Focuses on up to 5 people/players:
 - the person with TBI
 - family members
 - paid carers
 - established friends
 - people in the community (local business people, service providers, co-participants in community activities)

Intervention

- The interventions within the program have been shown to have at least sufficient clinical and/or theoretical evidence to indicate that they should work with this population
 - All beyond phase 0 evaluation on the Medical Research Council framework (Campbell et al. 2007)
 - Substantial number have been subjected to proof of concept evaluations and have been found to work (i.e. beyond phase 1 evaluation)



Knowing the evidence

INCOG Guidelines for Cognitive Rehabilitation Following TBI *(Journal of Head trauma Rehabilitation, 29, 2014)*

- **Methods and Overview** (Bayley, Tate, Douglas, Turkstra, Ponsford, Stergiou-Kita, Kua, & Bragge, on behalf of the INCOG Expert Panel, 2014)
- Previously published cognitive rehabilitation **recommendations were identified and tabulated.**
- An expert panel met to **select appropriate recommendations.**
- The team **enhanced the recommendations by reviewing available literature.**
- **Decision algorithms** incorporating the recommendations were developed.
- **Recommendations were prioritised** for implementation.
- **Audit criteria were developed** to evaluate adherence to best practice.

Evidence for community-based activity programs

- Tate, Wakim & Genders (2014). A Systematic Review of the Efficacy of Community-based, Leisure/Social Activity Programmes for People with Traumatic Brain Injury. *Brain Impairment*, 15, 157-176.
- **Conclusions:** interventions for this area need to be **planned and specific, structured and goal-driven, intensive and conducted over a period of months.**

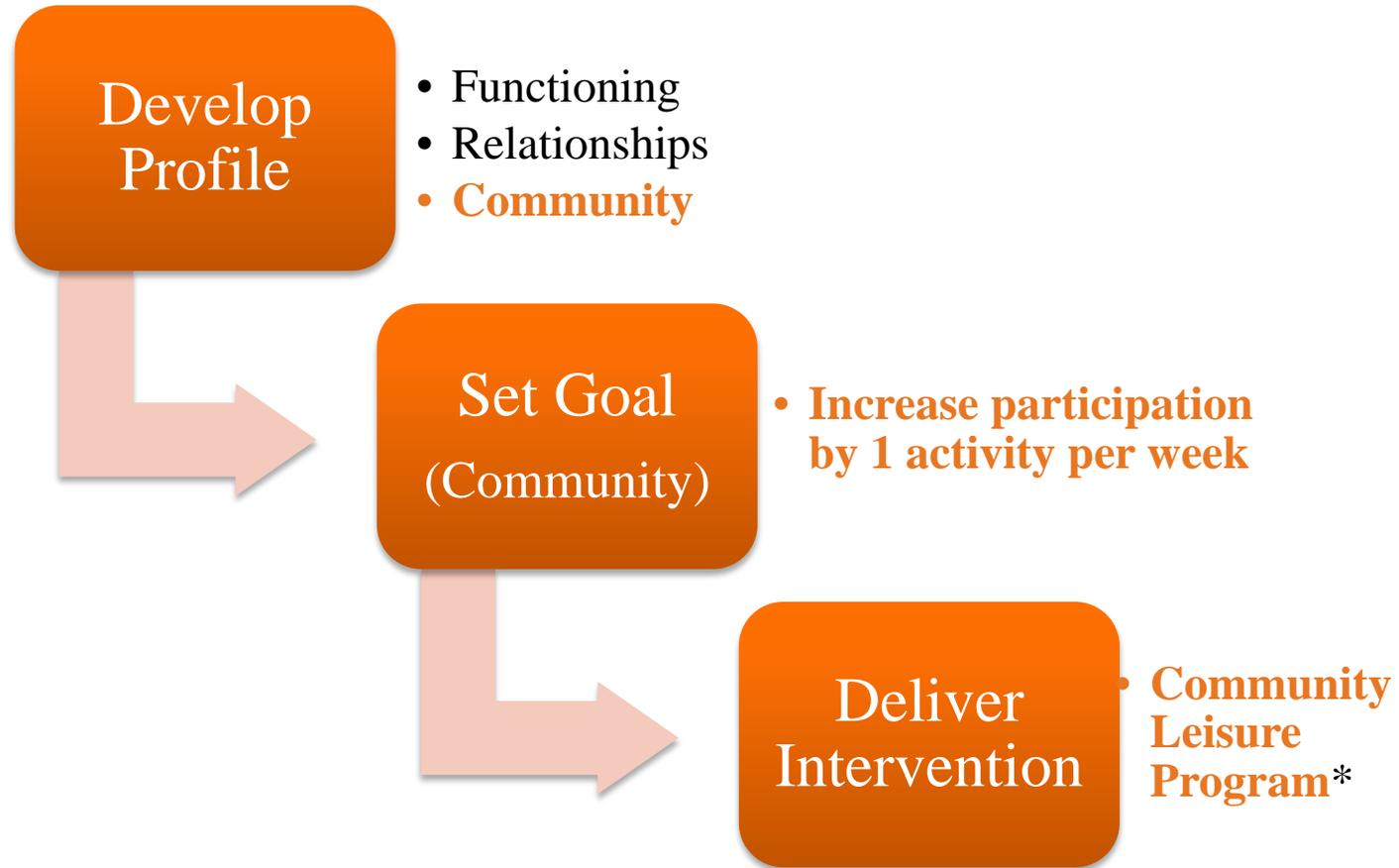


Applying the evidence to maximise community
connection: Michael and Samantha

Michael: *I don't like being alone....I get sad*

- At 20 years of age
 - living with his family
 - about to complete his apprenticeship as an electrician.
 - lots of friends.
 - in a steady relationship with his girlfriend
 - active in his local cricket club.
 - sustained a severe brain injury (GCS admission: 3, PTA duration: > 120 days)
- At 27 years of age
 - continued to live at home
 - significant levels of depressive symptomatology and anxiety
 - minimal social involvement

M-ComConnect: Michael



***Douglas et al. (2006)**; Mitchell et al. (2014); Tate et al. (2003)

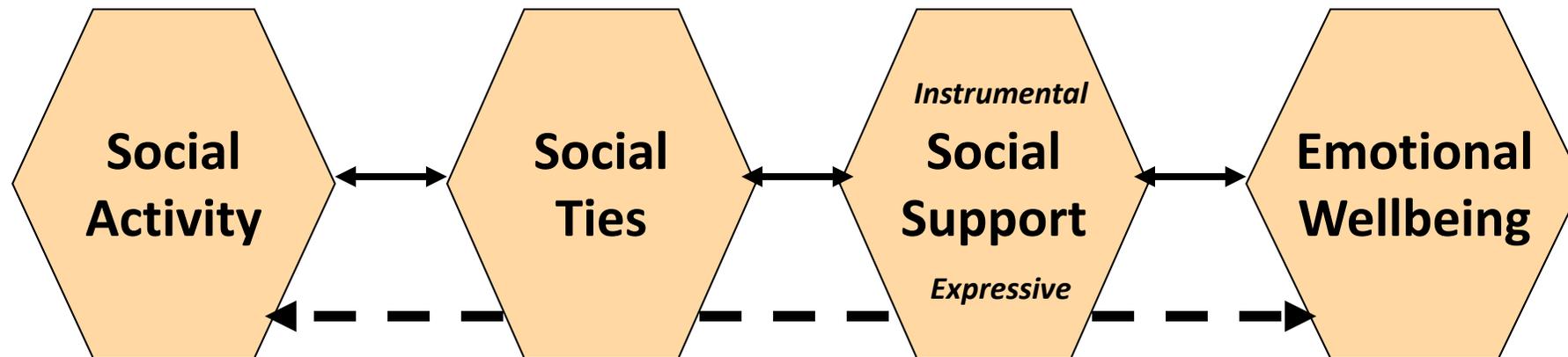
Michael: Before Group Community Program

Most activities (shopping, movies) with carers; weekly computer lesson; weekends - not much going on.

Mum and also the carers.

Can talk to Mum, if I have a problem - maybe Keith (cousin)

I'd like to be happy again



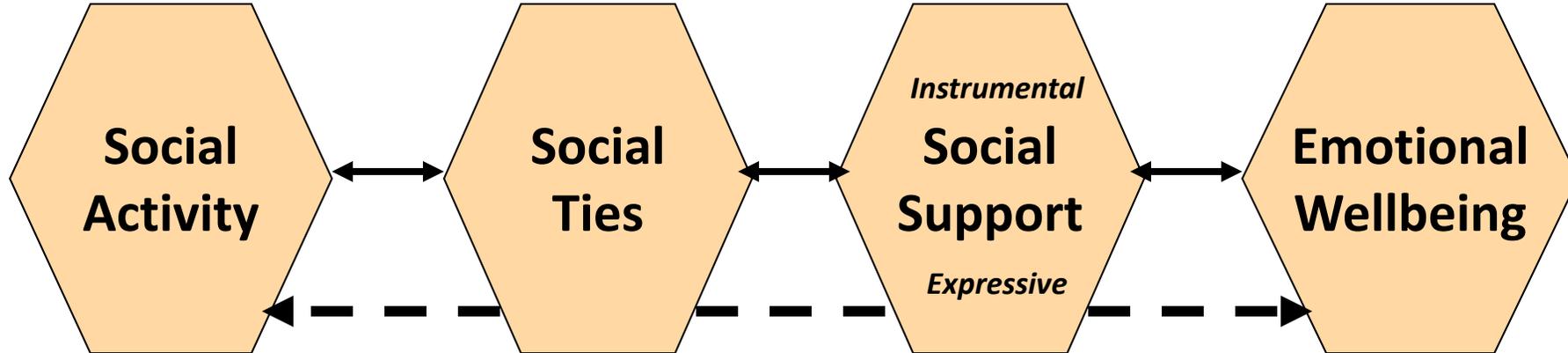
Michael: Before Group Community Program

Most activities (shopping, movies) with carers; weekly computer lesson; weekends - not much going on.

Mum and also the carers.

Can talk to Mum, if I have a problem - maybe Keith (cousin)

I'd like to be happy again



Enjoys: *activities - billiards, woodwork, dinner, indoor cricket team.*

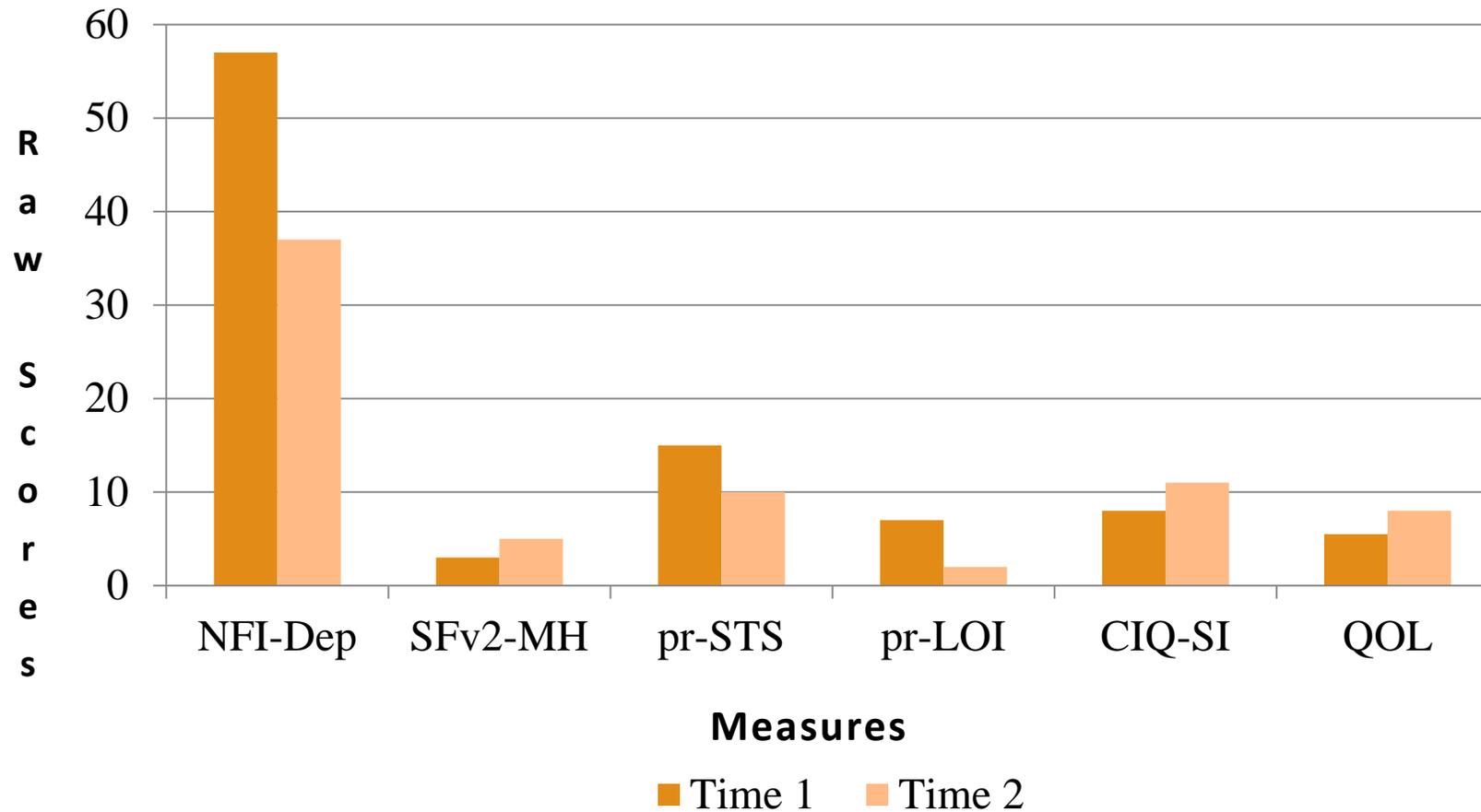
... met one person with similar interests

One or two friends I can talk to .. (Keith-cousin & 'new' cricket friend)

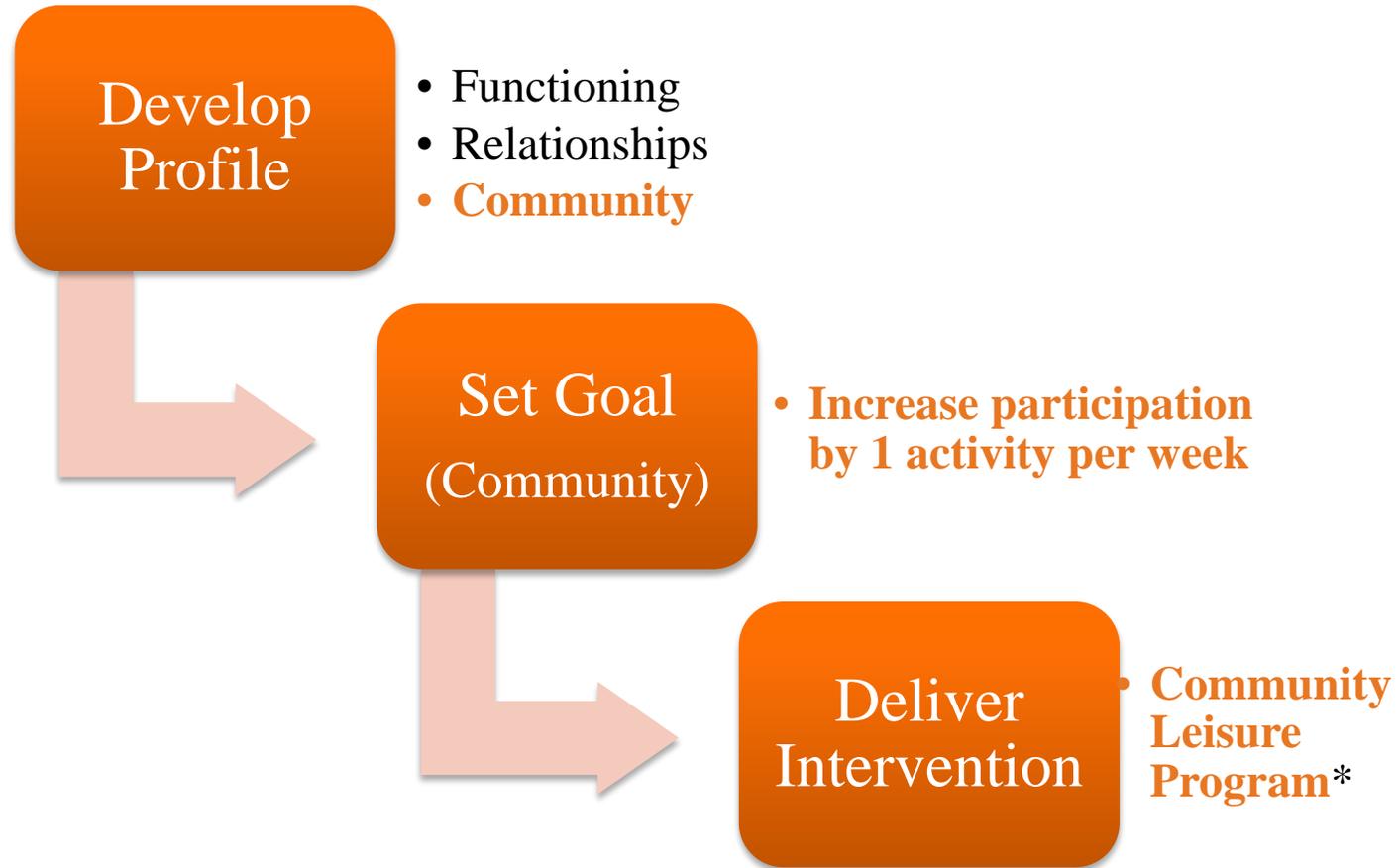
.. mainly positive but get a bit down because of tiredness..

After 6 Months in Group Community Program

Michael's pre and post test scores



M-ComConnect: Michael



***Douglas et al. (2006)**; Mitchell et al. (2014); Tate et al. (2003)

Review

- ✓ Self and social connection after brain injury
- ✓ Developing a multi-component community connection program
- ✓ Knowing the evidence
- ✓ Applying the evidence to maximise community connection
- ✓ Currently recruiting participants
- ✓ J.Douglas@latrobe.edu.au or L.Dixon@latrobe.edu.au

References

- Bayley, M., Tate, R., Douglas, J., Turkstra, L., Ponsford, J., Stergiou-Kita, M., Kua, A., Peter Bragge, P. On behalf of the INCOG Expert Panel (2014). INCOG Guidelines for Cognitive Rehabilitation Following Traumatic Brain Injury: Methods and Overview. *Journal of Head Trauma Rehabilitation*, 29(4): 290-306. (DOI: 10.1097/HTR.0000000000000070)
- Dikman, S., J. Machamer, J. Powell and N. Temkin. 2003. Outcome 3 to 5 years after moderate to severe traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, 10, 1449-57.
- Douglas, J. (2015). Placing Therapy in the Context of the Self and Social Connection. *International Journal of Speech-Language Pathology*, 17(3), 199-210.
- Douglas, J. (2013). Conceptualising Self and Maintaining Social Connection following Severe Traumatic Brain Injury. *Brain Injury*, 27(1): 60–74.
- Douglas, J., Drummond, M., Knox, L., & Mealings, M. (2015). Rethinking Social-Relational Perspectives in Rehabilitation: Traumatic Brain Injury as a Case Study (chapter 8). In McPherson, K, Gibson BE, Leplege A, (eds.), *Rethinking Rehabilitation Theory*, Boca Raton: CRC Press: (137-162)
- Douglas, J., Dyson, M., & Foreman, P. (2006). Increasing leisure activity following severe traumatic brain injury: Does it make a difference? *Brain Impairment*, 7, 107-118.
- Gardner W, Pickett C, Knowles M. “Social snacking” and “social shielding”: The use of symbolic social bonds to maintain belonging needs. In: Williams K, Forgas J, von Hippel W, editors. *The social outcast: Ostracism, social exclusion, rejection and bullying*. New York: Psychology Press; 2005. pp 227–242.
- Morf C. Editorial: Affirming the self as construct and journal. *Self Identity* 2005;4:97–100.
- Shaddon B, Hagstrom F, Koski P. *Life stories and narrative self*. San Diego, CA: Plural Publishing; 2008.
- James, W. 1890. *The Principles of Psychology* (Vol. 1). Cambridge, MA: Harvard University Press.

References

James, W. 1890. *The Principles of Psychology* (Vol. 1). Cambridge, MA: Harvard University Press.

Stein K, Markus H. The role of the self in behavioral change. *Journal of Psychotherapy Integration* 1996;6:349–384.

Tate, R., G. Broe, I. Cameron, A. Hodgkinson and C. Soo. 2005. Pre-injury, injury and early post-injury predictors of long-term functional and psychosocial recovery after severe traumatic brain injury. *Brain Impairment*, 6, 81-96.

Tate, R., Perdices, M., Rosenkoetter, U., Shadish, W., Vohra, S., Barlow, D., Horner, R., Kazdin, A., Kratochwill, T., McDonald, S., Sampson, M., Shamseer, L., Togher, L., Albin, R., Backman, C., Douglas, J., Evans, J., Gast, D. Manolov, R. Mitchell, G., Nickels, L., Nikles, J., Ownsworth, T., Rose, M., Schmid, C., & Wilson, B. (2016). The **S**ingle-**C**ase **R**eporting guideline **I**n **B**ehavioural interventions (SCRIBE) 2016 Statement. *Archives of Scientific Psychology*, 4(1), 1-9.

Tate, Wakim & Genders (2014). A Systematic Review of the Efficacy of Community-based, Leisure/Social Activity Programmes for People with Traumatic Brain Injury. *Brain Impairment*, 15, 157-176.

Wade, D., N. King, F. Wenden, S. Crawford and F. Caldwell. 1998. Routine follow-up after head injury: a second randomized controlled trial. *Journal of Neurology, Neurosurgery and Psychiatry*, 65, 177-183.

Thank you

Questions and/or Comments