

CONCURRENT SESSION 5

FRIDAY 6 OCTOBER | 9.00-10.30AM

HALL C – EMERGING TECHNOLOGIES

C.1 It's 2017 and machines can learn, but can they care?

Presenter and author: Adam Jahnke, Founder and CEO, Umps Health, Melbourne, Australia

We are now witnessing the widespread adoption of machine learning: the ability for machines to make informed decisions by absorbing and analysing complex datasets. This has been enhanced through study in neural networks – computers modelled on the human brain and nervous system. This type of computing intelligence has allowed machines to recognise behavioural traits of humans, and determine a person's mental, physical and emotional state. By giving machines a 'human brain' we have in a sense, given them the ability to care.

But providing care for someone is about supporting is an undeniably human act, requiring compassion, warmth and empathy. As we explore the Future of Caring, what role could machines play in supporting the provision of care? What opportunities do they create for carers and consumers of care?

In this presentation, Adam Jahnke will provide an introduction into machine learning and artificial intelligence, and how this is being used today to improve the way we live society. Drawing upon his own experience as a carer, he will provide an overview of the practical applications of machine learning and artificial intelligence for carers, and provide insight into the future services it will enable. Finally, he will discuss the likely models for delivery for machine learning and artificial intelligence.

Adam is the founder and CEO of Umps Health. Umps Health detects data about a person's interaction with home appliances, and raise alerts when behaviour is out of the norm. He has previously worked on smart city and smart home projects throughout Australia and South-East Asia. Adam is also conducting research on the international and intergenerational response to challenges associated with ageing at the University of Melbourne.

C.2 Technologies for health and care – potential for change

Presenter and author: Madeleine Starr, Director of Business Development and Innovation, Carers UK

The steady march of technology into our workplaces, homes and public services has delivered changes that have transformed how we live our lives. Yet the use of health and care technologies is still often spoken of as an area of ‘potential’ that is yet to be realised. If we are to realise that potential then it is vital to understand public awareness of and attitudes towards these technologies and to take action to promote them.

Research carried out by Carers UK found there is very low public awareness in the UK of health and care technologies. A YouGov poll of 2000 people found that even the most ‘tech savvy’ respondents did not think about technology for health and care even if they were using it in other areas of their lives such as banking or shopping. Only 1 in 3 had any awareness of how technology could support caring, yet when the kinds of technologies on offer were explained to them, 79% said they would use them if they were affordable.

Through its Carers Strategy for England, the UK government is supporting a public awareness campaign to help carers understand the benefits of health and care technologies. A separate campaign will also target health and care professionals and provide them with resources to help raise awareness of the benefits of technology, and the technology sector, highlighting the potential of the ‘carer market’ for their products and services.

This presentation will cover the essential features of the campaign and the strategies used to ensure the widest possible public reach, for example embedding the campaign in existing awareness opportunities such as Carers Week and Carers Rights Day, and using networks, events, social media and mainstream media. It will showcase the visual material developed to catch public attention and drive people to information on health and care technologies, the resources developed for commissioners and practitioners, and the report produced for the technology sector. Finally, it will look at the impact of the campaign – its reach and the difference it has made in helping increase take up of potentially transformational technologies.

C.3 Feasibility, useability and acceptability of a smartphone application to support carers of people with colorectal cancer

Presenter: Natalie Heynsbergh, PhD student, Deakin University, Victoria, Australia

Authors: Natalie Heynsbergh, L Heckel, M Botti, PM Livingston

Carers of people with cancer often experience physical, mental, social and financial burden during the caring period as well as unmet needs. There are few interventions addressing the needs of carers of people with cancer involving smartphone technology. This study will evaluate the feasibility, useability and acceptability of a smartphone application among carers of people with colorectal cancer.

Methodology involves four phases. Phase 1 is a systematic narrative review highlighting the feasibility, useability and acceptability of technology-based interventions in carers of people with cancer. Phase 2 involves focus groups and interviews with up to 80 carers and healthcare professionals, to discuss unmet needs and current attitudes and behaviours towards smartphone applications. Phase 3 involves the integration of data derived from Phases 1 and 2 to develop a smartphone application. Phase 4 is the trial of the application with up to 30 adult carers of people with colorectal cancer (CRC). Participants will have access to the application for one month and will be assessed at baseline and one month post-recruitment.

Feasibility, useability and acceptability of the application will be assessed through a utility survey. Carers will complete the Supportive Care Needs Survey- Partners & Caregivers (SCNS-P&C45) and the Zarit Burden Inventory (ZBI) to measure unmet needs and carer burden, to compare to trends indicated in the literature.

This study is the first in its kind to assess the feasibility, useability and acceptability of a smartphone application for adult carers of other adults with colorectal cancer. The research has the potential to provide carers with easy access to relevant information and support during the caring period.

HALL A – MENTAL HEALTH CARE

A.1 Developing support for carers from the military forces community

Presenter: Jennifer Kenward, Experience of Care Lead – Community, Primary and Integrated Care, NHS England, United Kingdom

Authors: Jennifer Kenward; Paul Watson (PhD student, Verans Hub, Northumbria University, UK); Jenny Franks, Helen Leadbitter and Toni-Marie Leaf (Children's Society, UK)

This presentation describes the development of NHS England's Commitment to Carers to address the needs of carers within military forces communities. NHS England leads the National Health Service (NHS). The Commitment to Carers programme employs partnership working with national charities, carer support organisations, NHS commissioners, local government and arms-length bodies, ensuring our work reflects the needs and values of carers. This development builds on connections made at the 6th International Carers Conference, improving knowledge and understanding of military forces communities and the challenges carers experienced by serving and veteran personnel.

Military carers and specifically young carers from military families have been identified as a vulnerable group, for whom support is not always accessible and are often not identified. NHS England has committed to developing improved processes of providing support for military carers working in partnership with the Ministry of Defence Covenant and Military Health Commissioning teams.

Academics, have explored the impact combat has on military personnel and the potential impacts experienced when returning home. In the UK the King's Centre for Military health and the Academic Centre Defence Mental Health lead research around the effects of combat on British service personnel and veterans' health. Research looks at pre and post combative effects on health including post-traumatic stress disorder (PTSD), traumatic brain injuries (TBI), pre-deployment stress, mental health, re-integration and military families. However, this research has not always been translated to delivery of services from the NHS for carers. Further research, predominantly from the USA highlights emotional effects combat on children and young people left behind during parental/sibling deployment, and their need for support.

The ambitions of this programme are to:

- develop the Commitment to Carers to encompass issues experienced by Carers from Military Forces Communities to align with the military covenant
- identify policy and operational objectives from emerging national and international research
- develop and implement integrated working agreements between military and universal service delivery leads to support carers
- agree key objectives for Young and Young Adult Carers within military forces communities to facilitate more timely identification and support.

A.2 Key alliances to support families - police and justice systems

Presenter: Debbie Childs, HelpingMinds, Perth, Western Australia

Authors: Julie Mcchesney and Debbie Childs (HelpingMinds)

For more than 41 years, HelpingMinds has supported the whole family through their recovery journey. HelpingMinds constantly seeks to improve carers' access to support and to better engage with mental health carers through different models of service delivery.

We will discuss two partnerships which address the need for early recognition, intervention and support of mental health carers; and to ensure improvements in longer term outcomes for carers and families. We will report on these interventions and engagement strategies.

Partnership 1 – Outcare and the Start Court (Mental Health Diversion court)

HelpingMinds works with Outcare to support carers of people in the criminal justice system who have co-occurring mental health issues. Outcare supports people prior to and following their release from prison as well as those at risk of entering the criminal justice system. The Start Court is Western Australia's mental health diversion court. HelpingMinds works with the Start Court team to ensure that mental health carers are referred for support, and its counsellors and peer workers support prison visitors who are mental health carers. Outcare provides HelpingMinds' Carer Packs to prison visitors who are mental health carers. HelpingMinds helped Outcare establish an effective recruitment process for their Carer Peer Worker and provided a Carer Peer Mentor. Outcare and Start Court refer mental health carers to HelpingMinds for education, support groups, peer support, respite and counselling.

Partnership 2

The WA Police Mental Health Co-Response team is being trialled across 50% of the Perth metropolitan region. The team responds to callouts that involve a mental health episode or someone threatening self-harm. The team includes specially trained self-nominated police officers and a mental health clinician. HelpingMinds is working with this team by providing Care Packs, which the police leave when they identify a mental health carer. Police are recording numbers of packs issued. Care Packs include information about the Start Court, the Drug Diversion Court, carers rights under the Mental Health Act, contact details for HelpingMinds. Carers will be included in the evaluation of the trial.

A.3 Using a problem-solving self-help manual to support carers of young people with first-episode psychosis

Presenter: Professor Terence V McCann, Professor of Nursing Research, Centre for Chronic Disease, College of Health and Biomedicine, Victoria University

Authors: Professor Terence V McCann; Professor Dan Lubman (Turning Point and Eastern Health; Eastern Health Clinical School, Monash University, Melbourne, Australia) and Eileen Clark (Clarks Clerks, Albury, Australia)

Caring for a young person with first-episode psychosis is typically a difficult, demanding and prolonged experience. Carers are often confronted by a range of physical, emotional and financial hardships. These adverse effects are associated with greater rates of relapse and non-recovery in the young person. Most approaches that aim to support carers are costly and resource intensive, which limits their reach.

An alternative, cost-effective approach to helping carers is to use a problem-solving self-help manual. These manuals are readily accessible and give readers the opportunity to re-read material at a later date. Carers can use self-help manuals more or less independent of health care professionals, minimising the need to travel to attend therapy. However, most studies on problem-solving self-help manuals with a mental health focus have concentrated on people with depression and anxiety, and not on carers.

The aim of the current study was to evaluate if carers of young people with first episode psychosis who used a problem-solving self-help manual reported a better experience of caring, less distress and better general health compared with carers who received the usual professional support. The effect on the interpersonal relationship between the carer and young person was also considered. A randomized controlled trial conducted with 124 carers in Melbourne found the self-help manual provided some short-term benefits, with participants who used the manual reporting a more favourable experience of caring and a greater reduction in negative emotions compared to those who received support as usual. This study provides preliminary evidence that a problem-solving self-help manual can offer non-threatening and low-cost therapy, with potentially good reach and penetration, in comparison to other more complex and resource-intensive family interventions. The use of a self-help manual could make a significant contribution as a cost-effective supplement to specialist support for carers, particularly in a climate of fiscal restraint.

HALL B – INTERNATIONAL CARING

B.1 Mobilizing action – family caregivers in Canada; together we make change happen

Presenter: Nadine Henningsen, President, Carers Canada

Authors: Nadine Henningsen and Catherine Suridjan (Public Policy and Stakeholder Relations Lead, Carers Canada)

Mobilizing Action: Family Caregivers in Canada is an integrated and shared plan to address the physical, psychosocial and financial needs of Canadian carers. Leveraging the commitment and momentum of over 60 stakeholders (caregivers, health professionals, service providers, community support groups,

researchers, governments, civil society and non-governmental organizations, employers and labour representatives), Mobilizing Action aims to effect real change that supports the integral role of carers in society. Developed through extensive consultations and endorsed by a broad range of stakeholders, the Integrated Action Plan contains seven strategic outcomes and 14 measurable indicators to support the achievement of 13 clear objectives and 92 recommended actions to better support carers. The action plan advances mutual priorities and objectives by targeting specific stakeholders and leveraging their sphere of influence.

This presentation will share the journey, strategies and tactics of Mobilizing Action that are rooted in collaborative engagement, credible leadership, as well as individual and collective accountability. Mobilizing Action is an example of how true partnerships, where a shared purpose is created among diverse stakeholders, have led to real change for carers. Within one year of the project, the support and commitment from stakeholders across sectors were rising and they were ready to start actions. A project that began with an intent of only developing a blueprint for a concrete plan has expanded its scope to an early execution of selected actions outlined in the plan.

The presentation will showcase the successes we have achieved in influencing and advancing the policy and program agendas for carers in:

- enhancing awareness of caregiver needs and facilitate their voice in care provision and the health care system
- improving access to caregiver support services and patient care resources
- alleviating financial burden placed on family caregivers
- create supportive workplaces that recognize caregiving obligations.

B.2 Mobilizing the UK carers movement over 50 years

Presenter and author: Heléna Herklots CBE, Chief Executive, Carers UK

The rights base and recognition of carers in the UK would not be what it is now without the involvement of carers themselves. Carers UK has been building a movement of carers for over 50 years. The way we have communicated and involved our members over time has changed, but the principles of being carer led and involving carers in our work is the same. Bringing the daily realities of caring for individuals and the demographic evidence to the attention of public and policy makers through the media, through our research with carers and through carers' own campaigns, has helped lead to a series of new rights for carers and greater public recognition.

This presentation looks at how Carers UK has continued to strengthen and grow the carers' movement and the ways in which it engages and collaborates with other organisations, public, private and voluntary sector, as well as with carers to build a carers' movement. Carers UK's membership has grown by one third.

It will also look at how we've sought to build a new framework to harness the skills, experience and passion of carers and former carers to volunteer in a wide variety of roles; from providing valuable peer support through our online forum and listening ear phone service to galvanising volunteers reaching out

into many more communities with information about support and to bring the voice of carers into local services. Our web-based technology tracks our volunteering and shows key partners how volunteers are achieving outcomes.

Delegates will learn about:

- key partnerships and collaborations that have helped Carers UK to drive the carers movement in the UK
- and share approaches to sharing carers' personal experiences and mobilising carers in campaigning including the outcomes
- and share approaches to engaging a membership of carers including in awareness campaigns and building a volunteering programme including the outcomes
- how the use of technology can support the demonstration of outcomes in volunteering.

B.3 Employment is respite service: An analysis of the situation and policy of 'employed carers' in Taiwan

Presenter: Tsuann Kuo, President, Taiwan Association of Family Caregivers

Author: Hsiao-Chan Chang, Deputy Director, Taiwan Association of Family Caregiver

OEDC countries have reminded and warned that working carers are often absent from work without reason, late for work, leave early and have more requests for leave. However, new carers are usually so nervous and busy, they might rush to resign from work. This hasty decision not only decreases family income, it also affects pension payment, which tends to lead the family to financially insecure situation.

The Long-term Care Services Act 2015 in Taiwan has firstly included supportive services for family carers, which demonstrates the attention to those people who are increasingly attached than before. However, the policy is not comprehensive. For working carers, long waiting lists for service application puts whole families in chaos alone in the early stages; family care leave allows seven days leave, but with no pay; official long-term care services in practice are provided only in daytime; working carers are difficult to link up care after work due to long working hours in Taiwan.

This study starts from the analysis of the process and limitation of the long-term care services in Taiwan. Furthermore, working carers facing the care problems and the user experience will be inspected. Finally, from the viewpoint of the friendly workplace policy, the suggestions for working carers policies and services will be issued as to:

- allow special leave for caring for the elderly for six months in accordance with parental leave
- revise the pension system and offer uninterrupted pension and years of service as legal safeguard
- plan a flexible long-term care service, such as extended service during night time and holiday.

ROOM H1 – COMBINING WORK and CARE

H1.1 The influence of carer focused workplace practices on perceptions of workplace climate for supporting care

Presenter: Dr Hugh TJ Bainbridge, Senior Lecturer, University of New South Wales, Sydney, Australia

Authors: Dr Hugh TJ Bainbridge and Dr Timothy Broady (Senior Research and Development Officer, Carers NSW, Australia)

Increasingly, organisations across the world are pursuing innovations in workplace practices to help employees with caring responsibilities. These practices are designed to offer carers flexibility and leave options in order to assist with managing work and care demands. While still relatively novel, these practices are a popular organisational response to the care responsibilities of their workforce and offer the potential to improve carer personal and work related outcomes. Despite this, limited attention has been given to studying: i) the outcomes of workplace practices, ii) explanations for why the practices contribute to these outcomes, and iii) whether these outcomes vary across different groups of carers.

In this study, we address these gaps via a survey of employees with unpaid care responsibilities for family members or friends with disabilities, mental illness, drug and/or alcohol dependencies, chronic conditions, terminal illnesses, or who are frail. In particular, we focus on job turnover intentions as employment is a major life role undertaken by many carers, and because the cessation of employment is associated with significantly lower carer financial, physical, and psychological wellbeing.

First, we considered the effects of offering carer supportive practices at work. Second, we explored one potential process by which workplace practices could affect turnover intentions. Third, we considered whether the effect of these practices varied across different groups of carers. In this presentation, we outline implications of these findings for carers, organisations and policymakers.

H1.2 Assistive technology and community networks supporting working carers

Presenter: Julie McCulloch, Program Manager, Carers WA, Perth, Australia

Authors: Victoria Amey and Clare Cullen (Marketing and Communications Manager, Carers WA)

The Working Carers Support pilot project, delivered in partnership with Carers WA and Technology Assisting Disability WA (TADWA), aims to support working carers by providing assistive technology solutions and a Community Care Network (CCN) to help the person with care needs remain safe and independent (at home alone).

The project's objectives are to:

- contribute to the economic wellbeing of carers and people who require care by creating opportunities for carers to access and/or to maintain paid employment
- provide respite for carers to improve their health and wellbeing

- promote inclusion and strengthen informal and community connections by creating opportunities for family, friends, neighbours and others, to contribute positively to the wellbeing of the carer/and person requiring care
- develop a service which is flexible, builds capacity, is sustainable and is based on principles of choice and control.

This innovative project tests a model of service that utilises the growing market of assistive technology, in combination with supporting carers to identify and reach out to their informal/natural supports. It employs an Occupational Therapist to work closely with the person requiring care and their carer, to assess their needs and determine how assistive technology could be tailored to meet their individualised needs; thus alleviating the stress of the carer whilst they are at work. Specialised staff from TADWA install the equipment and provide training and ongoing assistance.

Carers WA staff is responsible for the project coordination and service delivery. As an integral part of the project model, Carers WA works with the carer and the person requiring care to assist with identifying, building and maintaining a CCN. The role of the CCN is to support the caring relationship and respond to alerts activated via the assistive technology. Whilst assistive technology is readily available in the community, such as personal alarm pendants, the unique aspect of this model is the combination of the technology with the establishment of a CCN. This presentation will include outcomes of the pilot project.

H1.3 The Hidden Workforce

Presenters: Sally Morris, Response Training and Employment, Darwin, Australia and Teresa Smithson, Manager Care Services, Carers NT, Australia

The Carers NT Recognition Project, delivered in Darwin in 2016, addressed the need to formally recognise the skills and knowledge people have acquired in their role as an unpaid carer. Twenty carers registered to participate in the project, of whom 17 completed receiving a Certificate III in Individual Support. The project used the Australian Qualifications Framework (AQF) as the benchmark to align the skills and knowledge carers develop with competencies from CHC33015 Certificate III in Individual Support. This qualification provided the platform to realise the potential of carers as workers and/or providers of services under the National Disability Insurance Scheme (NDIS).

The project set strategies to address the disadvantages faced by many carers including:

- lack of recognition received for their carer role
- difficulty experienced in accessing education and training
- barriers faced when attempting to enter the paid workforce.

The Carers NT Recognition Project supported the implementation of the NDIS by establishing a process that enabled carers to transition from an unpaid carer to paid employment in the Community Services Sector. It established Carers Recognition as a sustainable recruitment strategy that will boost the pool of potential employees in a sector which is growing rapidly yet experiencing staff shortages. Through this project, we have already seen employment outcomes for several the participants; re-entering the workforce or entering the workforce for the first time.

The support provided by Carers NT through respite services and other carer services was a key element to the success of this project. The Carers NT Recognition Project provided opportunities for carers to engage with education and training, access paid employment, achieve a greater sense of wellbeing and improve their economic security.

ROOM H2 – CHALLENGING BEHAVIOURS

H2.1 Carers are the experts, we are not the experts

Presenter and author: Sandra Gilbert, Group Care Manager, NoosaCare Inc, Tewantin, Australia

Separation when a loved one is admitted into an Aged Care Facility can be an incredibly emotional time for the carer, with a variety of mixed feelings including relief, guilt and grief. This is compounded when this admission removes their caring role. However, you don't stop caring just because a person is admitted into care. In the past, the resident was handed over to the 'expert' staff and the carer was told to go home and the 'expert staff' would now handle all care. The irony of this situation is that the carer is the expert; they know this person better than anyone else. This is even more important when the person admitted is living with dementia.

This presentation will share the journey of NoosaCare when designing their Memory Support Unit. The decision was made to make family the focus of the home. The carer would be the expert and would teach and mentor the staff on how to care for their loved one living with dementia. Carers are positive care team members. This philosophy was also carried through into the design phase of the unit. With large outdoor areas, edible gardens, men's shed and a BBQ area to encourage families to visit. There are two fully functional homelike kitchens that carers and residents are welcome to use and cook their favourite meal. There is also an overnight hotel type room where loved ones are welcome to come and stay for the first few days of person's admission and to educate the staff, or they are welcome to stay in their loved one's room with them.

University of The Sunshine Coast is presently finalising research conducted on our new model, to understand the perspectives of older people, their families or carers and staff of the effect of a purpose-built Memory Support Unit on the transition into care. The initial findings have been very positive.

[30 mins]

H2.2 Identifying challenges that carers face: A systematic scoping review of the outcomes and interventions in the traumatic brain injury and spinal cord injury literature

Presenter: Dr Anne Baker, Lecturer in Occupational Therapy, Australian Catholic University, Melbourne

Authors: Dr Anne Baker; Samantha Barker (Institute for Safety, Compensation and Recovery Research, Melbourne); Dr Amanda Sampson (Institute for Safety, Compensation and Recovery Research, Melbourne); and Dr Clarissa Martin (Department of Physiotherapy, Monash University, Melbourne)

Although not studied together frequently, the two patient cohorts of traumatic brain injury and spinal cord injury provide an interesting point of comparison, with regards to rehabilitation requirements and outcomes. These two groups of patients represent two conditions of sudden onset - one affecting the brain and the other not - but both causing marked long term problems, often necessitating care over a long period of time. For informal care to be sustained, the outcome of the caregiving role needs to be positive. However, it is known that many carers are experiencing negative outcomes, such as high levels of burden, significant levels of distress and poor mental health. These are just some of the challenges faced by carers of the traumatic brain injury and spinal cord injury cohorts, and the need to respond to these challenges both within Australia, as well as internationally.

The aim of this review was to identify factors reported with negative and positive outcomes for carers of the traumatic brain injury and spinal cord injury cohorts; to investigate what interventions have been studied to support carers; and to report what effectiveness has been found. Scoping systematic review methodology - four electronic databases and key websites were searched from 1990 to December 2015. Studies were agreed for inclusion, using pre-defined criteria. Relevant information from the included studies was extracted, and quality assessment was completed. Data were synthesised using qualitative methods.

Few studies have looked at factors associated with if the caregiving outcome is positive in the traumatic brain injury and spinal cord injury cohorts internationally; most studies have focussed on negative outcomes. Burden of care is over-represented in the literature for both cohorts. Good family functioning, coping skills and social support are reported to mediate caregiver burden and promote positive outcomes. Interventions available to further promote positive outcomes for carers are limited, and require further testing to confirm their effectiveness. Problem-solving training offers a promising direction for further testing and subsequently implementation as an intervention for both the traumatic brain injury and spinal cord injury cohort of carers.

H2.3 Easy dressing for the disabled

Presenter and author: Cheryl J Campbell, Designer, Chelan Clothing Limited, Australia

The problem of dressing an elderly, injured or ill patient is a major concern of both carers and nurses. The worry that patients may find the procedure painful, or may even be further injured is a daily concern.

I am working on a new structure for clothing which is designed to make dressing the elderly or the sick and injured easier for the carer or nurse, and less painful for the frail. The clothing is designed to look just like ordinary clothing; indeed it is possible to adapt the patient's own clothing with this system. I have around 90 different designs, encompassing all types of Western clothing; both male and female. I am initially concentrating on a basic range, to keep the price of these garments down, but my long dress under this system shows that smart formal wear is also possible with my designs.

The method of dressing is less intrusive than normal clothes, and the patient doesn't have to bend their limbs in the same way as dressing in ordinary clothing, thus making it less painful for patients. It is also quicker to dress patients and less physically demanding. It is possible to dress a patient in the prone position, thus making lifting the patient redundant. I intend to bring out a formal range eventually, as it is known that the psychological aspects of patients are crucial to their well-being. It should be noted these garments are designed for sedentary use, such as those confined to a bed or wheel chairs, or engaged in very little movement, such as sitting still for most of the day.

ROOM H3 – CARER RESILIENCE

H3.1 Frames for fruitful partnership? Negotiation and cooperation between caregivers, care recipients and municipal health and care services

Presenter and author: Oddrunn Sortland, PhD candidate, Center for care research, Norway

This PhD project is framed by a sociological perspective on how different families cope and adjust in their everyday life. It further investigates how and why cooperation and negotiation between formal and informal carers in some cases succeeds, and in other cases not. Data material consist of interviews, conversations and observations of nine elderly and close family members over a period of one to five years in one rural and one urban municipality in Norway. In addition, interviews and observations have been made with professional carers and administrators of public services in home-care nursing and short-term units, as well as physical therapists and GPs.

The way each family handle their everyday life as caregiver and care-recipient is seen in relation to life history, past and present amounts and forms of capital, and possibilities and limitations in their current situation. Each family is unique, with considerable variations regarding history and available resources. Some family members take on a great burden in their care work, being at risk of developing serious health problems related to this. Other families are affected by conflicts and unsolved matters from their past, which effects how they react and adjust when need of care occurs. Preliminary analysis further investigates how forms and amount of capital impact on cooperation and negotiation between elderly, their family and different units in the public and private services. Even if user involvement is a goal in eldercare, there is a lack of routines regarding how this is performed, leading to great variations between the cases. There are, however, several examples of successful partnerships between the elderly, family and public services investigated in this study, as well as examples of families struggling to get the help that they need.

H3.2 Unpacking the 'carers' burden': Carers rights and the sustainability of care

Presenter and author: Amaya Alvarez, Future Social Service Institutes (FSSI) PhD Scholar, RMIT University, Melbourne, Australia

Carer burden is a highly problematic term, widely critiqued within the disability movement and by carers themselves as being too negative. Seeming to label the person with disability (as burden), and reducing caring to something burdensome. In this critical frame, 'carer burden' appears to undermine the positive dimensions of care. Yet despite these tensions the term persists.

Current strategies to deal with the high level of reported 'carer burden' in Australia (and elsewhere) appear to be faltering. Research confirms that carers are experiencing stress, carer fatigue, ill health and economic vulnerability in ever increasing numbers. Carer organisations appear increasingly frustrated with the lack of response. 'Carer burden' is an identified problem that governments acknowledge but struggle to address. A number of approaches to sustaining carers are being advocated. These include better education, peer support, respite, free counselling and building resilience. However worthy, many of these strategies still put the onus on the carer - to be better informed, to manage self-care and be more resilient.

In this paper I will unpack the term 'carer burden', examining it as a word that resonates and expresses something that carers are experiencing. I will use examples from carer consultancies and from NDIS feedback to illustrate why the word persists and to identify where the source of the burden may lie.

This presentation will suggest that burden does not simply lie in the care work, but in carers lack of redress for their own rights and needs. Rights and needs can be unpacked in a context of increasing expectations of the private contribution of carers, and the questionable sustainability of this contribution. Evidence reveals that marketisation reduces certain kinds of services for people with disability and for carers. Carer support services for example, are disappearing under the NDIS. This is partly because within marketised systems, care is seen as straight forward and transactional rather than multifaceted and relational. The presentation will argue that in a marketised system, the onus must still remain on the state to ensure social support is commensurate with the intensity and complexity of care, to avoid the entrenchment of 'carers' burden' and the expectation that carers will carry it.

H3.3 Siblings of people with disability: Their roles and needs within the changing disability/carer sector

Presenter and author: Kate Strohm, Director, Siblings Australia

There is still some uncertainty about how siblings of people with disability (including mental and chronic illness) fit in the carer sector, which results in many siblings, including those who care not receiving the support they need. In looking to the future we need to ensure there are both relevant and timely supports available for all siblings. Siblings intersect with the carer sector in two main ways - as children of parent carers and as potential or actual carers themselves for a brother or sister with disability, at various stages during their lifetime.

This presentation will look in more detail at the needs of both siblings and sibling carers and how the two intersect. It will also look at the challenges in meeting the needs of siblings, whatever their circumstances; and explore ways of supporting parent carers to feel less stressed and more competent in their parenting role for all of their children. The presentation will also report on major projects run through Siblings Australia, including a survey of adult siblings and an innovative peer support program for their support as well as a mapping project of support services for siblings (including those who care), and the gaps found.

The main aim of the presentation will be to enhance the capacity of the carer and other sectors to ensure that siblings are able to gain the support they need for their own benefit, but also for the benefit of their whole family. Providers and families will have a clearer picture of the needs of siblings into the future, especially within the changing disability world. There will be some reference to international approaches.

ROOM H4 – INNOVATION

H4.1 A place based approach to working with Aboriginal carers

Presenters and authors: David Crew, Manager, Yarkuwa Indigenous Knowledge Centre Aboriginal Corporation and Anny Druett, Manager, Cultural Bridge Builders

Caring is the subject of increasing levels of government policy and research. The question remains, however, whether such developments are reflecting the needs and interests of Aboriginal carers, particularly in regional/remote communities. In developing a response to this question, Yarkuwa Indigenous Knowledge Centre has developed a place-based approach to working with Aboriginal carers. This presentation first examines the tensions and disconnects between government hierarchical models of operation and the more diffusive and complex 'Aboriginal space'. Secondly, it uses this tension to examine some inherent challenges associated with current service delivery models in Deniliquin, in southern NSW. Thirdly, it discusses the concept of a place-based approach to working with Aboriginal carers, exploring key principles and points of difference. As such it meets the conference theme of innovation, partnerships, challenges and new opportunities, but in particular showcases an example of innovation through community development, crucial thought and situated praxis.

Two features of a place-based approach are discussed. The first is the development of person-based resources, as opposed to a written resource or community sector resources, where funding and investment is made in community member(s) who are able to connect and communicate with carers in an accessible and relevant way. We suggests that local engagement, ownership and agency are the best methods for ensuring Aboriginal carers are connected and empowered in relation to their caring roles. Further, that such ownership and agency is best achieved by working with organisations and communities embedded within the community who have the capacity to meaningfully communicate with carers. This project is supported through the NSW Carers Strategy 2014-2019.

This presentation draws together seven years of work in a local rural community, investigating impacts of changing government policy and local circumstance. It draws on process of place based community development and situate praxis, and reflects on process of critical thinking and reflection in creating benefits to families involved in caring.

H4.2 Approaching to the community –Carers’ Cafe in Taiwan: An innovative service project

Presenter: Ching-Ning Chen, CEO, Taiwan Association of Family Caregivers

There are about 760,000 people with disability and dementia in Taiwan, of which 10% users of long-term care, 30% foreign care workers, 60% family carers. According to the survey of the Taiwan Association of Family Caregivers (T AFC), the average time of care for family carers is 9.9 years, 13.6 hours per day, which causes them exhausted physically and mentally. Therefore, by way of our advocacy, ‘Family Carers Support services’ has been included in ‘Long-term Care Services Act 2015’.

Unfortunately, over 50 murder cases committed by family carers for last five years. The authority has met some obstacles owing to lack of resources, Chinese traditional filial piety culture, the public do not have much knowledge about long-term care, and people in need are unwilling to ask for help. Besides, many former carers keep staying isolated or unemployed due to bereavement or the lack of confidence. Since the carers have not been ready to walk out of the door, we try to approach them into their community nearby. That is how the idea of carers’ cafes comes up.

Since 2016, T AFC has started a four-in-one project cooperating with the cafes. This innovative project plans to turn the cafes into friendly service branches in local community. Firstly, the cafe plays a role as ‘information station’. Secondly, the free coffee incites carers to walk out and relieve the stress and tension. Thirdly, respite activity encourages carers for more social participation and contributes to organize supportive groups. Finally, it can be a ‘carers’ halfway workplace’. The cafes offer job opportunities for practice as transition to return to working career.

After pilot scheme for six months, T AFC has collaborated with six cafes and issued 1212 pamphlets. Free coffees and activities also helps to explore potential problems. Carers will be referred to social workers for intervention services and follow-ups. However, the cafe has successfully helped two carers return to work. This project has caught great media coverage in Taiwan. More and more social networking sites have paid attention and related services and policies are therefore widely spread.

H4.2 TBA

CITY ROOM 1 – PRESENTATION – CO-DESIGN IN THE NDIA

CR.1 Co-design in the National Disability Insurance Agency (NDIA)

Presenters: Maryanne Diamond, General Manager, Media Community Linkages and Engagement, NDIA, Matthew Wright, Branch Manager of Design and Inclusion, NDIA and Peter De Natris, Expert Advisor, NDIA

[30mins]

The National Disability Insurance Scheme (NDIS) knows that families and carers play an irreplaceable role in the lives of their family members with disability. We know that families and carers provide essential support to their family member. We also know that families provide help and support that cannot be replaced by formal services or paid support workers.

The NDIS will be presenting on:

- Co-design: We know that carers, from a life-long experience of supporting a person with a disability, have built specialist knowledge and expertise that is invaluable to improving the NDIS.
- Peer Support: Peer-to-peer networks aim to share information, experiences and advice in a format to better equip people to understand and navigate the NDIS, and to build an appetite for independence, self-direction and, over time, self-management. The aim of the Peer to Peer networks is to “build the capacity of people with disability and their families and carers to exercise choice and control, engage with the NDIS and other community resources, and ensure greater social and economic participant”.
- Employment and Carers: The NDIS provides reasonable and necessary supports for person with disability to have an ordinary life. An important aim of the NDIS is to ensure healthy sustainable carer arrangements. An important part of any Australians life is employment, in many ways it defines who we are and gives us an important role in society. The NDIS should deliver supports for its participants that create the option of employment for carers.

Maryanne Diamond joined the NDIA leadership over a year ago and her role is to guide the Community Linkages and Engagement Division as the General Manager. Branches within this Division include the Co-design Branch. Prior to joining the NDIA, Maryanne advocated for the Marrakesh Treaty, which created a mandatory set of principles that allows visually impaired, blind and print-disabled people to access published works. She was also elected president of the World Blind Union 2008-2012, held previous positions as General Manager of Advocacy, Engagement at Vision Australia for seven years and Chair of the International Disability Alliance. Maryanne also has a powerful voice in United Nations agencies and local boards, standing up for people with disabilities.

CITY ROOM 2 – WORKSHOP – YOUNG CARERS

CR.2 South Australia: Young carer service model and pilot

Presenter and author: Marianne Lewis, Senior Policy, Projects and Carer Engagement Officer, Carers SA

[30 mins]

In 2016, Carers SA initiated a Young Carers Assessment Research Project and evaluated individual, age appropriate young carer assessments that investigated caring tasks, roles and the impact of caring on young carers based on Joseph, S., Becker, F. and Becker, S. (2009) 'Manual for Measures of Caring Activities and Outcomes for Children and Young People'. Young carers from across metropolitan Adelaide and regional areas in South Australia participated in these assessments.

The summary results of the research gave a valuable and at times confronting insight into the life experience of young carers in South Australia. The results prompted Carers SA to investigate options for improvements to service strategies. The South Australian Department for Communities and Social Inclusion provided supporting funding for the development and testing of a results based Young Carer Service Model.

Carer SA has developed an adaptable and flexible model with the young carer's individual circumstances and stages of development in mind and based on sustainable outcome oriented intervention principles. The 'Caring Youth Spotlight' program, piloting this model has been rolled out for young carers in three metropolitan and country regions of South Australia. Carers SA will share the model's concepts and resources, and discuss the current learnings from the 'Caring Youth Spotlight' pilot program in this workshop presentation.

CITY ROOM 3 – WORKSHOP – FAMILY CENTRED CARE

CR.3 Supporting carers of veterans with hearing loss: Showcasing a family-centred care approach to hearing rehabilitation for the new world

Presenter: Nerina Scarinci, Senior Lecturer in Speech Pathology, The University of Queensland, St Lucia, Australia

Authors: Nerina Scarinci; Carly Meyer (The University of Queensland); Christopher Lind (Flinders University, Adelaide); and Louise Hickson (The University of Queensland)

Hearing loss is highly prevalent among older Australian veterans, and as such the demand for audiological care in Australia and across the world is increasing. Due to the important role of informal carers in supporting the communication skills of veterans with hearing loss, and the significant impacts of hearing loss on the family unit, new methods of supporting veterans, families and carers are needed. In a recent study, we explored the hearing rehabilitation needs of veterans with hearing loss and their family carers. Results indicated that as a result of hearing loss, carers and veterans experienced numerous communication difficulties, which often impacted the family and lead to tension within family relationships. Specific service needs were identified, including greater inclusion of carers in the rehabilitation process, better uptake of communication rehabilitation programs, and further provision of information to carers regarding hearing loss and rehabilitation options. Inclusion of carers in rehabilitation was reported to lead to more successful outcomes; however, participants indicated family carers were not routinely involved.

As veterans age, the complex nature of their health needs brings increased pressures on informal carers who are also ageing. In order to support carers of veterans with hearing loss, we argue that the involvement of family caregivers throughout the rehabilitation process is critical. Family-centred care is advocated to ensure that carers become partners in rehabilitation. As a result of this research, DefHEAR, a specialised and innovative program designed to meet the unique needs of carers and veterans with hearing loss was developed and trialled. The purpose of this workshop is to provide delegates with an in-depth understanding of the unique needs of carers and veterans with hearing loss and strategies to effectively implement family-centred care in their rehabilitation. Implications for the provision of services to veterans and their carers will be discussed, including opportunities to engage veterans and carers in decision making in order to improve outcomes.

CITY ROOM 4 – CONSULTATION – DIVERSITY OF CARING

CR.4 Development of an Aged Care Diversity Framework and Action Plans

Facilitator: Mary Patetsos, FECCA Board

This consultation is in relation to the Development of the Aged Care Diversity Framework and Action Plans.

The aims of the consultations are to give providers, consumers and peak bodies an opportunity to explain their perspectives in more detail in relation to:

- What each of the priorities and imperatives mean to individuals?
- What are the barriers and enablers against each of the priorities?
- How can outcomes be measured?
- addressing the universal themes that exist across all diverse groups
- other issues that have not yet been addressed.

Outcomes from this consultation will be incorporated into the action plans.