Deconstructing activity expectations in neoliberal unemployment policy discourses: Implications for participation and inclusion in everyday life

Aslam

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Financial disclosure: This study is supported by a Social Sciences and Humanities Research Council Insight Grant (# 435-2014-0847).

Background: Since the 2008 global recession, people unemployed for 26 weeks or longer have constituted a greater proportion of the unemployed population in the United States (USA) and Canada (CAN). Yet, little attention has been paid to how people’s everyday lives during long-term unemployment are structured by social policies. Neoliberal unemployment policies link participation in expected activities to the receipt of supports such as unemployment insurance. Although scholars have critiqued this activation policy approach, few studies have explored how neoliberal activity expectations relate to everyday participation and inclusion during long-term unemployment.

Purpose: To illuminate possibilities and boundaries for everyday occupation relative to neoliberal unemployment policy activity expectations.

Methods: Two collaborative ethnographic studies constitute this program of research. Study 1 utilized semi-structured interviews and observations with eight self-identified long-term unemployed workers in the USA and CAN. Study 2 is undertaking analyses of policy documents; interviews with 15 stakeholders at support service organizations; interviews and observations with 15 service providers; and focus group interviews with service providers in the USA and CAN. We have used thematic, critical discourse, and situational analyses to explore these data.

Findings: “Acceptable” activities during long-term unemployment include seeking work, retraining, going back to school, attending workshops, or volunteering in potential career fields. People who are unemployed report feeling “stuck” in unemployment or precarious work despite “doing all the right things” to meet activity expectations. Reports of “stuckness” appear to relate to the need for other life-sustaining occupations such as resource-seeking that must occur alongside activity expectations.

Conclusions: Neoliberal activity expectations idealize particular ways of participating in everyday life, but those ideals do not reflect the complexity of everyday experience or the likelihood that re-employment will result in precarious work. Such narrowly defined activity expectations may inhibit inclusion and occupational participation in wider social life.
Practices of exclusion through housing modification eligibility: A post-structural study

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Introduction: When New Zealanders with a long-term physical disability are no longer able to participate in essential occupations within their home, they may apply for housing modifications funded by the Ministry of Health. However the characteristics of some houses or properties can render applicants ineligible. A Foucauldian discourse analysis was used to open up the discourses deployed in determining Ministry of Health housing modification funding eligibility. Employing a genealogical approach, discourses in play from the past and the present were brought to light, to call into question the self-evident truth of current discourses that constitute eligibility for housing modifications.

Objectives: In post-structural methodology, there is no distinct line marking out proposing and undertaking research. This study aimed to examine discourses that establish, maintain and challenge the existing system of determining housing modification funding eligibility.

Method: Discourses evident in the academic literature led me to read widely, drawing from historic and current sources such as legislation, textbooks, manuals, and websites. The analysis attended to the ways in which the practices of subjects (including clients, occupational therapists, builders, homeowners, the Ministry of Health, administrators and the house itself) are formed. I then used Foucault’s concepts of governmentality and biopolitics to explain the strategies of governance that my initial analysis revealed.

Results: Crossing the borders of time and discipline revealed the contingent nature of knowledge regarding housing modification, enabling me to discern how housing modifications are governed. Strategies to exclude particular dwellings, and therefore those who live in them, from eligibility for funding are governed by discourses that have been established and reinforced by historical conditions. Histories of governing houses for population health and safety; housing strategies for governing people – in particular the unemployed and the colonised; and designing for the disabled can all be traced to current practices of exclusion from housing modification eligibility.

Conclusion: Problems of governmentality and biopolitics are evident in the practices of exclusion from eligibility for government funded housing modifications. Genealogical analysis of a specific housing modification phenomena (modified showers) provides a useful tool to explore the manner in which systems of governance influence the daily practices of its subjects.
Community-centred practice: Re-imagining occupational therapy ‘client’ as community

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Background: In many Western countries, governments require health services to devise effective ways of working with communities, which promote participation and inclusion, and improve population health and wellbeing. However, there is a paucity of research evidence to support those interested in working collaboratively with communities.

Aim: The aim of the research was to explore how health services can shift focus from individuals, and re-conceptualise ‘client’ as community? Opportunities for working with communities, and ‘community-centred’ practice approaches are explored.

Methods: Two qualitative case studies were completed, one of a Canadian community food security network, and one of a rural Australian community banking initiative. Data were critically examined using sociological perspectives to uncover and query meanings of ‘community’, and strategies used to enact community participation and inclusion.

Findings: Research findings were used to guide a reimagining of health services ‘client’ as community. Two sociological perspectives are proposed to inform conceptual development; including, ‘community as a social field’, and ‘community as a political tool’. Utilising an occupational science lens, ideas for occupation-focussed, community-centred practice are discussed.

Conclusion: To increase participation and inclusion within communities, health services are recommended to use a sociologically-informed conceptualisation of community, and an occupation-focussed, community-centred practice approach. Health practitioners can use this conceptualisation to expand their focus from individual to community-level practice, which will maximise potential for population health improvements.
An occupational perspective of child poverty

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Introduction: Poverty negatively effects the lives of many children in developed and developing nations, and Aotearoa New Zealand is no exception. The way poverty impacts health is well documented, however little is known about its effect on children’s patterns of occupation. Without that knowledge, occupational therapists will struggle to coherently articulate the profession’s role in addressing childhood poverty.

Aim or Purpose: To identify how poverty impacts childhood occupations, how the occupational impacts are associated with health outcomes, and what occupationally-focused public health interventions have been described at individual and community level.

Method: An extensive literature review was undertaken across occupational therapy and social science literature available through library databases.

Results: Consistent with research showing that childhood social circumstances influence their health, children living in poverty are at increased risk of disrupted cognitive, motor, social and emotional development, deficits in occupational performance affecting play, schooling and social life, and occupational deprivation. Occupational therapists working to address childhood poverty have been urged to ensure occupational outcomes are a key goal, act to create inclusive environments, utilise group activities that develop identity and belonging, listen to the needs of the community and work in partnership with communities to encourage collective action. Documented approaches include occupational therapists working with children in underserved communities to reduce health disparities.

Conclusion: While some developmental and health outcomes of children living in poverty appear to be associated with occupational deprivation, there is little concrete evidence of this relationship. Nonetheless, occupation-focused interventions are beginning to emerge. To maximise their uptake and efficacy, research into the occupational patterns of children living in poverty is needed to uncover the mechanisms by which their occupations are constrained and how that contributes to poor health.
Background: All children and young people have the right to access education within an environment that supports their capacity to be present, participating, learning and belonging in schools. This aligns with Part 8 (1) of the NZ Education Act 1989, where all children have the right to enrol at their local school. It also aligns with the government’s obligation to the Treaty of Waitangi and its guiding principles, and Article 24 of the United Nations Convention on Rights of Persons with Disabilities 2006 to access an inclusive, quality and free education on an equal basis with others.

The New Zealand Ministry of Education’s 2009 strategy “Success for All” outlines its commitment to achieving the goal of all schools attaining inclusive practices by 2014. One of the ways “Success for All” is achieved is to ensure the built environment meets the needs of all students so that they can participate in daily school occupations.

Theoretical Foundations: Occupational science emphasises the environmental context of activity and participation. The dynamic relationship of child/young person’s participation in school activities must be analysed within an environmental context. The process to facilitate environmental change requires a range of enablement skills. These include implementing universal design principles, advocating for the rights of the student and collaborating with the school, family and student and following Ministry of Education property modification guidelines.

Conclusion: Coming from barrier free philosophy and universal design principles goes a long way to creating universally functional and fit for purpose built environments for students in Aotearoa/New Zealand. This should be a given, rather than expectation in all societies.
Narratives of the lived experience of dementia intervention

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Financial disclosure: Funded by Alzheimer’s Association

Background: Abundant evidence indicates physical activity benefits older adults. Persons with dementia (PwD) are considered doomed to limited activity levels due to disease-related functional and behavioral changes. However, underestimation of abilities and lowered expectations by caregivers and the absence of supportive environments represent equally significant barriers. Most PwD lack the skills to follow an exercise program unassisted, but with appropriate supervision they can successfully engage in physical activities and benefit from them. Exercise programs tailored for PwD were designed to expand occupational options for this marginalized group.

Purpose: By participating in the development and implementation of their relative’s program, family members reassessed assumptions regarding the PwD’s potential for occupation and developed skills to facilitate participation in the occupation of physical activity.

Methods: Thirty older adults with mild dementia and their primary family caregivers participated in a three-month home-based, family-supervised physical activity program designed for PwD. The majority showed clinically significant improvement at follow-up compared to baseline performance.

Results: Family participants considered program implementation as a process to be negotiated, adapting the program to best integrate physical activities into everyday occupational routines. Follow-up focus groups and in-depth interviews with family exercise supervisors revealed their translation of program training into action within specific social and physical contexts. Rather than passively replicating the program, family members took active measures to adapt it to fit the individual needs/abilities of their PwD. Family members identified barriers and facilitators to program implementation, modifications that they made to the program to make it work for their relative, and criteria they used to define successful implementation.

Conclusions: An anthropological focus on context, meaning, and process provides insights into participatory dimensions of interventions. Narratives of participants’ lived experiences of an intervention designed for marginalized groups can provide critical insight into the process of implementation of that intervention and of its translation into everyday occupation.
Riding the Wrong: Sydney Cycling Sisters: A community development response to Islamophobia

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**Background:** The past 15 years have seen rises of Islamophobia incidents across Western nations and indeed in Australia. Past terrorist attacks, and current terrorism concerns have ignited fear and anger in the community towards Muslim people. Muslim women have been targeted and abused in public, with little intervention from onlookers.

**Aim or purpose:** This poster describes a project carried out by the first author. It has the following aims:

1. To explore the phenomenon of Islamophobia and its affect on Muslim women’s participation in community occupations.
2. To describe Sydney Cycling Sisters, a community development approach used to improve participation of Muslim women.

**Method:** This project used first hand accounts from women known to the first author and literature to understand Muslim women’s experiences in the community. This information was used to determine a strategy to improve these women’s participation.

**Results:** Common themes related to Muslim women’s experiences of Islamophobia included: experiences of depression and anxiety in response to attacks, fear in the community, and feelings of exclusion created by social forces within Australian society. It is evident that Islamophobic incidents influence when, where and with whom Muslim women choose to engage in community occupations. For some, this manifested in change of, or in some cases, complete avoidance of certain occupations.

The development and involvement of women in “Sydney Cycling Sisters” changed Muslim women’s perceptions of themselves as participants in community occupations, by supporting them to engage in cycling for leisure, transport and as participants in organised cycling events both within and outside of Muslim populated areas.

**Conclusions:** There is still a need to address the wider societal stereotypes towards the Muslim community perpetuated by the media. Sydney Cycling Sisters, a group inclusive to all women, provides a positive example of Muslim women as active participants within society.
Betwixt and between: Imagining the liminality of inclusion

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Background: Inclusion may be a desirable goal, but at the same time the means by which people are included or excluded, and the reasons for doing so, might not be universally approved. Understanding what lies on the continuum between inclusion and exclusion brings into question the liminal space and draws attention to what the state and process of inclusion is especially in relation to people’s everyday occupations.

Purpose: As part of a bigger project exploring one profession’s assumptions about the environment, an imaginative process was undertaken to conceptualise inclusion as a state and a process. To understand inclusion requires some thinking about the liminal space that divides inclusion from exclusion. A space implies a threshold that must be crossed or the initial part of a process, as well as freedom of movement within this space. Does crossing the threshold or margin between exclusion to inclusion remove the mantle of marginalisation?

Results: The poster presents some preliminary thoughts and images of what inclusion and exclusion might look like, as both a state and a process, if it was to be imagined for DOT (DOT representing a person, group, society, organisation or other entity). In drawing attention to the gap between inclusion and exclusion, the liminality can begin to be understood as not outside of either term, but in the between and betwixt the structures themselves. A series of reader engagement questions are presented and viewers will be invited to include their imaginings with whiteboard pens and space for drawing/writing on the poster.
Exclusion in occupational therapy

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Background: Inclusion is promoted in occupational therapy but historically rooted views of the person, environment and occupation, as represented in practice models and assessments, limit the profession’s ability to realise this goal. Questions need to be raised about how occupational therapy connects its practice philosophy to the ideals it aspires to.

Aim/Purpose: The poster presents one element of a larger project exploring historical perspectives of the environment within prominent occupational therapy theories. It seeks to ask whether these fundamental tenets support the values of inclusion and participation.

Methods: A history of ideas approach is used to critically examine the extent to which the fundamental assumptions proposed in occupational therapy models, approaches and interventions foster inclusion. Drawing on primary and secondary sources, it shows how ideas have not kept up with shifting world views about human rights, disadvantage, and discrimination. The approach provides a basis to reappraise hegemonic ideas and discard those that no longer fit with occupational therapy’s aim of promoting inclusion and participation.

Results/Findings: Analysis to date shows that over the last 40 years, the profession’s views have continued to create subtle or obvious pockets of exclusion. Little importance has been given to looking back at the historical context of practice and how it established a difficult footing for the goal of inclusion.

Conclusion: The results uncover how occupational therapy’s perspective has grown from the roots of the profession to be where it is today, helping therapists to be more appreciative of its complexities and to question the theories underpinning practice and whether they support an inclusive context for participation.
It was also about what I wasn’t doing: Not doing occupation influences health

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**Background:** Individuals’ participation in productive, domestic, leisure and self-care routines and occupations can be severely impacted by the serious mental illness and significant physical complications associated with bulimia nervosa (bulimia). In particular, their weight, body image and unhealthy thoughts surrounding food manifest as repeated binge eating, followed by compensatory behaviours to avoid weight gain. The process of recovery from this prevalent eating disorder is often prolonged because of the ways occupational performance and health are influenced by contextual factors, deeply held values and beliefs, and ongoing medical complications. Understanding how occupational experiences influence recovery from bulimia could help the proportion of persons who remain in a relapse-recovery cycle.

**Philosophical Foundations:** Rather than being a determinant of health, as occupational scientists assume, the routine and habitual patterns of participation of people with bulimia often undermine their physical and mental health. Recovery from bulimia challenges individuals to confront this contradiction and learn to participate in a repertoire of occupations that contribute to, rather than detract from, health. Negotiating this contradiction requires them to ban, eliminate, cease and prohibit certain occupations that threaten their recovery.

**Discussion:** The theme ‘It Was Also About What I Wasn’t Doing’ emerged as one theme in an interpretative phenomenological analysis of how occupational experiences influenced six female participants’ recovery from bulimia. This theme illustrates how not doing certain occupations, in and of themselves or in relation with others, was a determinant of health for participants.

**Implication:** This poster may promote discussion of the potential for occupational scientists to expand exploration of the dimensional nature of occupation’s influence on health. Consideration of the detrimental impact occupation might have on health and the potential benefit of banning, ceasing, eliminating or prohibiting certain occupations serve as discussion points.
Australasian Occupational Science Symposium, 21-22 April 2016
Inclusion and Participation
AUT University
Poster Abstract

A photovoice exploration of an occupation based treatment model

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**Background:** Vulnerable, at-risk, homeless, and impoverished youth commonly experience mental health issues severe enough to interfere with daily function, complicating their integration to healthy and productive adult living. Innovative occupation-based programs provided in community settings offer rich and diverse experiences to support youths spiritual, emotional, cognitive, and physical development. However, individual models of practice do not fully account for the impact such programs have on the youths or the communities in which they are based. Having a collective or community model could provide a lens through which to see the impact of programs.

**Aim:** Determine whether an occupation-based community program, for at-risk youth, could be modeled on a collective rather than an individualistic model for intervention using a participatory action process.

**Method:** A participatory research process, PhotoVoice, was initiated with a program situated in a rural community. Youth were trained using a standardized, published protocol, were invited to explore ideas about how images can represent events. The youths were asked to take photographs, for one week, highlighting the impact this program has had on their life and community. They were then interviewed, interviews were recorded, and transcribed, and verified. Other data included interviews with staff and volunteers. Interview data were combined and discussed in a series of focus groups, and a tentative model that could better represent this program was designed.

**Results:** The model reflects the healing power of the collective, of social belonging, and a meaningful, contributing social role. Youth were more likely to participate in training for productive work, altruistic activities, and novel leisure activities when there were threads of continuity between activities and people within the community. Youth distinguished less between “systems,” and categorization of participation than the adult volunteers.

**Conclusion:** The results highlight how using a collective model vs. an individual model of intervention reveals the person and community impact of occupation-based programs. It is hoped that this model could allow others to examine the effect that occupation-based interventions may have on inclusion and participation when directed at a collective level.
Activity engagement and neuroendocrine function: Testing a needs-based model of resilience

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Background: Linking occupation to health is essential for situating engagement in a balance of daily occupations as a critical component to thriving as a human being. Analyzing individuals’ occupations when paired with biological markers provides a glimpse into goal-directed behaviors and health at one point in time.

Aim: The intention of this study was to determine if there was a clear association between participation in goal-directed occupations (personal projects), lifestyle, and neuroendocrine responses.

Method: A sample of 40 female volunteers (mean age of 27.9) completed a series of personality questionnaires, demographic forms, health information (blood pressure and body mass index) and Personal Projects Pursuit (PPP) (goal-directed projects rated on key dimensions). Saliva samples were analyzed for cortisol, DHEAS, estradiol, and progesterone levels.

Results: The sample population was healthy and displayed a normally distributed range on most of the questionnaires and physiological measures, but had slightly higher perceived stress ratings. Personality questionnaires indicated that the population was primarily extroverted, agreeable and conscientious. On the PPP participants indicated a typical distribution of categories, the highest in work (30% combined) and health (18%). The PPP categories were correlated strongly with other psychological measures and with the neuroendocrine data. Results indicate that engagement and lifestyle are significantly and positively significantly correlated with cortisol am & pm baselines, DHEAS, progesterone, and negatively correlated to the ratio of PG to E2, SWLS and BNSI.

Conclusions: The correlations suggest a practical relevance linking balance of participation to healthy individuals as reflected by biological markers, those markers are associated with positive health outcomes. The utility of measuring PPP can help to highlight the link between participation in meaningful occupation and health. These data are not merely indications of statistical differences but provide support for the notion that participation in endeavors of daily life contributes to well-being.
An alternative model for stroke self-management

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**Background:** After stroke, people commonly experience disruptions to participation and are less satisfied with their engagement in social, productive and leisure activities. Over 60% experience difficulty returning to paid and volunteer work. Stroke survivors also report a reduced sense of wellbeing across all dimensions. In some studies over 80% rate their quality of life as less than prior to their stroke. Despite rehabilitation efforts, self-management programmes to empower individuals to participate in healthy patterns of occupations report, as best, modest benefits. One reason for this might be that current programs are predominantly based on the bio-medical model, which targets individuals and predetermined, specific health behaviors. Following professional recommendations is viewed as unproblematic and contextual influences are often not considered.

**Theoretical foundations:** The capabilities approach offers an alternate conceptualisation of health, emphasising that what individuals are able to do and be depends on both what they are personally capable of and the opportunities available in their context to use their knowledge, skills and resources. The health capabilities approach has been used as an alternative model in the self-management of other chronic conditions such as diabetes. This model views health as a synthesis of the social, economic and cultural forces which constrain, allow and shape the everyday choices people make and have available to them.

**Discussion:** A more holistic approach to self-management is required which can also address tensions between managing and compliance, and social circumstances and voluntary choice. For self-management to achieve its aim of empowerment, the theoretical foundations may also need to encompass strategies for reducing the societal conditions which create and perpetuate health inequality.

**Implications:** The Health Capability Approach could be a promising new theory to underpin stroke self-management.
Attitudes, values and beliefs that promote students’ occupational participation, inclusion and belonging in schools

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Background & Context: Aotearoa/New Zealand Government’s ‘Special Education 2000’ initiative sought to transform a social injustice within the compulsory schooling sector by advocating the rights of all children to access mainstream education as a choice (NZ Education Act 1989, 8:1). Up until then, “students with special education needs” were mostly accessing their education in segregated “special education” settings. Policies, practice and custom has had to align over the last 15 years to pursue the realisation of everyday educationally-relevant participation in school occupations for all Aotearoa New Zealand students, regardless of abilities, in mainstream schools.

Aim: To support enactment of a social justice framework to build inclusive schools/environments by identifying the core attitudes, values, beliefs that provide a foundational ethos for people who work in the compulsory school sector.

Methods: This ethnographic study utilized semi-structured face-to-face and email interviews with 13 voluntary participants employed by the Ministry of Education and working in mainstream schools to uncover rich insider perspectives of what attitudes, values, and beliefs support inclusive practice in schools. Data were thematically analyzed. Ethical approval was granted through the AUT Ethics Committee. Trustworthiness was achieved via audit trail, participant transcript validation and data triangulation; enhanced by researcher reflexivity, field observations and archival material.

Findings & Implications: In schools, culture and socio-politico contexts are interrelated. An ethos of building inclusive communities in schools and embracing school-based environmental practice best aligns with the government’s 2009 vision of “Success for All”, so that all students may be present, participating, achieving and belonging in mainstream schools. For the therapy professions, that ethos can facilitate the shift away from traditional biomedically dominated practices that attempt to “fix” children with special needs and towards a model of enabling students’ occupational participation and environmental access.

Conclusion: An ethos of occupationally and environmentally focused practice scaffolds the building of inclusive school communities, supporting the realisation of Aotearoa/New Zealand’s social mandate for inclusive education. It also supports a shift in societal attitudes away the biomedical model and goes a long way towards achieving the government’s vision of inclusion.
Karen youth transitions: Traditional dance as a vehicle for identity construction & social engagement

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Background: Thousands of ethnic Karen people from Burma have been relocated from refugee camps to Western countries due to persecution at home (Barron, 2007). For the Karen, maintaining their language and traditional dance, passing the skill of weaving on to the next generation, and cultural celebrations are of key importance. When a Karen leader was asked about maintaining cultural traditions and occupations he said, “We have to. It is all we have left” (personal communication, 2015).

Whiteford and Townsend (2011) discuss the need to participate in occupations that support social and cultural structures, contributing to personal and collective identity construction. Occupations “are opportunities to express the self, to create an identity” (Christiansen, 1999, p. 552).

A study drawing from interviews with Karen weavers in Salt Lake City, Utah, USA by Stephenson et al. (2013) demonstrated how potent the occupation of traditional weaving is to cultural identity construction and social support in a new context. This poster addresses another significant aspect of Karen culture, Karen traditional dance.

Aim/Purpose: This poster will present a study of Karen teenage youth who participate in traditional Karen dance. The focus is on personal perceptions of the meaning of this occupation to these youth and its relation to individual and collective identity construction and social engagement with their own and external communities.

Methods: Data are being gathered through 10 semi-structured interviews which will then be analyzed qualitatively exploring themes that occur across interviews.

Results/Conclusions: Interviews have begun with initial coding and iterative thematic analysis. Preliminary results suggest that these teens, who have spent half their lives in the US, are highly invested in maintaining their social engagement with their Karen community, find strength in Karen identity maintenance, educating the public, and passing this sense of identity along with cultural traditions to the next generation.
An occupational perspective of loneliness and older people

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Financial disclosure: The original study was funded by the Australian Research Council Linkage grant program 2007-2009 (LP0774983).

Background: For many older Australians, loneliness is a pressing social and health issue. As the world’s population ages, greater numbers of people aged 65 years and over are likely to experience negative social, emotional, and physical health problems associated with loneliness. A better understanding of loneliness will add to occupational science knowledge about the role of occupation in health and well-being as well as social inclusion.

Aim: The aim of this study was to gain an in-depth understanding of loneliness through an occupational lens.

Methods: The original qualitative study involved 60 interviews with older people in South Australia and Queensland and four focus groups in each state with service providers. Maximum variation sampling was employed to include people from metropolitan and rural areas and older people from a range of living situations. In this secondary analysis any data pertaining to engaging in occupations were extracted and analysed thematically. Ethical approval for the study was obtained through the Human Research Ethics committee at the University of South Australia. Reflexivity was employed during data collection, analysis and development of themes.

Findings: The two key themes were ‘Keeping active and engaged’ and ‘Social connections’. Lack of occupation results in boredom and is detrimental to well-being. Engagement in social and other meaningful occupations enables re-adjustment following losses and mediates loneliness. Social connections are achieved through occupational engagement with people with similar interests as part of an occupational community.

Conclusion: Loneliness for older adults is characterised by a lack of engaging occupations. Older people can manage loneliness by actively engaging with occupations and making meaningful social connections through occupational engagement. A sense of belonging, social connectedness and inclusion is achieved through belonging to occupational communities.
The lived experience of mothering a young child with severe multiple disability

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University Scholarship in 2013 from the Freemasons New Zealand

Background: As an occupational therapist I was aware that in order to create optimal therapeutic outcomes for the children I was working with, I also needed to form relationships with the mothers of these young children, however I knew so little about the lives of these women. In part, this is because mothering is so ever present within society that it has become ordinary, and rarely thought of. This research reveals the deeply transformative nature of mothering, in which ‘being a mother’ forms their mindset, self concept, and identity; and that of their child’s. The everydayness in the mothering is profound and its influence on how they, and their young child will engage and participate in society is thought provoking for occupational therapists, and other health professionals.

Aim or Purpose: The purpose of this hermeneutic phenomenological study was to explore the lived experience of mothering a young child with severe multiple disability.

Methods: Participants recruited were ‘mothering’ a child aged 3 to 7 with a physical disability coupled with at least one other significant disability of cognitive, behavioural or sensory origin. Semi-structured interviews of 60-90 minutes duration, and a brief demographic questionnaire were conducted. Interviews were taped, transcribed and worked into discrete stories of incidents and perceptions of mothering, which were checked for accuracy by the mothers. Themes were identified through hermeneutic interpretation, with thematic statements isolated using selective/highlighting. Commonalities in texts and themes were identified.

Findings: Participating in the everydayness of mothering revealed three major themes; 1) Being visible; 2) Being challenged; and 3) Being acquiescent.

Conclusions: This research highlights the struggles and intensity within the occupation of mothering in its everydayness, how mothers evolve and endure, shaping their journey and that of their children.