



INSWABI Progress Report

Vol 11, Issue 1

January 2017 – June 2017

1. Introduction

Welcome to the first Progress Report of 2017. We open with a profile of long-term INSWABI member Lauren Tyrrell from Victoria Australia. This is followed by a report on a Disability Conference attended by A/Prof Thomas Strandberg; and a precis of INSWABI member Mark Holloway's doctoral project titled Acquired Brain Injury: The lived experience of relatives and friends. Congratulations to the recently graduated Dr Mark Holloway. A new research project currently being undertaken by INSWABI members in Ireland on Family meetings in

rehabilitation settings is also outlined and a poster presented by INSWABI member Jacinta Sadler on Complex discharge planning at an Australian Brain Impairment conference in May 2017. New publications by INSWABI members are then profiled and upcoming conferences for 2018. An update is then provided on the work with the INSWABI website and the INSWABI executive committee meeting.

We hope you enjoy reading this report.

Grahame Simpson Patti Simonson

2. Membership Profile



Lauren Tyrrell
BSW & Masters Family
Therapy

Social Work Clinical Lead –
(Barwon Health) McKellar
Community Rehabilitation

Centre, Geelong, Victoria, Australia.

Lauren Tyrrell trained in social work at Deakin University-Geelong and last year completed her Masters in Family Therapy through Latrobe-Melbourne under the Bouverie Centre program. She has a long background in youth work within the community sector and State Government working in Residential Care, Teenage Foster Care, Placement & Support, Drug & Alcohol Projects and as a Program & Service Advisor. Qualifying as a social worker in 2007 meant Lauren could pursue her dream of working in public health, embracing opportunities in Barwon Health, establishing social work roles in the Rapid Assessment & Planning Unit and

Emergency Department, General Medicine and eventually joining the Women's & Children's Service. When covering a Senior position at McKellar Out Patients in 2010 Lauren discovered a passion for working in ABI & Spinal rehabilitation. This same year she met West Mead ABI & Spinal social workers presenting at the Dublin Social Work Conference. These new networks became invaluable resources and helped to start paving her way towards defining the social work role in the rehabilitation journey by bringing family focused programs such as West Meads Strength-to-Strength program and Bouverie's Family-to-Family Link Up program to Geelong. INSWABI networks also helped evolve her keen interest in the area of parenting with an ABI. Honoured to work with Mark Holloway from Head First in the UK to publish an article on the topic in the newly establish INSWABI journal, this work prompted her to seek funding from the Traffic Accident Commission to host a Parenting with ABI Forum, positioning public health to

INSWABI Progress Report

January 2017 – June 2017

educate the community sector about the McKellar service & ABI sector in Geelong, about ABI and its impact on families and the need for services to work closer together to support families. The McKellar ABI team continue to run this event yearly and are researching the impact of the forum with the sector. Lauren also links closely with social worker Jane Wexler and is influencing the use of Jane's Reflective Practice Peer Supervision model across social work and allied health.

3. Past Conferences



Thomas Strandberg PhD
Örebro University, Örebro,
Sweden

Activities from Sweden

May 3 – 5, 2017 the Swedish Network on Disability Research together with the Nordic Network on Disability Research arranged the NNDR 14th Research Conference on disability with the theme; Living with disability. The conference was attended by 350 participants from 21 countries and hosted at Örebro University Campus. The spring had just arrived to Sweden and the weather was nice and sunny.

During the conference five keynote speakers were invited to present actually research on disability, 30 poster presentations and nine symposiums were performed and approximately 180 parallel seminars were held in different teams:

Life courses and history; Health and social justice; Gender and diversity; Technology and universal design; Education and inclusion; Service, support and rehabilitation; Childhood, youth and family; Labour market and occupation; Citizenship and welfare policy; Body

and sexuality; Theory and interdisciplinary research.



The conference delegates were researchers, policy makers, activists and practitioners within the field and the photo below shows a meeting with the NNDR board, Nordic Welfare centre and The Swedish Agency for Participation. The conference dinner was held at Club700 in the city centre and during the dinner NNDR's new president, Professor Patrick Kermit and the new board were presented. Please see <http://nnnr.no/board/> for more information.



The Örebro student choir performed with songs and hymns, and the dinner was a success as well as the whole conference.

The next NNDR conference will be held in Copenhagen in 2019. Please see the flyer below. On the 14-15th June a small conference/work shop was held in Gothenburg with the theme: Group dwellings for people with disabilities in the future: about research, architecture and technical support. Thomas Strandberg was invited to give a speech on disability research in the Nordic countries. Past, present and future demands were discussed, and approximately 30 delegates from the field attended the two-day seminars.

INSWABI Progress Report

January 2017 – June 2017

4. Research



Dr Mark Holloway DipSW

MA DSW

**Brain Injury Case Manager,
HeadFirst**

Higher degree by research

Congratulations to INSWABI member Mark Holloway has been awarded his Doctorate of Social Work through the University of Sussex. The title of his thesis was “Acquired Brain Injury: The lived experience of relatives and friends.”

Thesis Summary

Family members are themselves affected by the impact of Acquired Brain Injury (ABI) upon their relatives and they play an important role in the rehabilitation and long term support required. The study aims to understand how families are impacted and their views on the formal and informal support received directly or indirectly as a consequence of the ABI. To date there has been very little research undertaken by social workers in relation to ABI and/or the experience of family members.

A mixed methods research design was employed to capture the lived experience of family members of people with ABI. The results of the quantitative and qualitative data were triangulated against the literature.

An online survey was completed by 110 relatives of people with an ABI, seeking their experience of the condition, its impact upon their lives and their views of services. The results of the survey were collated and organised in SPSS (version 24). Non-parametric Spearman's Rho Correlations (non-parametric test) were performed upon the results. In-depth, semi-structured interviews were conducted with 16 family members of people with severe ABI to ascertain the family members' experience of

their relatives' condition, its impact upon them and their views of the associated formal and informal support received. Inductive thematic analysis of the transcribed interview data was undertaken to identify themes.

The quantitative element of the research identified strong correlations between the relative's assessment of the invisible impairments suffered by those with an ABI (cognitive, executive, behavioural and emotional difficulties) and lack of insight. This correlation was not present in relation to physical impairment. It was observed that increased loss of insight and behavioural difficulties were strongly correlated with loss of friendships by the non-injured family member. The results of the inductive thematic analysis identified 7 themes which were:

- ◆ The Context;
- ◆ The All-Encompassing Challenge;
- ◆ Family Loss and Grief;
- ◆ The Unavoidable Burden;
- ◆ The Poor Experience of Support;
- ◆ Positive Support and Change;
- ◆ The Curator of Narrative.

The research identified that family members' experience is complex and enduring, encompassing most aspects of life, and is affected by the context in which it occurs as well as by formal and informal support structures. The particular nature of the grief and loss experienced by families is ambiguous, develops over time and leads to ambivalent feelings for family members who perceive no option but to remain involved. Informal and formal support frequently fails to take account of the reality and complexity of the condition and fails to integrate the relative by recognising their own losses and trauma.

INSWABI Progress Report

January 2017 – June 2017

Relatives' views on the services received identified significant gaps in practitioner knowledge, most especially of those aspects of life that were of most concern to them, the invisible impairments and issues with insight. Practitioners that were valued were more likely to be specialists in the condition and practiced as "expert companions" supporting the relative to develop a new "neuro-narrative" to reconstruct their identity in the face of their ongoing grief. The specific nature of the condition requires such an approach if input is to be effective.

Greater understanding of the complex lived experience of family members may support more effective responses to both them and the individual with ABI, integrating services and families to improve quality-of-life. As ABI is a process with changes to functioning developing over time, the information and knowledge required by loving and supportive relatives needs to be created with them, being person-, family-, injury- and context-specific.

'Family Meetings - An exploration of patient, family member and staff experiences.'



**Anne O'Loughlin, Principal
Social Worker**

**National Rehabilitation
Hospital Dublin**

INSWABI members who are part of the social work team at the National Rehabilitation Hospital (NRH) Dublin Ireland have initiated the following project. We look forward to hearing about the results.

The Family Meetings Survey of patients and their families who attend the NRH is a joint

research project being undertaken by Dr Paul Carroll, Rehabilitation Consultant, NRH, the Social Work Department, NRH and Dr Sarah Donnelly, School of Social Policy, Social Work and Social Justice, UCD. This project will examine patient, family and staff member experiences of Family Meetings in the NRH. Family meetings are an integral part of our work and of the patients/family journey. We devote a substantial amount of time and staffing to the meetings and the study would like to get feedback on the experiences of patients, families and staff over a 3-4 month period.

Research questions to be addressed include:

1. What is the purpose and role of Family Meetings for patients and families in a rehabilitative hospital setting?
2. What are patients, family member and IDT member views and attitudes about Family Meetings and their participation within this forum?
3. What level of involvement/participation have patients, their family members and IDT members at Family Meetings?
4. Are patients and their family members satisfied with the level of participation and control afforded to them at Family Meetings?
5. Do IDT members feel sufficiently trained in the skills required to participate in Family Meetings?

The Outcomes we want to achieve:

1. To have an in-depth understanding of patient and family members current experiences of Family Meetings and their suggestions for improvements.
2. To have an in-depth understanding of IDT members current experiences of Family Meetings and their suggestions for improvements.

INSWABI Progress Report

January 2017 – June 2017

3. To identify if there are unmet training needs for IDT members in relation to skills required for Family Meetings.
4. To make changes to practice based on study findings that will result in greater satisfaction and more effective and efficient Family Meetings experience for all participants.

About the Researcher

Dr Sarah Donnelly is currently employed by University College Dublin as a Lecturer in Social Work. Sarah carried out a similar research project on care planning meetings on a Stroke Unit regarding persons who had capacity issues in Tallaght Hospital. The research led to agreed protocols and guidelines for these meetings and training for staff. The study will be an action research approach where members of the Social Work Department will act as co-researchers in the data collection and assist patients/families to complete the questionnaires. The Social Workers will not interview their own clients/families or be involved in questionnaires about meetings they were present at to reduce bias.

Poster presentation



Jacinta Sadler
Senior Clinician Social Worker

**ABI Unit Rehabilitation,
Caulfield Hospital**

Melbourne Australia

Congratulations to INSWABI member Jacinta Sadler who was involved in the following poster presentation at the Australasian Society for the Study of Brain Impairment Conference in Melbourne on the 2nd of June 2017.

When all the doors close: Complex Discharge planning for Individuals with severe cognitive-behavioural changes: A case study

By: Danielle Sansonetti (Occupational Therapist), Dr Mithu Palit (Rehabilitation Consultant) and Jacinta Sadler (Social Worker), Acquired Brain Injury unit at Caulfield Hospital In Melbourne Australia

Background and Objectives

Cognitive impairment combined with behaviours of concern can have a considerable impact on discharge destination options available to individuals following severe brain injury. Many accommodation facilities are not able to provide a specialised and consistent approach to managing behaviours of concern that would afford sustainability of these living arrangements, leading to a lack of suitable accommodation options for individuals who are unable to be supported in their own home setting.

Aims

- (i) To describe the complexities and challenges that exist throughout the discharge planning process for individuals with behaviours of concern and cognitive impairments following severe acquired brain injury.
- (ii) To explore the enablers and barriers to complex discharge planning for people with severe cognitive-behavioural disturbances following an ABI

Method

This descriptive case study outlines the considerations and process of exploring least restrictive discharge options for a 50 year old man with severe cognitive-behavioural impairment across a 12 month rehabilitation timeframe.

INSWABI Progress Report

January 2017 – June 2017

Case study

The poster focussed on a case study of a 50 year old man who sustained a hypoxic brain injury. He had a history of Type 1 diabetes which he managed independently prior to sustaining his ABI. He was admitted for inpatient ABI rehabilitation, assessment and discharge planning. He was living independently prior to his injury.

The complex discharge planning issues were:

- ♦ Severe cognitive impairment – severe memory loss, lack of flexibility, impaired awareness of deficits and need for rehabilitation.
- ♦ Significant behaviours of concern – including frequent and significant verbal aggression, refusal of medical care and treatment, repeated threats of absconding.
- ♦ Risks – consistent inability to manage own diabetes (Patient's beliefs about required insulin does would have resulted in death), refusal of inpatient and community based support, inability to initiate most aspects of his daily routine.
- ♦ No discharge destination – The patient was unable to return home to live independently. There was a lack of sustainable discharge options identified that could support his needs and assist to manage his challenging behaviours.

Results

A focus group was completed with clinicians involved in the case to explore what were the strengths which enabled effective discharge planning. Results were grouped into the following themes:

Patient factors - early establishment of rehabilitation goal setting;

- ♦ effective engagement and the development of a trusting relationship between the patient/family and the treating team on an ongoing basis
- ♦ continuing to explore with him his hopes for the future and allowing him to be empowered in the decision making with ongoing support from clinical staff
- ♦ using the patient's inflexibility, the team developed a written rigid fixed dose of insulin management that he was able to contractually agree to.

Family engagement – the patient's family were an integral component and the team worked effectively and collaboratively with the family to support discharge family. The family were heavily involved in facilitating the patient's acceptance and agreement to continue to participate in therapy and to explore and consider discharge accommodation options.

Innovations in cognitive-behavioural interventions – generalisation of cognitive behavioural supports and the use of behavioural plans applied in the inpatient rehabilitation setting to the accommodation setting. This was achieved by effective clinical handover and involving accommodation staff with the delivery of elements of care by accommodation staff with support from the rehabilitation team. This process facilitated familiarity and trust with the delivery of care within this environment, along with greater acceptance of this setting as a future living arrangement.

Positive risk taking – moving the patient out of a supportive ABI inpatient unit with consistent and highly specialised diabetes and behaviour management plans into alternative accommodation posed some challenges and

INSWABI Progress Report

January 2017 – June 2017

risk. A positive risk taking model was used to support the discharge planning process, which focussed on the patient's strengths, self-determination and empowerment.

Conclusions:

Discharge planning is a complex process that requires an integrated team approach that includes the patient and significant others as central in this process. Innovative approaches are required to meet patient and significant others' aims for suitable community living.

References:

Cruz, K., Unsworth, C., Roberts, K., Morarty, J., Turner-Stokes, L., Wellington-Boyd, A., Matchado, J., & Lannin, N. (2015) "Engaging Patients with Moderate to Severe Acquired Brain Injury in Goal Setting", *International Journal of Therapy and Rehabilitation*, 23(1): 20-31.

Rehmann, K. (2015) "Ethical Considerations in Discharge Planning on an Inpatient Behavioural Health Unit", *Journal of Human Behaviour in the Social Environment* 25(7): 723-730.)

Sloan, S., Callaway, L., Winkler, D., McKInley, K. & Ziino, C. (2012) "Accommodation Outcomes and Transitions Following Community-Based Intervention for Individuals with Acquired Brain Injury", *Brain Impairment*, 13 (1): 24-43

Veselinova, C (2014) "Principles for Positive Risk Taking for Individuals with Disabilities", *NRC*: 16(9): 526- 529)

5. Publications, Resources, New Initiatives

Publications



Matérne, M., Lundqvist, L. O., & Strandberg, T. (2017).

Opportunities and barriers for successful return to work after acquired brain injury: A patient perspective. *Work*, 56, 125-134.

Whiting DL, Deane FP, Simpson GK, McLeod HJ, Ciarrochi J.

Cognitive and psychological flexibility after a traumatic brain injury and the implications for treatment: A conceptual review.

Neuropsychological Rehabilitation 2017; 27: 263-299

6. Upcoming Conferences



The Joint World Conference on Social Work, Education and Social Development

is being held in Dublin from 4-7 July 2018. See www.SWSD2018.org for more information or contact Anne O'Loughlin (Anne.O'Loughlin@NRH.IE)

January 2017 – June 2017



The 15th Nordic Network on Disability Research

will be held in Copenhagen Denmark from May 8-10 2019. Contact Thomas Strandberg (*Thomas.Strandberg@oru.se*) for more information.



The 41st annual conference of the Australian Society for the Study of Brain Impairment

is being held in Adelaide from 2-4 May 2018. A/Prof Grahame Simpson is one of the invited national keynote speakers, and a pre-conference day of social workers from key Australian brain injury rehabilitation centres is being organised. See <http://www.assbi.com.au/confhome.htm> for more information about the conference or contact (Grahame.Simpson@sswahs.nsw.gov.au) for more information about the social work pre-conference workshop.

7. Website

The INSWABI website is progressing very well. We hoped to launch the website sooner but due to a couple of setbacks it took longer than we thought. The website is now in the final stages which is exciting. The INSWABI executive committee are meeting in late September so we are hoping to review the progress and launch it soon after that. When Graeme forwards you our progress reports in the future, there will be links to the articles which will take you to the website. We would love to hear your feedback about the website. Our hope for the website is that it is a place for you to access information, read about the latest research, resources and upcoming conferences in the ABI area.

8. Committee news



The INSWABI Executive Committee was established in 2010 during the International Social Work conference held in Dublin. The committee runs on 3-year terms. The Executive Committee for 2016-2019 is having its fourth meeting in September 2017 to finalise the INSWABI website and kick off the psychosocial assessment framework project.

INSWABI Progress Report

January 2017 – June 2017

9. Welcome

New members

A warm welcome to our new members from

Jade Gomez Australia

Jacquie Tulloch Garcia Australia

Testimonials

Bronwyn Gregory NZ

Changing jobs

I have greatly appreciated your support and assistance over the years and have found being a member of INSWABI very useful! My only regret is not making it to one of the conferences.

I wish you and all the INSWABI members all the very best!

Bob Lomax Canada

Retiring

I have been a member for a number of years and last year contributed some resources from my program. I am to retire on July 13, 2017 after 22 years of working with people with TBI. I just wanted to inform you of this and that you can remove me from emails etc as my work email will cease to exist. All the best in yours and the members continued work in this area.

10. Pass this on.

Please circulate the progress report to any of your colleagues who might be interested.

11. Interested in joining INSWABI?

Patti Simonson

(United Kingdom, Ireland, Europe, North America)

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