

# ADVANCING SOCIAL WORK RESEARCH - IMPACT CASE STUDY

GRAHAME SIMPSON

Title of Case Study:

## STRENGTH TO STRENGTH: UNDERSTANDING AND BUILDING RESILIENCE AMONG FAMILIES SUPPORTING RELATIVES WITH TRAUMATIC INJURY

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**Other academic and clinical partners:** Royal Rehab, Sydney; Avondale College; Griffith University; University of NSW; University of Sydney; University of Wollongong; Wayne State University; Michigan Institute for Rehabilitation; Mid-Western Brain Injury Rehabilitation Service, Bathurst NSW; Mater Hospital, Brisbane; Hampstead Rehabilitation Centre, Adelaide; Monash Health Paediatric Brain Injury Services; Agency for Clinical Innovation NSW Brain Injury Rehabilitation Program and NSW Spinal Injury Services with collaborating researchers and clinicians.

### 1. CONTEXT

The case study focuses on family caregiver well-being in the field of neurotrauma. Contextual factors include theoretical frameworks which have defined how family well-being is understood within the field; the current service delivery models that target families; the growing awareness of government agencies of the value of informal care in maximizing outcomes for people with neurotrauma; and the role of Australian social work within neurorehabilitation. Traumatic Brain Injury (TBI) and Spinal Cord Injury (SCI) are two primary types of neurotrauma. Both constitute major public health issues, globally and within Australia. At the severe end, both result in lifelong impairments which create significant challenges in the domains of occupation, relationships and independent living. The aggregated estimated costs of TBI and SCI to the Australian economy is \$10.6 billion dollars. The effects on family members when a relative sustains severe TBI can be widespread and multilayered, with all members of the family system potentially affected. Depression or anxiety is common among family members, with rates between 20% and 40%. The impact on family functioning can include reduced affective involvement, communication, general functioning, and role change. Instrumental impacts can include reduced family income, reduced hours of work, and higher levels of help-seeking behaviour and increased medication use.

Theoretically, the first three decades of research into the impact of neurotrauma on families has been framed in terms of family vulnerabilities, psychopathology, systems dysfunction and risk factors. The course of care has been framed as one of increasing burden and burnout. Coping and social support have been identified as mediating factors but depicted in terms of individual capacity and valued for the extent to which caregiver psychological distress is reduced and satisfaction with life supported. The research has rarely been systemic, overwhelmingly focusing on single individuals classed as the 'primary caregiver'.

Current service delivery has been influenced by this framework and has classically focused on providing carer education or support groups to build knowledge and reduce carer psychological stress. Treatment is delivered in silos, with little attempt to devise interventions that might cross diagnostic boundaries, and with little indication about how they might equip families to play a support role over the long term. In terms of policy and future service planning, there is recognition that the existing Federal NDIS program and the state-based insurance compensation schemes are not able to provide the volume of services needed to adequately support people with neurotrauma. Informal care plays a critical role in maximizing the independence and participation of people with TBI or SCI. In its totality, informal care is worth \$44 billion dollars annually to the Australian economy and \$450 billion to the US economy, but little is known about the extent to which families provide informal care to relatives affected by neurotrauma. Moreover, finding means for supporting families in playing this role over the long-term is of crucial importance.

Social work (SW) in Australian rehabilitation is well placed (compared to other major Western countries) to tackle these issues. The profession's position in the multidisciplinary team is widely accepted across the public health sector, and its lead role in working with families relatively unchallenged. There are also strong clinical networks among social workers working within the field of neurorehabilitation within NSW and nationally. However, the profession is vulnerable due to the limited underlying evidence base and weak research capacity relative to other allied health professions. In particular, within the Australian context, there seems to be limited examples of intervention research, either evaluating existing social work practice, or developing and testing novel interventions within the health context.

### 2. SUMMARY OF IMPACT

This case study focuses on the impact of the Strength to Strength (S2S) psycho-educational program for families. S2S is the first intervention internationally that targets family resilience in neurorehabilitation. It comprises a 10-hour psycho-educational group-based program that aims to build resilience among family members caring or supporting relatives with a TBI or SCI. The program was developed and evaluated over an initial five year period (2008-2012).

S2S was developed by a group of senior social work clinicians from metropolitan and rural neurorehabilitation centres in NSW servicing people with TBI or SCI. The project content was drawn from a literature review (publication 17, section 4), several focus groups with families and health professionals, and an empirical study (*study 2*, section 3). The program was also informed by therapeutic techniques drawn from grief and loss theory, learning theory, Cognitive Behavior Therapy, narrative and solution-focused therapies and group work theory. The program was then evaluated via a multi-centre controlled clinical trial involving 49 family members that were recruited from seven rehabilitation centres across NSW. This original phase of S2S was funded by the i-care Lifetime Care and Support Scheme, the NSW state government insurance compensation scheme for people sustaining catastrophic injuries as the result of road accidents (predominantly TBI and SCI).

The success of the trial has laid the foundation for a process of scaling-up the delivery of the intervention. The i-care Lifetime Care and Support Scheme now funds the delivery of S2S to the family caregivers of scheme participants statewide as their frontline family intervention. S2S is now also delivered as a part of routine practice by social workers in neurorehabilitation services in metropolitan and rural NSW as well as units in South Australia and Queensland. To address sustainability, a permanent S2S steering committee was established (2013-current) to coordinate the further development and expansion of S2S. Since 2013, 70 staff from services in NSW, Queensland, Victoria and South Australia have attended one-day training workshops to learn how to deliver S2S, coordinated by the S2S steering committee. A community of practice network is also being developed to support practitioners who have attended the facilitator training in the ongoing delivery of S2S. Moreover, there are a number of initiatives that have commenced addressing the replicability and adaptability of S2S to a broader range of practice and international contexts (sections 3 and 5).

The ongoing development of the intervention program has been undertaken in parallel with a broader program of resilience-focused research, with both intervention and observational studies informing each other. This includes the first ever study to have administered a resilience questionnaire to families supporting relatives with TBI or SCI. In combination, the program places social work at the leading edge of work in family resilience within the field of neurorehabilitation, both nationally and internationally.

### 3. RESEARCH UNDERPINNING IMPACT

The research underpinning the impact has comprised three interrelated streams comprising the intervention research; research translation; observational studies with either a clinical or health services focus; and has been underpinned by a number of literature reviews. The research has involved collaboration with a wide range of partners, and comprised a series of funded projects; HDR student projects; and projects supported out of the existing resources of research staff and a broad clinical network of SW practitioners working in neurorehabilitation across NSW with support from Qld and SA.

See Table 1.

Using a Translational Research framework, the observational studies and the literature reviews informed the development of the S2S building resilience program (Idea generation). It has also continued to expand understanding of the nature and role family caregiver resilience, both from an individual and systemic perspective, within the context of neurorehabilitation (*studies 2, 4-7, 9, 12, 14*). The developments are then be fed into future refinements of the S2S program and the development of complementary programs (i.e., developing a family skills in challenging behavior on a web-based platform; Staff training in approaches to spiritual care within neurorehabilitation) (*studies 10, 11*). The initial intervention study comprised a controlled clinical trial which established the Efficacy of the intervention (*study 3*). The current feasibility/ acceptability pilots in paediatrics and Alcohol and Other Drugs; the case series with the pre-post designing the phone-based delivery of the abbreviated version of S2S; and the RCT testing the applicability of S2S within the United States context, all address the Replicability and Adaptability of the S2S program (*studies 13, 15-17*). Finally, the translation study addressed the Scalability of the program, which has now been demonstrated statewide within NSW icare Lifetime Care (at the organizational level) and a number of state health settings (at the level of individual units) (*study 8*).

## 4. DETAILS OF IMPACT

### *Approach to impact*

Prof. Simpson attributes the success of the research program and the S2S program to the strong clinical networks involved in rehabilitation; the co-location of the researchers with hospital clinicians which also enhances the credibility of the researchers; the active involvement of social workers in health and the value they place on the evidence the research provides; having had an eye to impact and a planned approach from the outset. Impact is measured from the completion of the first three studies (section 3; 2008-2012) including the development and original evaluation of S2S.

*Impact on service delivery:* Current practice in working with families in neurotrauma has focused on reducing psychopathology and risk factors among individual 'primary caregivers', with limited or no focus on enhancing resilience and well-being on an individual or systemic basis. This stems from the predominant deficits-based research paradigms employed to date in researching the family experience within the field of neurotrauma.

- Our research has demonstrated empirically that resilience and the associated constructs of hope, self-efficacy and positive affect play a role in mediating family outcomes (*Studies 2,6*), supporting the importance of family intervention programs that focus on resilience and well-being

Broadening the construct of resilience to incorporate spirituality

- Our research has demonstrated empirically that there is a strong association between spirituality and resilience among family members (*study 9*) but there are no programs and virtually no practice suggestions in the literature to guide staff in neurorehabilitation centres in ways of providing spiritual care/support to families (*publications 2-4,8*)

Broadening the construct of resilience to systemic family resilience (*study 12*)

- Currently completing a 'first' examining a systemic approach to understanding resilience among families (investigating differing patterns by which care/support roles are distributed within family systems and whether this links to resilience)

### *Manualised Program*

Simpson, G., Jones, K., Pfeiffer, D., Unger, C., Oosthuizen, H., Francis, J., Young, D. (2012). *Strength2Strength: Building resilience among families supporting relatives with traumatic injury*. LifeTime Care and Support Authority; Sydney, NSW.

The national level scale-up for practice within neurorehabilitation as outlined in section 2 is ongoing. To underpin this scale-up, the following mechanisms have been developed:

- development of facilitator training manual and evaluation of facilitator training workshop (*study 8*)
- steering committee established to (i) provide ongoing training; (ii) provide consultation about S2S delivery issues; (iii) establish a community of practice to contribute to ongoing fidelity; (iv) and developing mechanisms to expand the original core group of trainers
- complete a pilot of a phone-based delivery (*study 13*)

International initiatives for adapting and implementing S2S are also underway

- funding has been achieved to conduct a RCT of S2S (targeted at families supporting relatives with TBI) at the Michigan Institute for Rehabilitation in Detroit, with Professor Simpson have travelled to Detroit in January 2018 to provide training to the lead therapist
- provided a one-day training workshop in the UK hosted by the Brain Injury SW Group on family resilience (see <http://www.biswg.co.uk/past-events/brain-injury-workshops-dr-grahame-simpson/>).

New studies are now being undertaken to explore the applicability of S2S to other clinical groups

- pilot studies underway to adapt and evaluate feasibility/acceptability of delivering S2S to families supporting children/adolescents with brain injury; and to families supporting adolescents/young adults with drug and alcohol issues

### *Enhancing clinical leadership within the social work profession:*

With one previous exception, all family intervention programs that have been published in the field of TBI and SCI (i.e., nationally and internationally) have been developed by health professions other than social work (e.g., nursing, psychology, occupational therapy). Therefore, the development of S2S helps to solidify the profession's credentials in playing the lead role in supporting families in neurorehabilitation. S2S is an intervention that is congruent with SW values and is informed by SW clinical practice. Social work clinical leadership is

- as originators of the program
- responsible for the sustainability strategy, including delivering the facilitator training
- the S2S facilitator training has attracted other professions apart from social work (e.g., clinical psychology, speech pathology, occupational therapy)
- the United States study is led by Clinical Psychology and Neuropsychology
- social work has taken the lead in providing the S2S program to the icare LifeTime Care participants (running 4-6 groups per year, a new role for SW in relation to icare LifeTime Care

### *Impact on service effectiveness and costs.*

It is too early to evaluate the impact of S2S on service effectiveness or longer term costs. However the groundwork is being laid:

- The first Australian study into the level of informal care provided by families supporting relatives with TBI has been completed (Publication 18)
- The longitudinal study will collect data on service utilisation and family resilience (*study 14*)
- The family systems study will examine the extent to which current figures on family caregiving (based on reports of 'primary caregivers') underestimate the true extent of family care (*study 12*).

### *Impact on quality of life of community members*

The S2S program has demonstrated its value as a psycho-social educational program that can assist in building family member resilience in a range of rehabilitation health care contexts (TBI, and SCI).

Evaluation data from family participants attending S2S is routinely monitored and shows high levels of satisfaction with the intervention.

## 5. ENGAGEMENT

Engagement for the resilience research flows from Professor Simpson's employment history and position within the state health sector. This drives the collaboration among clinicians and consumers supported by the local health services and medical research entities (SWSLHD, LBIRU, Royal Rehab, IIAMR) in connection with industry as well as national and international academic partners.

### *Foundation for engagement*

(i) Prof Simpson's has worked at the Liverpool Hospital Brain Injury Rehabilitation Unit (LBIRU) for over 30 years, as a social worker and social work team leader (1987-2000) including working closely with families; and then in the LBIRU Research Officer position (2000-current) and still employed on the Social Work/Allied Health award, Sydney South West Local Health District.

(ii) His role as RO includes ensuring that all disciplines based at the LBIRU are involved in research

(iii) Established Brain Injury Rehabilitation Research Group in 2012, based in a Medical Research Institute (Ingham Institute of Applied Medical Research), co-located with Liverpool Hospital.

### *Clinical partners*

(iv) co-founded Social Workers In Brain Injury in 1987 a special interest practice group of the AASW (NSW). He also has close links with the social

workers/NSW social work practice network in spinal injury. These practice networks are derived from the NSW Brain Injury Rehabilitation Program and the NSW State Spinal Injuries program respectively, providing a strong foundation for multi-centre research

(v) The coordinating directorate for the NSW Brain Injury Rehabilitation Program, funded by the NSW Health Agency for Clinical Innovation, is part of the Brain Injury Rehabilitation Research Group, further embedding clinical engagement and a multi-centre network focus into the family resilience research program

(vi) Social work practitioners have played multiple and prominent roles in the family resilience research process. SW practitioners have

- been project officers on key studies (study 3,8)
- partnered in the development of the S2S program (co-authors Simpson and 6 senior NSW Health SW practitioners) (study 3)
- co-led consumer and health professional focus groups in developing S2S
- co-delivered the S2S program in the original efficacy trial (6 sites, study 3)
- led recruitment in the largest observational family study conducted in NSW (study 6)
- assisted with local ethics approvals
- delivered conference presentations on study results
- have been co-authors on papers published in peer reviewed journals
- lead development of S2S adaptations (study 16)

(vii) The ongoing sustainability program for S2S is co-led and coordinated by a SW practitioner based at the Royal Rehab centre (study 8), and local SW practitioners who have previously delivered the program are now training new facilitators

(viii) The SW practitioner who worked as the project officer (Studies 1-3) has completed her Masters, PhD and has now organised postdoctoral funding working in the area of family resilience and neurotrauma

#### Consumer involvement

(ix) Consumers have been involved in key elements of the family resilience research program:

- original development of the S2S program and the next generation staff spiritual training program through focus groups (family caregivers studies 3,10)
- consumer volunteers videoed speaking about their experiences for inclusion in the S2S programs
- consumers or consumer advocacy agencies represented on project steering committees (studies 3,10)
- providing structured feedback about adapted versions of S2S (study 13)
- lead media coverage on the S2S program (e.g., interviewed as part of a story on Channel 10 national news)

#### Industry partners

(x) NSW i-care Lifetime Care, the state agency for compensation for people injured in road and work accidents have:

- funded a number of linked projects around family resilience
- offer S2S as usual care to all family members

## 6. RESEARCH INCOME

The specific research program related to family resilience and the S2S program has attracted grants totaling more than \$ 1,441,839.

#### Category 1 (international and national competitive)

1. Hanks, Rapport, Simpson, Millis, Waldron-Perrine, & Reslan. Evaluation of the S2S Program, 2017. US National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR), Disability and Rehabilitation Research Projects Program: Traumatic Brain Injury Model Systems Centers Program US\$800,000 (est) AUD\$1,056,266.

#### Category 2 (government)

2. Simpson, Jones, & Unger. Sustaining resilience among families supporting relatives with traumatic injury: Translating Strength2 Strength, 2013. NSW LifeTime Care and Support Authority \$31,651.
3. Simpson & Jones. Building resilience: Equipping families to support people with TBI / SCI, 2008. LifeTime Care and Support Authority \$102,557.

#### Category 3 (Other industry)

4. Simpson, Gopinath, Anderson, & Cameron. Impact of resilience on the longer-term well-being of family caregivers, service utilisation and client community participation, 2017. Icare Lifetime Care \$102,816.

5. McDonald, Newby, Grant, Gertler, & Simpson. The Way-Ahead: On-line support for families managing challenging behaviour after TBI, 2016. Icare Lifetime Care \$146,043.
6. Ehrlich, McNiven, Bates, McIntyre, & Simpson. Understanding family workload and capacity following catastrophic injury. 2016. Hopkins Centre Interdisciplinary Seeding Grant \$40,000.
7. Anderson & Simpson. Testing a predictive model of resilience among family caregivers supporting relatives with acquired neurological disability, 2012. Avondale College / Australasian Research Institute/ Liverpool Brain Injury Rehabilitation Unit \$60,000.
8. Simpson, Forstner, Dall'Armi & Simpson. Information resources for head and neck cancer, 2006. Cancer Institute of NSW \$37,000.

## 7. RESEARCH OUTPUTS

Academic outputs relevant to the research include: a chapter in an edited book; 8 articles in peer-reviewed journals; six abstracts published in peer-reviewed journals; the manual of the S2S program; and an unpublished Masters and Doctoral dissertation. The literature output has included 1 systematic and 3 scoping literature reviews. Selected publications are:

1. Simpson GK, Yuen F. (Eds.). (2018). *Contemporary perspectives on social work in acquired brain injury*. London, UK: Routledge. ISBN: 978-1-138-55974-5
2. Jones KF, Dorsett P, Briggs L, Simpson GK. (2018). The role of spirituality in spinal cord injury (SCI) rehabilitation: Perspectives of health professionals. *Spinal Cord Series & Cases*, 454 <https://doi.org/10.1038/s41394-018-0078-3>
3. Jones K., Dorsett, P., Simpson G., Briggs, L. (2018) The contribution of spirituality towards family resilience after spinal cord injury. *Rehabilitation Psychology* doi: 10.1037/rep0000229. [Epub ahead of print]
4. Jones KF, Pryor J, Unger C, Simpson GK. (2018) Spirituality and its relationship with positive adjustment following traumatic brain injury: A scoping review. *Brain Injury* (in press)
5. Simpson, G., Pfeiffer, D., Keogh, S. (2016). Describing an early social work intervention program for families after severe traumatic brain injury. *Journal of Social Work in Disability and Rehabilitation*, 15 (3/4) 213-233. doi.org/10.1080/1536710X.2016.1220888
6. Simpson, G., Dall'Armi, L., Roydhouse, J., Forstner, D., Daher, M., Simpson, T., White, K. (2015). Does resilience mediate family caregiver distress after head and neck cancer? *Cancer Nursing*, 38 (6), E30-E36. doi: 10.1097/ncc.0000000000000229
7. Anderson, M., Simpson, G., Daher, M. & Matheson, L. (2015). The relationship between coping and psychological adjustment in family caregivers of individuals with traumatic brain injury: A systematic review. In C.E. Kasper & Y.P. Conley (Eds.), *Annual review of nursing research: Traumatic brain injury*, 33,1, pp. 219-248. New York, NY: Springer Publishing Company. <https://doi.org/10.1891/0739-6686.33.219>
8. Jones, K., Simpson, G., Briggs, L. & Dorsett, P. (2015) Does spirituality facilitate adjustment and resilience among individuals and families after SCI?, *Disability and Rehabilitation*, 38:10, 921-935, DOI: 10.3109/09638288.2015.1066884
9. Simpson, G., Jones, K. (2013). Resilience among family members supporting relatives with traumatic brain injury or spinal cord injury. *Clinical Rehabilitation* 2013; 27: 367-377

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*Advancing the production, use and impact of Australian social work research*  
Research team: Clare Tilbury, Christine Bigby, Mark Hughes, Mike Fisher  
October 2018

**Table 1: Underlying research (2008-current) (1-9 completed; 10-17 active)**

Type of research	Design	Title	Findings	Personnel
1. Review	Scoping review	Resilience within family adaptation to traumatic injury: A literature review and theoretical analysis.	No studies could be identified that had investigated family resilience after TBI or SCI	Masters student (SW)
2. Observational-Clinical	Cross-sectional correlational	How important is resilience among family members supporting relatives with TBI or SCI?	Resilience associated with higher levels of positive affect and lower levels of negative affect and caregiver burden among families supporting relatives with TBI or SCI. Findings incorporated into Studies 3,6.	Project officer (SW)
3. Intervention	Controlled (non-randomised) clinical trial	Evaluating a psycho-educational program for building resilience among family members supporting relatives with TBI or SCI: A controlled trial	Family members (supporting relatives with TBI or SCI ) who received the S2S program made significant gains in resilience, self-efficacy and increased use of carer management strategies compared to families receiving usual care. Findings incorporated into Studies 8, 13, 15- 17.	Project officer (SW) + SW practitioners
4. Observational-Clinical	Cross-sectional correlational	Does resilience mediate family caregiver distress after head and neck cancer?	Families with low resilience scores had a 88% chance of probable depression; families with high resilience scores had a 6% chance of probable depression.	Project officer (Allied Health)
5. Review	Systematic review	Relationship between coping and psychological adjustment in family caregivers of individuals with TBI: A systematic review	7 articles identified, but study quality generally low. Found that emotion-focused coping and problem-focused coping were associated with psychological adjustment in caregivers. Findings incorporated into Study 6.	Masters student (Nursing)
6. Observational-Clinical	Cross-sectional correlational	A predictive model of resilience among family caregivers supporting relatives with TBI or SCI: A structural equation modelling approach	Model accounted for 63% of variance in resilience. Resilience had a direct effect on positive affect in caregivers; and a protective role in relation to caregiver burden mediated through social support. Findings incorporated into Study 14.	Project officer (Psychology) + SW practitioners
7. Observational-Health services	Cross-sectional correlational	A study of long term service utilisation following TBI and SCI	Found ratio of informal care (IC) to formal care was 45% : 55% for TBI (27 hours IC) and 41% : 59% (33 hours IC) for SCI. Findings incorporated into Study 12.	PhD (Business Studies)
8. Translation	Mixed methods	Sustaining resilience among families supporting relatives with traumatic injury: Translating S2S into practice	Developed and evaluated a program to train facilitators in the delivery of S2S. A S2S steering committee established to monitor and support long-term sustainability of S2S implementation.	Project officer (SW) + SW practitioners
9. Observational-Clinical	Mixed methods	The contribution of spirituality towards family resilience after SCI	Spirituality played an important role in facilitating positive adjustment after SCI. Spirituality was strongly correlated to resilience. Rehab staff identified a lack of knowledge and skills in how to support spirituality among clients/families.	PhD (Social Work)
10. Intervention	Feasibility/acceptability pilot	Spiritual care practice: Trial and evaluation of a staff training program in TBI and SCI	(i) To survey rehabilitation health professionals about their experiences/attitudes/knowledge in addressing client/family spiritual care needs; (ii) develop and evaluate a training program.	Post-doctoral (SW) + SW practitioners
11. Intervention	Feasibility/acceptability pilot	The-Way-Ahead: On-line support for families managing challenging behaviours after TBI	To develop and pilot the feasibility/acceptability of a supported on-line knowledge and skills training resource for families managing relatives with TBI who display challenging behaviours.	Project officer (Clin Psychology) + SW practitioner
12. Observational-Clinical	Mixed methods	Understanding family workload and capacity following catastrophic injury	To look at how the 'work' of informal care is distributed across family networks, rather than centred on a single 'primary caregiver' after TBI or SCI. To investigate whether the degree of distribution of care is associated with the level of family resilience.	Project officer (Nursing) + SW practitioners
13. Intervention	Pre-post case series	Is S2S effective for family members in rural areas supporting relatives with TBI when delivered by phone?	To test whether delivery of S2S by phone is as effective as face to face for family caregivers of people with TBI in rural areas	Practitioners (SW + Clin Psych)
14. Observational-Clinical	Prospective longitudinal	A predictive model of resilience among families supporting relatives with TBI or SCI: A follow-up study	A 3-year follow-up of the cohort from study 5 to determine the impact of resilience on the longer-term wellbeing of family caregivers, service utilisation and client community participation.	Project officer (Psychology) + SW practitioners
15. Intervention	RCT	Will S2S be effective in building resilience among families supporting relatives with TBI in the US?	To adapt and test S2S with family caregivers of people with TBI in the United States	Project officer (Clin Psychology)
16. Intervention	Feasibility/acceptability pilot	Can S2S be adapted to families supporting adolescents with AOD?	To adapt and test S2S with family caregivers of adolescents/ young adults with AOD	Practitioner (SW)
17. Intervention	Feasibility/acceptability pilot	Can S2S be adapted to families with paediatric TBI?	To adapt and test S2S with family caregivers of children/ adolescents with TBI	Practitioners (SW, Clin Psych, Neuropsych)