Speaker Profiles and Abstracts

Abstracts are listed in chronological order.

Girdler, Sonya (Edith Cowan University, s.girdler@ecu.edu.au)
Non-presenting authors: Melissa Scott, School of Exercise and Health Sciences, Edith Cowan University, Perth, Australia; Kitty-Rose Foley, School of Exercise and Health Sciences; Edith Cowan University, Perth, Australia; Telethon Institute for Child Health Research, University of Western Australia, Perth; Jenny Bourke, Telethon Institute for Child Health Research, University of Western Australia, Perth; Dr Helen Leonard, Telethon Institute for Child Health Research, University of Western Australia, Perth

'I have a good life': The meaning of well-being from the perspective of young adults with Down syndrome

To date research examining the experience of living with intellectual disability has focused on the perspectives and reflections of parents and carers'. The views of the people with intellectual disability themselves have been overlooked. The purposes of this study were to explore what makes for a 'good life' from the perspective of young adults with Down syndrome and to identify the barriers and facilitators to participation in life situations. Twelve young adults with Down syndrome took part in individual and group discussions. Analysis of the transcripts revealed 'a good life' could be described by four main themes: 'Feeling loved', 'Hanging out with friends', 'Making my own decisions' and 'My Dreams'. These findings highlighted the participants' desire for autonomy, particularly in the domains of living independently and employment. Family relationships and community services were described as both facilitators and barriers to participation in life situations. Overall, the findings from this study revealed that the young peoples life perspective was positive, with a general consensus of, 'I have a good life'. This study yielded many recommendations that could be integrated into transition models of service delivery for young adults with Down syndrome as they transition from adolescence into adulthood.

Health and well-being across the lifespan, Research / academic, Paper
Wednesday 7 November, 10:45am - 11:15am, Main Auditorium

Taua, Chris (The University of Queensland, chris.taua@cpit.ac.nz)
Non-presenting authors: Associate Professor Christine Neville, The University of Queensland; Associate Professor Julie Hepworth, The University of Queensland

From rhetoric to action: Consent and participation strategies for people with intellectual disability having a voice in research

Non inclusive research about the care and treatment of people with disabilities is part of history. The future must tell a different story. Health care research with people with intellectual disability shows a paucity of person informed research, yet for a long time now they have had the same rights as other members of society in regard to research participation. Central to the process of inclusive research is the importance of consent and with people with intellectual disability this was often seen as a complex task to be avoided. Their right to give informed consent was too often disregarded alongside untenable assumptions about capacity.

This paper arises from a PhD study being undertaken to explore mental health inpatient care for people with intellectual disability. The study gathers the perspectives and experiences of three groups of people in a care relationship (1) people with intellectual disability and mental health issues, (2) carers and (3) nurses. After firstly overviewing the study the focus will be on how this research approached the issue of consent. Important consent processes and considerations that were

put in place to gain ethical approval and support full participation for this research will be presented and explained. Examples from the field will be used to support the discussion.

Easy English Abstract:

Learning about the ways people with intellectual disability can be part of research studies.

For a long time, people with intellectual disability were not asked to tell their stories to people doing research. The people doing the research worried that the people with intellectual disability couldn't decide to take part. That often meant that the researchers and other people really didn't understand what their needs were. But we now know that's not so true and that people can easily tell their stories as long as the right people make it a safe environment and take the time to listen.

I am going to talk to you about some research I am doing where I talked to 3 groups of people; (1) people with intellectual disability who have had to go to hospital for mental health care, (2) carers in the community and (3) nurses working in the hospital. The main part of my talk will be about how important it was to make sure that the people with intellectual disability understood how to take part in the research and that they felt safe and listened to. I will also give you some examples of how this happened. Hopefully this will then help other people who want to do research. You might also want to tell me what you would like researchers to do for you.

Bioethics, Research / academic, Paper
Wednesday 7 November, 10:45am - 11:15am, Civic 1

Brown, Felicity (MINDA, brow0650@uni.flinders.edu.au)

Real Lives Real Places

A rights-based approach has been developed within Minda Incorporated, a South Australian Disability Organisation and its positive outcomes will be presented within this symposium. Three papers will be presented which illustrate how one organisation is responding to the guiding principles of the UN Convention on the Rights of Persons with Disabilities. The first paper will overview a Framework that has guided the overall Demonstration Project. The second paper will illustrate how the voice of sell advocates has been facilitated, whilst the third will present and discuss the findings of an outcome evaluation of an aspect of the project where people have chosen to live within several houses or apartments within the suburbs of Adelaide.

Easy English Abstract:

In this paper you will hear about how a large organisation in South Australia has made changes to support people to gain more rights; they do this by choosing where they wish to live. People have also learned how to become self advocates and how to speak up about the things that are important in their lives. You will hear the good news from a group of researchers who visited the organisation to find out how it was for people when they moved into the community.

Values into practice, Practice, Symposium
Wednesday 7 November, 10:45am - 12:25pm, Civic 2

Symposium Papers

Brown, Felicity (MINDA, brow0650@uni.flinders.edu.au), **Manuel, Brad** (Mentor, brad.manuel@minda.asn.au)
Non-presenting authors: Deb McGrath, Executive Manager Service Development; Joanne Park, Community Facilitator

Real Lives Real Places: An organisational perspective of implementing Person Centred Thinking and Active Support within a Human Rights Framework

Minda Incorporated, a South Australian Disability Organisation has embarked on a journey to modernise its practices and move from a traditional service delivery model to a contemporary

approach. These thoughts have resulted in a review of the current service delivery model through the Real Lives Real Places Program consisting of over 30 projects. In addition Minda has adopted the guiding principles of the United Nations Convention on the Rights of Persons with Disabilities. In short, future service at Minda will necessitate a rights based approach where individual strengths and human rights result in effective person centred thinking and includes embracing the Active Support approach within the framework.

The first step to implementing this framework was carried out through the Demonstration Project. The project piloted these approaches across five homes including existing community homes and newly opened homes. All people living in the homes live with intellectual disability and included people already living in the community, moving from an institution and moving from family homes. Support staff were trained in Person Centred Thinking, Active Support and Community Engagement. In addition two new roles were created, the Mentor and Community Facilitator who supported staff to turn their theoretical learning into practice across the entirety of the project.

The project has been running for over eighteen months and is producing positive outcomes for the people living in the homes. There has been an increase in social networks, domestic participation and community participation. The presentation will elaborate on the Demonstration Project, its findings and moving Real Lives Real Places forward.

Easy English Abstract:

In this paper you will hear about how MINDA, a large organisation in Adelaide, is setting up homes in the community. Staff did courses in person centredness and active support. People now go to more activities in the community. You will hear about how people have joined local craft groups and also how people have become cooks for a local club where they meet and mix with other members of the club.

Brown, Felicity (MINDA, brow0650@uni.flinders.edu.au), **Dickson, Janet** (Self Advocate, janet.dickson@minda.asn.au), **Bergin, Chris** (Self Advocate, chris.bergin@minda.asn.au), **Masters, Brenton** (Self Advocate, brenton.masters@minda.asn.au), **Manuel, Brad** (Mentor, brad.manuel@minda.asn.au)

Non-presenting author: Deb McGrath, Executive Manager Service Development

Promoting the right to Express Yourself

Minda, a South Australian Disability Organisation has recently adopted the guiding principles of the United Nations Convention on the Rights of Persons with Disabilities. This convention recognises that everyone is equal, has the right to make their own decisions, and should be treated with fairness, dignity, and respect. For people with an intellectual disability who have had a lifetime of limited decision making it may be a difficult task for them to have a voice. So, over the last year Minda has undertaken a Self Advocacy Program which has two components- establishment of a self-advocacy group, and training in how to be a self-advocate for people living with intellectual disability. These two projects are giving some of the people Minda supports not only the opportunity to speak up for their rights but also the support and training to understand how they can do this.

The aim of the Self Advocacy Program at Minda is to give people living with an intellectual disability a voice within the organisation, but most importantly the confidence and life skills to link in with their own local community and become a valued community member. This is achieved through providing Self Advocacy Training to the person and then further facilitated through the outcomes that the Self Advocacy Group works towards.

The presentation will explain the Self Advocacy Program and how its introduction has facilitated the implementation of a human rights framework within the organisation. This story will be told from both the perspective of the organisation and the perspective of a self-advocate.

Easy English Abstract:
In this paper you will hear about how people in MINDA, an organisation in Adelaide, have set up a Self Advocacy programme. You will hear the story of how to become a self advocate. You will also be told about what happens in self advocacy training sessions and find out what it was like to speak up at conferences.

Riches, Vivienne (Centre for Disability Studies, vivienne.riches@sydney.edu.au)
Non-presenting authors: Dr. Marie Knox, Centre for Disability Studies, Professor Patricia O'Brien Centre for Disability Studies, Rachel Dickson, Claire Gore

Being in the community: A story of creativity, flexibility and resilience

Aim: The purpose of this study, Real Lives Real Places was to evaluate the effectiveness of people moving from long stay residential care to four locations within the community. Earlier studies of community integration resulted in commentary that people were now living in the community but were not necessarily part of it. This study was premised on the belief that by taking a person centred approach people would be able to lead more engaged lives.
Method: A case study approach was taken to documenting the journey that people experienced within the three community based houses and two joining apartments. Each case study reflected a mixed method approach. On moving into the house the members of the CDS research team facilitated a PATH (Planning Alternative Tomorrows with Hope). At the same time all people completed both a Community Participation, and Quality of Life Scale. The research team visited the houses four times over one year. At each visit the outcomes for the PATH were reviewed, new ways forward identified and participant observations made. Discussion was audio recorded and transcribed.
Findings: Case studies revealed that people had choice over both large and small decisions. Control no longer was institutional but rather centred around what people enjoyed doing. Being socially connected was not just an aspiration but arose through responding to individual needs creatively, flexibly and with resilience. Findings revealed sustained networking and building of relationships.
Discussion: The role that a person centred approach has played in underpinning daily choice, control, letting go of routines and building social connectedness will be reflected upon
Easy English Abstract:
In this paper you will hear how researchers visited the new houses that people had moved to into in the community. The researchers will tell you about how people were spending their time, and which places they were going to. People said they had more choice in their lives and were happy that they were now starting to make new friends. Some people were now seeing members of their families after many years. People also said that they were speaking up more about what they wanted to happen in their lives. They were happy.

Dean, Anne-Marie (Optia Inc, adean@optiainc.org), **Boud, Amy** (Client Representative)
Non-presenting authors: Judy Prodan, Client Services Manager, Optia, jprodan@optiainc.org; Gayle Brown, Client Services Coordinator, Optia, gbrown@optiainc.org; Crystal Alderson - Client Representative

Client Representation – Best practice model

In 2003, Optia Inc was awarded a Certificate of Recognition Best Practice for our Client Representation Model by ASSID. At that time our process was on a smaller scale that it is today; involving meetings with clients in residential homes to discuss important issues, minutes of these being reviewed and then sent to advocacy services for discussion at a consumer-group meeting. Client representatives from this meeting then provided a report to Optia's Board, supported by advocates.

In the past 9 years, Optia's Client Services team have expanded this process as the organisation has grown and in line with changes in the field of disability, such as client engagement, inclusion and self-advocacy. While the process remains virtually the same, Client Representatives continue to develop their self-confidence, depth of knowledge of the process and are acknowledged as a significant component of the operational processes within Optia.

Optia's policies now reflect the importance of this process and the benefits of clients having maximum input into the service delivery of the organisation.

Client Representatives* will outline their experiences throughout the process and give insight into how they have benefited and developed through their opportunity to be involved in the collaborative process. (Film from each step of the process will be shown, demonstrating the extent of Client input). (*With Staff support)

Values into practice, Practice, Paper
Wednesday 7 November, 10:45am – 11:15am, Civic 3

Johnson, Hilary (La Trobe University/Scope, h.johnson@latrobe.edu.au), **Iacono, Teresa** (La Trobe Rural Health School, La Trobe University, T.Iacono@latrobe.edu.au)
Non-presenting authors: Ass. Prof Jacinta Douglas,Dept of Human Communication Sciences, La Trobe University; Prof Christine Bigby, Dept of Social Work and Social Policy, La Trobe University

Social interaction for adults who communicate at a symbolic but nonlinguistic level

Aim: This presentation focuses on the social interactions that occur between an adult with an intellectual disability who communicates at a symbolic but nonlinguistic level and those with whom he has positive relationships. Method. The main methods of data collection were participant observation and interviews. The data were analysed using a grounded theory approach. Results. Data for this presentation have been drawn from one case study, Brian, who participated in a larger study. Brian obtained scores on the Vineland Adaptive Behaviour Scales that indicated he had a profound disability, but he demonstrated communication that varied to that usually associated with this level of intellectual disability, that is, unintentional or intentional but non-symbolic. Rather, Brian demonstrated symbolic, but nonlinguistic skills, and used formal and informal means of communication for a range of pragmatic functions. His social interactions in relationships with family members and paid workers included aspects of having fun and hanging out

Conclusion: Brian's communication profile challenges assumptions about the skills of people with profound intellectual disability. Adults who are symbolic nonlinguistic communicators develop relationships with others in unique ways that may not always be recognised. Hence, support may be needed to foster their relationships.

Cultural and social contexts, Research / academic, Paper
Wednesday 7 November, 10:45am - 11:15am, Square Affair

Underwood, Lisa (Institute of Psychiatry, King's College London, lisa.underwood@kcl.ac.uk)

Intellectual disability among a prison population: recognition, pathways and comorbid mental health problems

In the UK, intellectual disability is not routinely screened for within the criminal justice system. The consequence is that people with intellectual disability may not be directed to the most appropriate prison location or departments to receive the support they require. This study aims to establish the extent of unrecognised intellectual disability among prisoners at Her Majesty's Prison (HMP) Brixton. The study will explore the characteristics of prisoners with intellectual disability; the extent to which they have additional mental health problems and examine the prison pathways and healthcare resources they use. The study aims to interview all prisoners currently at HMP Brixton and all those

arriving at the prison over a six month period. In addition to intellectual disability, participants will also be screened for autism spectrum disorder (ASD) and attention-deficit hyperactivity disorders (ADHD). All those screening positive for any of these disorders will assessed for additional mental health problems and substance misuse. A case note review will look at the care pathways of prisoners with intellectual disability in terms of resources required and locations used in comparison to the general prison population.

Results: The study is at the recruitment stage and will approach around 1000 prisoners. Data will be presented on the proportion of participants with 1) an existing diagnosis of intellectual disability and 2) previously unrecognised intellectual disability. Rates of ASD, ADHD and comorbid mental health problems will also be explored.

Legal issues and developments in forensics, Research / academic, Paper
Wednesday 7 November, 10:45am - 11:15am, Lion Harbourview

Rogers, Kevin (Citizen Advocacy Auckland Inc, noddyrogers@hotmail.com), **Hartnett, Fran** (IDEA Services, fran.hartnett@idea.org.nz), **Espiner, Deborah** (Auckland of University, d.espiner@ auckland.ac.nz)

Confinement, Commune, Community: One individual's life experience

This paper will outline one individual's perspective on his life course experience from confinement through communal living, to being an active and contributing member of his community. This is a human story of resilience, empowerment and flourishing. The presenter will share how life experiences have impacted on his understanding of himself as a person, a citizen and a contributing member of society. The paper will trace the presenter's journey from being segregated and devalued, to living in a community based on spiritual values and bi-culturalism, to taking up the role of citizen in his community. Examples of the roles the presenter has played in various settings will be shared. Specific experiences that have shaped the presenter's awareness of the importance of belonging and contribution will be discussed. Despite moving away from the commune, the presenter remains connected to fellow members of this community. He has played an important role in contributing to research about the commune and the publication of a well received book. During the paper the presenter will share some personal stories about his time living with one of New Zealand's most iconic figures. This presentation will be of interest to those participants who would like to gain an insight into a unique slice of New Zealand history and be inspired by the presenter's journey from confinement to commune to community.

Easy English Abstract:

This paper will tell the story of one person's life history. It will outline his move from living in an institution to living with a community group led by a famous New Zealander, to being a valued member of his local community. If you come to this paper you will find out more about an exciting time in New Zealand's history. You will also hear about how the presenter's experiences helped him to become a self advocate and a spokesperson for people with intellectual disability.

Health and well-being across the lifespan, Lived experience (self advocate, family), Paper
Wednesday 7 November, 11:20am - 11:50am, Main Auditorium

Strnadová, Iva (University of New South Wales, i.strnadova@unsw.edu.au), **Cumming, Therese** (University of New South Wales, t.cumming@unsw.edu.au)
Non-presenting author: Dr. Marie Knox, Centre for Disability Studies

Becoming an Inclusive Research Team: A journey towards learning and friendship

Aim: Inclusive research has traditionally had to overcome many obstacles, most glaringly the prejudice centered on the misguided belief that individuals with intellectual disabilities do not

possess the abilities to undertake a researcher's role. This prejudice is present not only in the wider public, but also in some academic circles, despite a growing body of literature describing positive experiences with inclusive research (Bigby & Frawley 2010; Gilbert 2004; Walmsley 2004; Williams et al. 2005).

Methods: Building on the social model of disability and using an inclusive research framework, the authors will present their experiences of developing an inclusive research team. The 15-week long research skills training was conducted for both academic researchers and researchers with intellectual disabilities. Following the research training, the research team has undertaken a one-year research study of coping skills of ageing with intellectual disability. The data on building an inclusive research team (video-recorded training sessions and reflections of research team members) are being continuously analyzed using the grounded theory approach.

Results: The authors - three academic researchers and four researchers with intellectual disabilities – will describe the modified researcher-training program they have developed. The project employed innovative iPad technology to support the researchers with intellectual disabilities in more fully participating in all phases of the research project. These strategies can be adapted to support this population in future studies.

Conclusions: The authors will conclude with a vision for inclusive research for the immediate future and beyond.

Easy English Abstract:

The authors describe their experience with research. There were 4 academic researchers and 3 researchers with intellectual disabilities. They met 15 times to learn about research. Then they started to work on a research project. The research project looks at lives of older women with intellectual disabilities. The authors will talk about how they became a team.

Health and well-being across the lifespan, Research / academic, Paper
Wednesday 7 November, 11:20am - 11:50am, Civic 1

Anderson, Sian (LaTrobe University, s7anderson@students.latrobe.edu.au)
Non-presenting authors: Professor Christine Bigby, LaTrobe University; Associate Professor Paul Ramcharan, RMIT University

Building positive, included identities: The experience of engagement in self-advocacy by adults with an intellectual disability

For newer, more positive social identities for people with intellectual disabilities to emerge, there needs to be a reframing both of community perceptions and the ways in which people with intellectual disabilities see themselves. Whilst some studies of self-advocacy have offered glimpses of the potential of self-advocacy to positively impact the lives of adults with intellectual disability, few have addressed the impact of engagement in self-advocacy and self-advocacy organisations on the social identity of the participants. This paper describes doctoral research undertaken with self-advocates in the UK where self-advocacy is well-developed and has a long history compared with Australia where self-advocacy groups have struggled in a less supportive policy climate. The research involves in-depth interviews with 25 self-advocates from 6 self-advocacy organisations and 10 of their supporters. The study has uncovered many examples showing that involvement in self-advocacy has led to a strong sense of purpose, employment, status, a sense of power over their own lives and new social identities for self-advocates. Findings from the study indicate the need to examine the priority disability policy gives to support and funding of self- advocacy groups.

The author would like to acknowledge the support of this research by IASSID through the SINGA scholarship.

Easy English Abstract:
This presentation is about self-advocacy in the UK and Australia. The researcher has asked people who are self-advocates and some of their supporters what they get out of being involved. People said that self-advocacy has been a very positive and important part of their lives in many different ways.
Values into practice, Research / academic, Paper
Wednesday 7 November, 11:20am - 11:50am, Civic 3

O'Brien, Patricia (Centre for Disability Studies, University of Sydney)
Non-presenting authors: Roy McConkey, University of Ulster; Edurne García Iriarte, National Institute for Intellectual Disability, Trinity College, Dublin

The key concerns of persons with intellectual disabilities: an international comparison

In recent years, national research studies have been undertaken in five countries – New Zealand, England, Scotland, Croatia and Ireland - aimed at identifying the key concerns of people with intellectual disabilities. Although differing methodologies were used – focus groups, postal questionnaires and individual interviews - a number of consistent themes emerge across all five nations. These include living accommodation, employment, educational opportunities, leisure pursuits, money and friendships. This paper explores the universality in the lived experience of persons with intellectual disabilities and the reasons for the continuing mismatch between their aspirations and present support systems. The implications for the role of research in closing this gap are discussed.
Easy English Abstract:
In five countries people with intellectual disabilities described their lives. They lived in New Zealand, England, Scotland, Croatia and Ireland. The same things were mentioned across all the countries. People wanted better living accommodation, more paid work, improved educational choices, more leisure activities, more money and more friends. We try to explain why people do not get the opportunities they want. We discuss the role that research can play in improving people's lives.
Cultural and social contexts, Research / academic, Paper
Wednesday 7 November, 11:20am - 11:50am, Square Affair

Ellem, Kathy (UnitingCare Queensland/Griffith University, k.ellem@griffith.edu.au)

Leaving prison: Experiences of people with intellectual disability in Queensland, Australia

What happens to prisoners when they leave prison has bearing on community safety, and many ex-prisoners need assistance to remain crime-free (Walsh, 2004). This paper examines the experiences of leaving prison for people with an intellectual disability in Queensland. The findings are part of a PhD study on the life stories of ex-prisoners with intellectual disability. A total of ten participants with intellectual disability (7 male, and 3 female) were interviewed using the life story method. Interviews were respectful of the communicative styles of participants and often involved multiple interview sessions, ranging from two to nine interviews per person. Community re-entry after prison was considered challenging for participants, as they faced factors such as poverty, homelessness, substance abuse issues and poor physical and mental health. The study shows how the time of release can be a very emotional event for prisoners with an intellectual disability, clouded with uncertainty about what the person may expect on the outside and confusion about when this change will happen. The need for concrete information and hands on assistance negotiating supports in the community have significant implications for correctional and community services.
Easy English Abstract:
This paper is about people with an intellectual disability who left prison in Queensland. Ten people with intellectual disability told their life stories. This was for a PhD study. People said it was really

scary leaving prison. They had trouble finding somewhere to stay. They didn't have enough money. They found it hard to stay healthy. Some people had problems with alcohol and drugs. People with intellectual disability who have been in prison need help to live in the community.
Legal issues and developments in forensics, Research / academic, Paper
Wednesday 7 November, 11:20am - 11:50am, Lion Harbourview

Knox, Marie (Centre for Disability Studies, University of Sydney, marie.knox@sydney.edu.au), **Susan Adrian, Sarah Butler, Julie Deane, Robert Griffith, Suzy Jessup, Marie Knox, Lesley Lewis, Annie Mills, Patricia O'Brien, Glen Pudney, Peter Rondo, Mark Walters and Elizabeth Young**, CDS Inclusive Research Network
Non-presenting authors: Emma Doukakis, Liz Hammond and Brendan O'Connell, CDS Inclusive Research Network

Life as a Worker: An inclusive research approach to exploring the experiences of people with intellectual disabilities

Inclusive research is research where people with intellectual disabilities own the research question, have a vested interest in the outcomes, participate as co-researchers and work on accessible outcomes. The Centre for Disability Studies (CDS) Inclusive Research Network conducts research consistent with this approach.
A team of co-researchers with and without intellectual disability have conducted a small study to explore the experiences of people with intellectual disability of the impact of the Convention on the Rights of Persons with Disabilities (CRPD) in their daily lives in the areas of home, employment, education and health. These areas were identified by the Network as important areas of everyday life, and are consistent with the domains detailed in the CRPD.
This paper reports on the findings from one of these areas: participants' employment experiences. Researcher teams (consisting of one co-researcher with an intellectual disability and one without) conducted semi-structured interviews with 20 participants with intellectual disabilities.
Interview transcripts and reflective memos comprised the study data and were analysed to identify the key themes and their interrelationships. The analyses from individual co-researcher teams were brought to regular Inclusive Research Network team meetings for discussion and further analysis. Preliminary findings indicate varying experiences of employment satisfaction and rewards, and indicate the importance of tailoring flexible supports consistent with the person's input.
The paper will also report on the learnings of co-researchers from the inclusive research experience.
Cultural and social contexts, Lived experience (self advocate, family), Paper
Wednesday 7 November, 11:55am - 12:25pm, Main Auditorium

Stace, Hilary (Victoria University of Wellington, hilary.stace@vuw.ac.nz)

Doing ethical disability research

The numbers of disabled people within the community are growing due to a variety of factors including medical advances, the closure of institutions and increased expectations of supported independent living. However, while they are still a largely unresearched population, disabled children and adults are becoming an increasingly attractive population for researchers as they can provide valuable information on a wide variety of topics including genetic conditions, effects of medications and service evaluations. Disabled people also have the right to participate in mainstream research. The challenge is to ensure that all aspects of the research process are ethical. Unfortunately, history shows that research can be very risky for disabled people with numerous examples of abuse notably the 'silent holocaust' of the Nazi regime when hundreds of thousands of disabled children and adults were experimented on, sterilised and euthanized. Ongoing vigilance about ethically appropriate

research is therefore vital. Patient information sheets and consent forms must be in plain language and emphasise such principles as informed and ongoing consent including the right to withdraw at any time without affecting service provisions. Even with the best of intentions researchers may be unaware that this is a population which may have learnt to be compliant, as non compliance may have led to punishment or withdrawal of services, that participants may have been coerced into participation, or that others are speaking for them. In such cases the information may be flawed or harm an already vulnerable population.

Easy English Abstract:

Disabled people, such as self-advocates, have a lot of information that can be valuable to researchers. Disabled people also have a right to take part in research which is not just about disability. However, researchers have to respect their disabled research participants (the name for people taking part in the research). Researchers need to be aware that disabled people have their own views and opinions and do not want their carers or family members speaking for them. Bad and abusive research has happened to disabled people in the past. So we must make sure that those taking part in research know what the research will mean for them and that they are safe and respected.

Bioethics, Research / academic, Paper
Wednesday 7 November, 11:55am - 12:25pm, Civic 1

Hutchinson, Oana (IDEA Services, oana.hutchinson@idea.org.nz)

Supporting individuals to gain more control in their lives while 'feeling settled' in their living environment: One organization's exploration of the challenges, the process and outcomes

The paper will present one organisation's approach to finding alternatives to the group home model and the practices inherent in this model. It will explore the components of a more individualised and person-centred way of supporting people with an intellectual disability than that typically found in group home settings. This alternative model aims to maximize individuals' choices and control over their lives, while enabling individuals to remain 'settled' in their existing home environments. The presentation will discuss the rationale and framework for the organisation's alternative residential living project and provide information on the process used to involve the individuals, family/whanau, staff and management in the new approach. This project was informed by learning gained from the 'Feeling Settled' project in UK.

Information will be shared on the tools adapted to New Zealand population to ascertain the extent of self-determination which individuals could exercise at the beginning of the project. Data will be also shared on the results of evaluation of outcomes 10 months into the project. A key question is what is the connection between the quality of an individual's life and the setting in which the person lives and the way staff assist and support the person. This paper will provide information based on the experiences relating to 2 group homes based in the Auckland area. The learning from this project will be applied to future initiatives which aim to provide more flexible residential living options to people with an intellectual disability.

Easy English Abstract:

This paper is about a project to support people with intellectual disability to live more independently in their own home. The people lived in a group home where they received a lot of help from staff to do daily jobs. People are now learning to do more things for themselves with less support from staff. The paper will talk about how we involved people and their families/whanau. The paper will talk about the training staff received. One service provider will share information on how people are getting on 10 months later and what we have learnt.

Values into practice, Practice, Paper
Wednesday 7 November, 11:55am - 12:25pm, Civic 3

Ottmann, Goetz (Deakin University/Uniting Care Community Options, goetz.ottmann@deakin.edu.au)
Non-presenting author: Ms Jenny Crosbie, Deakin University, Research Officer, Jennifer.Crosbie@
deakin.edu.au

Involving people with an intellectual disability in stakeholder consultations: Which methods mix works best?

People with learning disabilities and their families are increasingly asked to participate in stakeholder consultation rounds. What methodology should be employed to achieve this? Although a consensus is emerging among researchers that a mix of methods should be employed in order to generate a more accurate representation of the voices of people with a disability, the question around which mix of methods is most appropriate has not been answered conclusively.

This study examines the utility of seven qualitative methodologies (included survey/questionnaire, semi-structured interview, focus group, 'case in point' ethnographic observation, photographic intervention, carer proxy response, and service provider proxy response) in order to determine which mix of methodologies generates a good representation of the most important issues in the lives of people with an intellectual disability.

Ten participants and their carers/family members and 57 service provider staff contributed to this study over the course of 11 months. The one single question that formed the focus of all methods was 'what are the most important issues in the lives of people with an intellectual disability'.

The research suggests that more formal methods tend to generate 'big ticket' responses whereas informal methods tend to highlight everyday life issues that are no less important to participants. In order to obtain an accurate and cost-effective representation of participants' views responding to open ended questions a mix of semi-structured interviews and photographic intervention is recommended. Moreover, additional methods can be used to triangulate results.

Easy English Abstract:

People with learning disabilities and their families are often asked to join in planning and evaluation of services. People who do this work are not sure what the best way to do this is. We looked at seven different ways to get information and asked people with disabilities what was best for them. We found that talking with people, looking at photos then talking about the photos was a good way.

Cultural and social contexts, Practice, Paper
Wednesday 7 November, 11:55am - 12:25pm, Square Affair

Smith, Amanda (AUT University, grubz@orcon.net.nz)

Experiences of the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003

Individuals with an intellectual disability have been overrepresented in the criminal justice system in New Zealand for some time. The Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 was passed in order to better meet the care and rehabilitative needs of intellectual disabled offenders. The legislation represents a unique departure from legislative processes utilised in comparable jurisdictions internationally for this group.

This paper presents preliminary results from a study exploring the implementation of the ID(CC&R) Act six years on through the experiences of 'care recipients' and those individuals who work with them. Using a Social Constructionist methodology the question was asked, 'What discourses come into play when participants speak about care recipients under the Intellectual Disability (Compulsory Care and Rehabilitation) Act and how do those discourses construct individuals who are subject to the Act?'

Semi-structured interviews were utilised and data was analysed to identify discourses within the legislative framework. Identified discourses were then critically analysed using discourse analysis for criteria such as identities, power relationships and material conditions for care recipients.

The study focuses on the period of transition both shortly prior to and following release. Knowledge regarding this legislation is likely to contribute towards shared understanding of this framework that will ultimately impact on both the lives and the social position of individuals with an intellectual disability who are going through the criminal justice system.

Easy English Abstract:

People who have an intellectual disability are involved with the police and Courts more than they should be. The Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 is an Act that provides help for some of these people. In this study I talked to people who are helped by this Act and people that work with them to explore what it has been like for them and how it has changed their lives.

I explored what they said that was similar about their experiences. These themes have the potential to tell us about the social position of people with intellectual disabilities. The study looked at the time for people just before they came under the Act and just after they came under the Act. We want to be able to tell services and staff who are involved with the Act about what people experience when coming to the end of the Court orders.

Legal issues and developments in forensics, Research / academic, Paper
Wednesday 7 November, 11:55am - 12:25pm, Lion Harbourview

Matthews, Martyn (Timata Hou/IDEA Specialist Services, martyn.matthews@timatahou.org.nz)
Non-presenting authors: Kumari Fernando and Brigit Mirfin-Veitch

Autism Spectrum Disorder and co-morbid psychiatric disorders

Internationally, there has been an increase in the range and type of research examining the mental health of those individuals with Autism Spectrum Disorder, largely from identification or diagnostic viewpoint, rather than focused on treatment or support services. Within New Zealand there is limited information about the diagnosis, assessment, treatment and support provided for or required by these individuals. Though some specialised services are being provided by intellectual disability or mental health organizations, there has been no evaluation as to whether these services are meeting current needs, but much anecdotal evidence that they are not.

As many adults with autism spectrum disorder also have intellectual disability (the majority being in the moderately to severely intellectually disabled range), diagnosis of co-morbid psychiatric disorder can be a time consuming and complex process, often relying on information provided by family members or support service workers. There are a range of tools designed to assist clinicians in making diagnoses, (e.g. the Reiss Screen for Maladaptive Behaviour, PIMRA and PAS-ADD). At present, there is no data available as to prevalence or types of additional psychiatric disorder in this population group for New Zealand.

This poster will give an overview of the current literature around the mental health needs of adults with ASD and an outline of preliminary data from a research project, examining the types of comorbid disorder and the treatment, services and supports required by individuals who have both ASD and mental illness.

Health and well-being across the lifespan, Research, Poster
Wednesday 7 November, 12:35pm – 1:05pm, West Court

Trembath, David (Olga Tennison Autism Research Centre, La Trobe University, D.Trembath@latrobe.edu.au), **Iacono, Teresa** (La Trobe Rural Health School, La Trobe University. T.Iacono@latrobe.edu.au)
Non-presenting authors: Dr Giacomo Vivanti and A/Prof Cheryl Dissanayake

Understanding Visual Attention and Learning in Children with Autism Spectrum Disorders: An Augmentative Communication and Eye-tracking Study

Children with Autism Spectrum Disorders (ASD) are often described as 'visual learners,' and those who use little or no functional speech may benefit from Augmentative and Alternative Communication (AAC). However, recent eye-tracking studies indicate that children with ASD display differences in the way they visually-attend other people's actions, compared to children without ASD. It is not known whether these differences have any effect on their ability to benefit from picture-based AAC instruction. Therefore, the aims of the study were to examine (1) the extent to which children with and without autism visually attended to a picture-based AAC system used by a teacher to convey a set of instructions, (2) whether or not children performed better when her verbal instructions were accompanied by pictures, and (3) any relationship between visual attention and performance within the groups. Twenty children with ASD and 18 typically developing (TD) peers watched eight short videos on a Tobii eye-tracker in which a teacher instructed them to manipulate a set of objects. Half of the instructions were delivered via speech alone, while the other half were delivered using speech and pictures. Both groups attended to the pictures during the AAC condition, but there was no significant difference in their performance under the AAC condition. The results provide preliminary evidence that children with ASD are looking when taught using picture-based AAC systems, but further research is needed to explore the link between 'looking' and 'doing', as well as individual within-group differences.

Values into Practice, Research/Academic, Poster
Wednesday 7 November, 12:35pm – 1:05pm, West Court

Husner, Frauke (Cara, fhusner@cara.org.au)

Service Transformation-Implementation of Individualised Funding at Cara

The "Service Transformation" project has been funded by the Australian Government Home and Community Care (HACC) program.
The aim of the project is:
- To engage and empower people with a disability to redesign and transform their HACC funded respite services provided by Cara to an Individualised Funding model

Processes and systems such as forms, financial changes and other arrangements will be put in place to engage and empower participants to redesign and transform their HACC funded respite services into an Individualised Funding package.
The paper will outline:
- The highlights of the journey; experiences from families and Cara perspectives.
- What have been the challenges for families and Cara.
- What feedback Cara received about the approaches we introduced.
- What changes and challenges Cara experienced as a result of this project.
- The developed and delivered change management strategies that support ongoing and sustained implementation of Individualised funding within Cara.
- How has this project assisted Cara to be ready for the introduction of Individualised Funding by the South Australian Government.
- Resources developed to assist Cara manage the transition to individualised funding.

Please note that one of the Outcomes of the Project is to share the learning and resources developed with the Sector including templates and toolboxes. Electronic copies of tools and resources will be available for presentation at conference.
This is a companion paper to the paper by Robbi Williams and Alicia Fidock on 'Small money, big changes?' on Thursday 8 November, 2:35pm - 3:05pm.
Values into practice, Practice, Poster
Wednesday 7 November, 12:35pm – 1:05pm, West Court

Stace, Hilary (Victoria University of Wellington, hilary.stace@vuw.ac.nz)

Autism policy in New Zealand: the importance of right relationships and respecting lived experience

How can autism policy in New Zealand be improved? Why is it often difficult to find appropriate support and services such as welcoming schools and understanding health or social services? Hilary's PhD research looked at autism policy in New Zealand, its historical context, its place within 'disability', and whether it fits the criteria for 'wicked' policy. She also considered how we might improve support for people with autism, and their families, using the premise that this is a problem for society, not just individuals. She suggests that key to improving policy and implementation is getting relationships right and respecting the expertise of those who live daily with autism. One example would be identifying and nurturing policy entrepreneurs from within the autistic community.
Easy English Abstract:
When you have autism it is sometimes hard to find people to help you. Some schools don't want children with autism. Finding a job can be difficult. Hilary has studied this problem and tried to work out how we could fix it. She thinks that government people should ask people with autism about the problems, as they are the experts. If people from government and different agencies took more time to talk to each other and to people with autism and their families they could work out the answers together.
Values into practice, Research / academic, Poster
Wednesday 7 November, 12:35pm – 1:05pm, West Court

Burns, Lyn (IDEA Services, burnslyn@xtra.co.nz)
Non-presenting authors: Dr Margi Martin, Victoria University Wellington

Living to Die: Not Waiting to Die. Sensory Holistic Retreats for Palliative Elderly

This paper explores the development of specialized retreats and holidays that enable the elderly to reminisce using the 'senses' and improve their well-being and self-esteem. Benefits of holidays have been identified in the literature review and the results were analysed using the New Zealand Te Whare Tapa Wha Maori model of health.
Research identified specialty retreats for specific illnesses such as cancer or dementia patients but there was no identified research specific to the elderly population.
What was identified was the impact on caregivers and the elderly when they moved from a routine, task focused care to a more flexible, collaborative approach.
A holistic approach gives nurses and carers the opportunity to be innovative and creative in their practices by providing retreats and holidays for palliative patients or those with chronic illnesses. These retreats involved families and staff which resulted in a multi-disciplinary approach to palliative care.
Health and well-being across the lifespan, Research / academic, Poster
Wednesday 7 November, 12:35pm – 1:05pm, West Court

Oxnam, Paul (Queensland Forensic Disability Service, paul.oxnam@gmail.com)

From a tough start to a good life: understanding and addressing the emotion-regulation needs of offenders with an intellectual disability

We know most people with an intellectual disability live positive and functional lives in the community as is the case for the general population; however, a small number become involved in the criminal justice system and cause harm to others. In the past, such offenders were inappropriately placed in prisons and mental health facilities. The past decade has seen the advent of

specialist forensic intellectual disability services in Australia and New Zealand, following on from the development of these services in the United Kingdom. This has allowed researchers and clinicians to further extend their understanding of why some people with an intellectual disability come to offend and how best we can assist those individuals to pursue better lives. This symposium will share some of those insights. Professor Bill Lindsay will begin by discussing the impact of attachment difficulties and early life experiences on the development of anger and aggression problems. Paul Oxnam and Emma Gardner will then discuss the evolution and successful implementation of Stepping Stones, a group therapy programme specifically designed to address such emotion-regulation difficulties. Finally, Jared Watson will discuss how the Good Lives model of offender rehabilitation can be used as a comprehensive strengths-based framework for understanding and addressing the emotional and behavioural needs of offenders with an intellectual disability.

Easy English Abstract:

Over the past ten years the government has built special services for people with an intellectual disability who have broken the law. During that time, researchers have tried to find out why those offenders behave the way they do and what needs to change for them to be able to live better lives in the community. This symposium will teach you about some of the things the researchers have found. Professor Bill Lindsay will start by talking about how people who grew up in violent homes and did not receive good parenting can end up becoming criminals and have difficulty managing feelings like anger and worry. Paul Oxnam and Emma Gardner will then talk about a group programme for intellectually disabled offenders that they run in New Zealand and Australia. This programme helps people to deal with their feelings in better ways and teaches them some of the skills they need to be able to get on with others. Finally, Jared Watson is going to talk about why it is that some people break the law rather than use safe ways of working through their problems. Jared will use examples from his work to show that these people can use their strengths to develop better ways of coping and can live eventually live good lives in the community.

Legal issues and developments in forensics, Practice, Symposium
Wednesday 7 November, 2:15pm - 4:20pm, Main Auditorium

Symposium Papers

Lindsay, Bill (Professor of Learning Disabilities and Forensic Psychology, University of Abertay, Dundee, billlindsay@castlebeck.com)
Non-presenting authors: Lesley Steptoe and Derek Carson

Attachment, anger and psychological symptoms in offenders and controls with intellectual disability

Background: There is now a fairly well established relationship between attachment difficulties in childhood, and the development of problems associated with criminal behaviour and poor mental health in adulthood (Farrington et al 2006, Quinsey et al 2005). In studies on offenders with ID abuse and neglect in childhood has been associated with offending in adulthood (Lunsky et al 2011, Carson et al 2010). These studies suggest that proxy measures for attachment problems (childhood adversity) have a strong relationship with criminal behaviour in adulthood.

Method: firstly we established the reliability and validity of the Adapted Relationships Questionnaire (ARQ) measuring secure, anxious and avoidant attachment in people with ID. We used the Emotional Problems Scale (EPS) the Brief Symptom Inventory (BSI) and the Dundee Provocation Inventory (DPI) to assess anger and psychological symptoms in 38 offender and 25 non offender participants.

Results: the non offenders had significantly more individuals with anxious attachment but numbers were small. For both groups there were significant negative relationships between secure attachment and all measures of anger, hostility and aggression. Insecure attachment styles were associated positively with anger/hostility. For non offenders there was a negative relationship between depression and secure attachment.

Conclusion: this study provides further evidence that anger and aggression are associated with insecure attachment styles. Conversely, secure attachment is associated with lower levels of anger, hostility and depression. Separate evidence suggests that lengthy periods of consistent treatment can ameliorate relatively stable problems associated with insecure attachment (Lindsay, Douds and Emara 2012).

Easy English Abstract:

Researchers have found that when you have family troubles for your whole childhood it can lead to problems when you grow up. Some criminals and people with mental health problems have not been looked after properly or their mum and dad have been bad to them for a long time. We think that not being looked after properly when you were growing up might be one reason that people commit crimes or go to hospital with mental health problems.

We asked 63 people with intellectual disability questions about how they got on with their parents and questions about how angry and aggressive they felt. We also asked them about their anxiety and sadness.

We found that people who got on better with their parents did not get so angry and aggressive. People who got on better with their parents didn't get so sad. People who said they got on worse with their parents said they got more angry and aggressive. We think we can help people who have had trouble with their parents by keeping them in services for a while with the same carers. They might begin to trust the carers and get less angry.

Oxnam, Paul (Queensland Forensic Disability Service, paul.oxnam@gmail.com), **Gardner, Emma** (Clinical Psychologist, emma_willcock@yahoo.com)

Stepping Stones - A group therapy programme for the treatment of emotion regulation difficulties in offenders with an intellectual disability

Based on the anger management package developed by Murphy, Lindsay and Cox (2007), Stepping Stones is an innovative 42-week group-therapy programme that comprehensively addresses the needs of offenders with an intellectual disability.

Since its inception in 2008, Stepping Stones has evolved to meet the requirements of forensic clients in community and inpatient settings in New Zealand and Australia. Clients engaged in the Stepping Stones programme complete 13 modules targeting emotion regulation, distress tolerance, relationships, problem solving and skills for living in the community. Client willingness to share and learn from negative life experiences in a safe environment has been a prominent feature of the programme.

Care staff have described feeling more confident to work with challenging clients and reportable event data indicates a reduction in both the incidence of aggression and the need for physical and chemical de-escalation. Clients who have completed Stepping Stones demonstrate a greater understanding of their emotional responses and an improved ability to use functional means of managing distress and solving life problems. In addition, they express pride in their achievements and enhanced confidence for pursuing a life worth living in the community.

Stepping Stones programmes for adolescent and female offenders are currently in development, along with a training package for clinicians wishing to facilitate Stepping Stones in other services.

Easy English Abstract:

Stepping Stones is a group therapy programme for people with an intellectual disability who have broken the law and have trouble managing feelings like anger, sadness and worry. The programme is 42 weeks long and is based on a package that was developed by a group of people from Scotland. By coming to Stepping Stones, clients learn good ways of coping when they feel upset, what do to if they are having a hard time with their friends and family, and how to solve problems like not being able to do the things they want to do. Stepping Stones is also a safe place for people share their worries and learn from each other.

At the service where Stepping Stones started out, the clients who have completed the programme don't go off as often as they used to. This means that they that they feel better about themselves, get on better with staff, and get to have more leave to do fun stuff, like going fishing or to the movies. Clients who have done Stepping Stones also say that they aren't so worried about how they are going to manage when they move back to the community.

Stepping Stones programmes for teenagers and females are coming out soon, along with a training package for staff who want to run Stepping Stones for clients in other services.

Watson, Jared (Te Korowai Whariki - the Central Region Forensic Mental Health, Rehabilitation and Intellectual Disability Service, jared.watson@ccdhb.org.nz)

The utility of the Good Lives Model in a forensic intellectual disability setting

The Good Lives Model (Ward and Maruna, 2007) is a comprehensive strengths based theory of offender rehabilitation that focuses on promoting individuals' important personal goals while at the same time reducing and managing their risk of offending.

A core idea of the GLM is that all meaningful human actions reflect attempts to achieve human goods. These are innate needs, states of mind, and characteristics that are universal and intrinsically beneficial to human beings and sought for their own sake rather than as a means to an end. These primary goods broadly fall into the categories of relatedness, agency, inner peace/emotional equilibrium, knowledge, mastery in work and play, creativity and community. The GLM aims to equip offenders with the capabilities and resources to obtain these primary needs in socially acceptable and personally meaningful ways. The Good Lives Model has shown promise within the forensic mental health context (Barnao, Robertson and Ward, 2008). This presentation focuses on the utility of the GLM within the forensic intellectual disability setting. These ideas will be explored and a case study presented.

Easy English Abstract:

The Good Lives Model is a way of helping people who have committed crime to stay out of trouble in the future. The Good Lives Model is also helpful to professionals who work with criminals so that they can work out what sort of things can help them. The main idea of the Good Lives Model is that if a criminal has a good life then they will not want to offend and will stay out of trouble. A person has a good life if they:

  • have good friends, family and people that love them,
  • do things they enjoy,
  • have work that makes them feel good about themselves,
  • have options and a say over what happens in their lives.

This presentation is about how professionals can use the Good Lives Model with people with an intellectual disability and who have committed crimes.

Mills, Annie (Ability Options, annie.mills@abilityoptions.org.au)

Inclusive education in the tertiary sector: experiences and voices from the field

Education at any level contributes to an individuals' economic, social and emotional development. In particular the potential benefits to individuals from attending higher (post- secondary) education include improved self-esteem, new friendships, the development of professional relationships and of course, academic knowledge; all of which facilitate the opportunity for individuals to move towards achieving greater independence.

People with disability, particularly those with an intellectual disability, are less likely to have access to, or indeed access, higher education. Programs and models supporting people with intellectual disability to attend higher education facilities have been developed in universities across the globe, with varying success. Unfortunately, to date, there has been limited reporting of employment or

other outcomes for these students. In Australia at the present time, opportunities for supporting access to higher education for people with intellectual disability are limited in number.

A consortium, comprising university academics, staff from a range of Non-Government Organisations and government agencies, was formed to facilitate the implementation of a pilot program of inclusive education through the Centre for Disability Studies at the University of Sydney. Five participants, all persons with intellectual disability were recruited to pilot the study.

This symposium will commence with a paper on the successful implementation of an inclusive education model in Ireland, followed by a paper describing how students with intellectual disability have been able to audit classed at the University of Sydney, and will conclude with a paper where the voices of students from both Ireland and Sydney will be heard.

Easy English Abstract:

We will give 3 presentations about inclusive education within universities. The first speakers will talk about inclusive education in Ireland. The second presentation will be about opportunities at the University of Sydney. In the last presentation students will tell us what it is like to be a student with intellectual disability at University in Ireland and in Sydney.

Values into practice, Research / academic, Symposium
Wednesday 7 November, 2:15pm - 4:20pm, Civic 1

Symposium Papers

Lally, Niamh (University of Sydney, lallyn@tcd.ie)
Non-presenting author: Patricia O'Brien

Rolling out inclusive higher education for students with intellectual disabilities throughout Ireland: Lesson learned

Aim: The study explored the transfer of an inclusive higher education programme for students with intellectual disabilities from Trinity College Dublin to 5 higher education institutes across Ireland.
Methods: Multiple sources of qualitative data were collected to gain an understanding of the experiences of students, course tutors, 'champions' who pioneered the initiative in each setting and student family members. Data was gathered via focus groups, interviews, action plans and surveys.
Results: Personal growth and development was a major theme to emerge across stakeholder groups. Students spoke of increased confidence in their self perception, social interactions, and their abilities to claim their educational rights. Tutors gained experience in innovative learning and assessment methodologies targeted on this group and a changed attitude associated with intellectual disability. For 'champions' it was a questioning of how best to include students with intellectual disabilities in higher education. For family members, seeing their son or daughter in a new light brought with it the challenge of 'letting go' and a focus on where to next.
Conclusions: The study highlighted some key drivers and barriers to the implementation of inclusive education for students with intellectual disabilities in higher education.
Easy English Abstract:
In this paper the speaker will tell you about how students with intellectual disabilities have gone to university across Ireland. They will tell you how:
*   the students said that they felt more confident
*   the tutors said that they now had new attitudes towards people with intellectual disabilities
*   the family members now realised that their sons and daughters could become more independent and that they had to let them go
*   the university champions were now working to make sure that students with intellectual disabilities could always now come to university.

O'Brien, Patricia (Centre for Disability Studies, patricia.obrien@sydney.edu.au)
Non-presenting authors: Nicola Hayhoe, Annie Mills, Emma Doukakis, Minerva Rivas Velarde and Marie Knox

Inclusive education in the tertiary sector: the Sydney University experience

It has been suggested the failure of students to achieve is not 'a reflection of a lack of ability in the students but of the failure of the system to meet their individual needs' (National Disability Strategy Consultation Report 2009, p.47). Higher education opportunities for people with disability in Australia, specifically within the university context, are limited. This is reflected in the numbers participating in higher education programs. The Disability in Australia report (AIHW 2008) notes people with intellectual disability were less likely to participate in higher education than those without disability (1.6% compared to 7.6%). The success of the 'Up the Hill' program at Flinders University in South Australia, and similar programs in Canada and Ireland, have shown the potential for such programs to improve outcomes for students with intellectual disability; students have reported increased confidence, broader social networks, opportunities to develop job related skills and engage in off-campus social activities.

A consortium, comprising university academics, staff from a number of disability service providers and government agencies, was formed to develop a project to facilitate the inclusion of people with intellectual disability at the University of Sydney. An inclusive individual support model, similar to that run in South Australia, with students self-selecting classes to audit and engaging in a range of university activities, was proposed. This paper will report on the process of establishing this program, engaging staff and mentors, enrolling prospective students, challenges faced establishing the program and identifying measurable outcomes, and plans for moving forward in 2013.

Easy English Abstract:

A group of people, some who work at the Centre for Disability Studies, University of Sydney and others who work with people with disability, have come together to start a program to support people with disability to go to university. In this project students were able to choose which classes they wanted to attend. They also got to choose what other activities they wanted to be involved in.

The speakers in this presentation will talk about what they had to do to support people to gain entry into the classes that they audited. They will talk about how

- students and university staff became part of the project
- what worked well
- what will happen next.

Lally, Niamh (University of Sydney, lallyn@tcd.ie), **Hayhoe, Nicola** (Ability Options, nicola.hayhoe@abilityoptions.org.au)**, Butler, Sarah** (Ability Options)
Non-presenting author: Meilin Yap or Tomas Murphy

Inclusive education in the tertiary sector: participants' experiences in Ireland and Sydney

This final paper will present the stories of inclusion at university from two participants in these programs, one from Ireland and one from Sydney. The model of inclusion at each of these sites differed. The Irish model is a hybrid model where students with intellectual disability participate in classes and activities with their peers as well as in classes specifically for people with disability. The model piloted at the University of Sydney is an inclusive individual support model, where students receive support to audit established classes with their peers. Participants experiences expressed through their stories, form an essential component in understanding the subjective impact of this program; providing an opportunity to learn about their experiences of being a student, their relationships with their mentors, other students and lecturers and involvement with the broader university environment.

In addition to these stories we will present a brief summary of the types of courses attended by all the students, attendance levels, participation in university social or cultural activities and the availability and accessibility of classes.

Easy English Abstract:

In the last presentation we will hear from two people who have been a part of an inclusive education program at university We will hear stories and see images of what it was like for them to be a student at university. One will tell us about their experience in Sydney and the other in Ireland.

In Ireland, students with disability participate in classes and activities with other students as well as in classes specifically for people with disability. At the University of Sydney students had support from mentors to attend classes with other university students. These students' stories give everyone an opportunity to learn:

- about their university experience,
- their relationships with their mentors, other students and lecturers
- their participation in other activities in the university.

Williams, Sarah (Te Roopu Taurima O Manukau Trust, sarahw@terooputaurima.org.nz), **Emery, Brian** (Te Roopu Taurima O Manukau Trust, briane@terooputaurima.org.nz)

Kawa of Care - Using the code of ethics to measure the quality of client outcomes

We defined the kawa of care as the protocols and customs of quality care. We took the ASID code of ethics/competencies for carers, (kaiawhina) and house leaders (kaiarahi) and turned them into practices (kawa) of care and support to mokopuna (clients). The practices are set within a framework (kawa of care) where we have added a point of difference i.e. the context of tikanga (custom, lore). Tikanga brings a mauri (life force) to how kaiawhina practice, and yields a life essence (outcome) for the mokopuna.

Accordingly, the kawa of care produces desired outcomes (nga hua) when kaiawhina learn and know intimately the mokopuna (clients) wants and aspirations. These are found through the whare tapawha (four dimensions):

- Taha wairua (spiritual wellbeing) - What are the mokopuna goals and aspirations?
- Taha tinana (physical wellbeing) - What keeps the mokopuna healthy?
- Taha hinengaro (emotional/mind wellbeing) - What makes mokopuna happy, sad, and what help they need with their personal cares?
- Taha whanau (relational wellbeing / sense of belonging) - Who is important to the mokopuna?

Kaiawhina and kaiarahi demonstrate the kawa of care when they demonstrate values such as being non-judgemental, valuing, kind, supporting, nurturing, and protective. We have given the kawa of care a set of key performance indicators and quality measures. These can be continually measured and evaluated for every kaiawhina against the outcomes achieved by the mokopuna. Consequently, through the kawa of care, we can give mokopuna their best life choices.

Values into practice, Practice, Paper
Wednesday 7 November, 2:15pm - 2:45pm, Civic 2

Frawley, Patsie (LaTrobe University, Living with Disability Research Group, c.bigby@latrobe.edu.au)
Non-presenting authors: Professor Christine Bigby, LaTrobe University, Leader, Living with Disability Research Group, c.bigby@latrobe.edu.au; Dr Paul Ramcharan, RMIT University, Centre for Applied Research

"The thing is I believe in fighting for rights of people with an intellectual disability": Understanding self advocacy through the eyes of Victoria's first generation self advocates

Background: Self advocacy has been described as a social movement of people with intellectual disability. Most knowledge about the nature of self advocacy has been derived from life stories of self

advocates primarily from the UK. Little is known about its history, activities or outcomes, and even less from the perspective of Australian self advocates themselves.

Method: As part of a larger collaborative group study on the history of self advocacy in Victoria, thirteen people who were the 'first generation' of self advocates were interviewed, and an archive established of key documents about Victoria's first self advocacy group. Initial data were analysed as data were collected, followed by more rigorous coding by academic partners and discussion of emergent themes with all research group members. This paper presents findings about what self advocacy has meant from the perspective of self advocates involved in the movement since the 1980s.

Findings: Participation in collective activities has defined self advocacy for self advocates. The nature of activities has changed from 'radical' action and attendance at camps and conferences in the early days (1980s-early 1990s) to more specific projects and consultation in later years. An enduring characteristic has been close ties of friendship and alliances with other advocacy groups. That much of the work of self advocates has not progressed further than the 'event', suggests the need for policy makers and supporters of self advocacy to partner more closely with self advocates to provide strategic support to progress and disseminate their wide ranging and potential contributions to social change

Easy English Abstract:

People with an intellectual disability have been involved in self advocacy for many years. In Victoria Australia, self advocacy has been going since the early 1980's. But we do not know much about what it has done and what is has meant to be involved in self advocacy for the people involved.

This paper will present some ideas about self advocacy that have come from self advocates. The research that this paper comes from interviewed thirteen self advocates and looked at the history of self advocacy in Victoria from what they talked about and from the files, photos, videos, and other papers kept by one self advocacy group.

The research has found that the most important things for self advocates have been the things they have done as a group about their rights, like running conferences and making videos. It also found that a lot of their work has been about running the organisation, having meetings, doing planning together and running other events.

Through self advocacy work people have made strong connections with each other and with people outside their group. They have talked a lot to government and done projects and campaigns with other advocacy groups.

The research tells us that people from outside self advocacy need to understand what it is about by listening to self advocates and working with them to help them make their work count.

Values into practice, Research / academic, Paper
Wednesday 7 November, 2:15pm - 2:45pm, Civic 3

Buchanan, Angus (Curtin University, a.buchanan@curtin.edu.au)
Non-presenting author: Carmel McDougall, Curtin University/Therapy Focus

Towards a conceptual framework for understanding carers' occupational adaptation and engagement

Background: The caregiving role can demand carers' attention 24 hours per day, seven days a week, which leaves little time for their own occupations.

Purpose: To investigate the impact caring for a person with an intellectual disability, in a rural location, has on the occupations of carers.

Method: In-depth semi structured interviews were conducted with seven carers. Interpretive phenomenological analysis was used to identify themes.

Results: A primary theme emerged, occupational adaptation and engagement, which determined four possible ways carers' occupations may be affected by caring: changes to opportunities to develop occupations, developing new occupations, adapting occupations, and ceasing occupations.

Five influencing themes affecting carer's engagement in occupation were ascertained: lifestyle and occupational roles, wellness and health, engaging quality supports, societal and community context, and vision for the future.

Implications: The findings highlight a way to conceptualise carers' occupational adaptation and engagement, and offers a framework to guide further research.

Cultural and social contexts, Research / academic, Paper
Wednesday 7 November, 2:15pm - 2:45pm, Square Affair

Fairthorne Jenny (Telethon Institute for Child Health Research, jfairthorne@ichr.uwa.edu.au)
Non-presenting authors: Prof. Helen Leonard, Telethon Institute for Child Health Research (TICHR); Dr Nick de Klerk, TICHR

The physical, mental and overall health of the parents of children with intellectual disability compared to that of parents of children without disabilities: a review of the literature

Background: Over half a million Australasians have an intellectual disability (ID) and the majority resides with their parents until middle-age. This review is extracted from a systematic review which compares the health of parents of children with ID and/or autism spectrum disorder (ASD) to the health of parents in the general population. This is a prelude to an analysis by the presenter comparing the health of the mothers of children with ID and/or ASD to the general population using linked hospitalisation data.

Methods: Original, high quality and relevant research from 1985 to 2012 and published in English in peer reviewed journal was chosen for this review.

Overview: The health of parents of children with ID is compared to that of parents in the general population, along with the health burdens of groups of parents of children with ID but with other primary diagnoses such as ASD with ID and Down syndrome. Other topics presented are the benefits and challenges of living with ID, the health of mothers versus that of fathers and links to poorer health in these parents. These include child behaviour, parental expectations and economic disadvantage.

Conclusions: The likely benefits of increased awareness and understanding of the health burden of parents of children with ID, both in terms of the wider community and affected families, are presented.

Easy English Abstract:

Title: The health of the parents of children with intellectual disability compared to that of other parents: the results of research

Over half a million Australasians and New Zealanders have an intellectual disability (ID). Most live with their family until middle-age. This presentation is taken from a broader study which looks at the health of parents who have children with ID and/or autism and compares their health with other parents. Later there will be another study that looks at the health of mothers by looking at hospital records.

The presenter read good research on this topic written since 1985. They were looking at the health of parents of children with ID and other disability types, like autism with ID and Down syndrome. The research talked about benefits and challenges of living with ID. it also compared the health of mothers versus that of fathers. it looked at why they might have poor health.

There will be many benefits if we strive to understand the burden of parents of children with ID. These include benefits to the child with the disability, siblings, parents and the wider community. These will be discussed.

Health and well-being across the lifespan, Research / academic, Paper
Wednesday 7 November, 2:15pm - 2:45pm, Lion Harbourview

Buchanan, Angus (Curtin University, a.buchanan@curtin.edu.au), **Waters, Rebecca** (Curtin University, School of Occupational Therapy and Social Work r.waters @curtin.edu.au)
Non-presenting authors: Dr Matthew Molineux, Director, Allied Health, Clinical Education and Training Queensland (ClinEdQ), matthew_molineux@health.qld.gov.au; Wendy Coxs Director Accommodation Services, Disability Services Commission, wendy.coxs@dsc.wa.gov.au

The outcomes for adults living in formal supported accommodation: a new way of thinking urgently required!

Background: Despite significant service development and changes in values, adults with intellectual disability living in formal group accommodation remain at risk of low levels of meaningful participation in socially valued activities leading to occupational deprivation and alienation.
Purpose: To develop an understanding of the current reality for an adult with intellectual disability living in supported accommodation (group homes).
Method: Over 2 semesters Occupational Therapy students in pairs (240), as part of their core learning, took time to get to know well an adult with an intellectual disability working within a person centred perspective. Each student pair produced a detailed summary of their findings including information on relationships, activities – current and potential, and community connections. Following formal ethics approval data was then analysed to provide an understanding of the current circumstances. 80 sets of data were included in the analysis.
Results: The data suggests that adults living in supported accommodation continue to be at a high risk of limited informal relationships, not engaging in regular meaningful activities (occupations), having limited positive community connections and being isolated, congregated and segregated.
Implications: Despite the significant progress made in the reform of formal accommodation services for people with intellectual disability the findings indicate that people are at risk of adverse social and health outcomes. The presentation will provide some thoughts on how to refocus this issue considering it within the framework of Occupational Justice.
Values into practice, Research / academic, Paper
Wednesday 7 November, 2:50pm - 3:20pm, Civic 2

Johnson, Hilary (La Trobe University/Scope, h.johnson@latrobe.edu.au)
Non-presenting authors: Ass. Prof Jacinta Douglas, Department of Human Communication Sciences , La Trobe university, J.Douglas@latrobe.edu.au; Prof. Christine Bigby, Department of Social Work and Social Policy, La Trobe University, C.Bigby@latrobe.edu.au; Prof. Teresa Iacono, La Trobe Rural Health School, La Trobe University, T.Iacono@latrobe.edu.au

Processes underpinning positive relationships for adults with severe intellectual disability

Relationships are central to developing social inclusion. This presentation focuses on describing the processes that occur between people with severe intellectual disability who are symbolic but non-linguistic communicators and those with whom they have positive relationships. Participants included six participants with intellectual disability and limited communication and those with whom they had positive relationships. Data were collected from participant observation and interviews and analysed using the grounded theory method.
Five core, non-linear processes were revealed. People who had positive relationships experienced sharing the moment while getting to know the person and recognising the individual. In addition the process of connecting occurred incorporated providing security and adjusting communication. Feeling good was experienced by everyone. Feeling good encouraged people in positive relationships to share the message and inform others about the central participants' activities and personalities. Understanding and valuing the fundamental aspects of these relationships will assist in focussing on specific aspects of staff recruitment and training that will better support social inclusion. The model

provides evidence from which to develop training in relationships and may be applicable to support a broader range of people with disabilities.

Easy English Abstract:

People with severe intellectual disabilities have limited communication skills and few people who spend time with them in social interaction. Social interaction builds relationships and having relationships makes people happier.

This study involved a researcher looking at what happens between people with a severe intellectual disability and the people with whom they liked to spend time. Participants included six participants with intellectual disability and limited communication and those with whom they had positive relationships. Data were collected from participant observation and interviews and analysed using the grounded theory method.

A model was developed that has five parts. The parts are recognising the individual, sharing the moment, connecting, feeling good and sharing the message. The parts together show what helps to support relationships. Knowing how relationships are supported will help others to develop and support relationships for people with a severe intellectual disability.

Values into practice, Research / academic, Paper
Wednesday 7 November, 2:50pm - 3:20pm, Civic 3

Muller, Robert (Le Va - Pasifika within Te Pou, robert.muller@leva.co.nz), Ben Tafau

Le Va's Engaging Pasifika: Disability training programme – helping the disability sector engage effectively with Pacific peoples living with disabilities and their families

Le Va is the National Pacific Health Workforce Development programme within Te Pou in New Zealand. Le Va has been contracted by the Ministry of Health to implement the Faiva Ora National Pasifika Disability Plan 2010-2013.

In 2011, Le Va carried out research that identified a need to develop an evidence-based, effective and appropriate Pacific cultural competency training programme for the disability sector. We also identified an opportunity to shift some of our current Pacific cultural competency training into an online training module which acts as an introductory course to our live training. This new online training module would enable us to ensure our live training participants share a similar level of knowledge around Pacific cultural competency and allow more time for engagement and interaction at the live trainings.

The Engaging Pasifika: Disability training programme was developed in conjunction with the Faiva Ora National Pasifika Disability Leadership Group, as well as the disability workforce and community/consumer groups. The development of the online training module, Introduction to Engaging Pasifika, began in December 2011. A working group involving cultural advisors, education consultants, the Faiva Ora National Leadership group and the Le Va team developed the structure for the online training.

The Introduction to Engaging Pasifika online training module and the Engaging Pasifika: Disability training programme will be piloted during May 2012 in Auckland, Hamilton and Wellington with selected disability support services.

This presentation will outline the development process of the training, the results of the pilot programme and subsequent roll out of both programmes.

Easy English Abstract:

Le Va leads Pacific Health Workforce Development in New Zealand. We carry out the Faiva Ora National Pasifika Disability Plan 2010-2013. This is the Ministry of Health's work plan for helping Pacific people with disabilities and their families.

In 2011 Le Va did some research that showed a need to develop training for people working for

disability services that will help them work better with Pacific people with disabilities and their families.

We also decided to take some of our current Pacific training and create an online training module. This module will be an introduction course to our live training. The new online training module means that people who do our live training have a good base level of knowledge about Pacific people before they do our live training programme. It also means that there is more time for discussion at our live training.

The training programme we developed is called Engaging Pasifika: Disability. The online module is called Introduction to Engaging Pasifika. People who helped us develop the training include:

- The Faiva Ora National Pasifika Disability Leadership Group
- The disability workforce
- Community groups
- Pacific people living with disabilities and their families
- Cultural advisors
- Educational consultants.

Both training programmes will be piloted during May 2012 in Auckland, Hamilton and Wellington with disability support services.

This presentation will talk about how we developed the training, the results of the pilot programme and how the training has been running since then.

Cultural and social contexts, Practice, Paper
Wednesday 7 November, 2:50pm - 3:20pm, Square Affair

Ellem, Kathy (UnitingCare Queensland/Griffith University, k.ellem@griffith.edu.au)
Non-presenting authors: Professor Jill Wilson; Ms Carmen Bonner, Manager, Shared Care and Family Services, UnitingCare Community

"Sorry, but we can't help you": Families' experiences of relinquishing care of a child with a disability

When families give up their caring role for a child with a disability, they are often physically and emotionally exhausted and socially isolated in their local communities. Relinquishment often initially leads to an unstable situation for the child with a disability, as permanent out-of-home accommodation has not been planned (Nankervis et al 2011). It can be a traumatic experience for both family and child, and presents significant challenges for practitioners in child protection and disability service contexts. This paper presents preliminary findings from a qualitative study of ten families who have relinquished their caring role either of their young or adult children with a disability in the context of Queensland, Australia. The research was part of a collaborative effort between Shared Care and Family Services, UnitingCare Community, the University of Queensland and Griffith University. Through semi-structured in-depth interviews, the study explored the perspectives of families before, during and after relinquishment in terms of the impact on their child with a disability and themselves. Families were also asked to comment on the roles and actions of professionals involved in supporting them during these times. Families' stories were de-identified and analysed thematically using NVivo 9 software. The preliminary findings illustrate a lack of expertise and coordination in services to support individuals with complex behaviour and their families. While the findings are not generalizable to all families in similar situations, the data presents a rich understanding of the difficulties for families in ensuring appropriate long-term care for their family member.

Easy English Abstract:

Some families find it hard looking after their child with a disability. They may feel so stressed that they leave their child with a disability service or with child safety. This study talked to ten families

who did this. The families told the researcher what happened. They talked about how services helped them and didn't help them. The families' stories may help services find better ways of working with families and with people with a disability.
Health and well-being across the lifespan, Research / academic, Paper
Wednesday 7 November, 2:50pm - 3:20pm, Lion Harbourview

Grant, Trish (IHC New Zealand Inc, Trish.grant@ihc.org.nz)

Education is a Human Right: A campaign for inclusive education

IHC has lodged a complaint under Part 1A of the New Zealand Human Rights Act. The complaint argues that disabled children and young people experience discriminatory outcomes at their local school. IHC has collected evidence from families, principals and schools about the problems associated with New Zealand Special Education policy. The presentation will outline the process of the complaint so far and the evidence which will be put before the Human Rights Review Tribunal.
Easy English Abstract:
IHC is standing for the rights of disabled children and young people to be able to go their local school.
Values into practice, Practice, Paper
Wednesday 7 November, 3:50pm - 4:20pm, Civic 2

Murphy, Lucy (annecto - The People Network, lucy.murphy@annecto.org.au), **Schickerling, Adam** (SE Regional Manager - Innovation and Leadership, Adam.Schickerling@annecto.org.au)

Changing squares into circles –The participatory leadership story of annecto

One of the most significant challenges facing services organisations is the current need to adapt and evolve our Leadership methods in meaningful and sustainable ways to meet the opportunities created by Self-Directed Approaches. In responding to this challenge annecto has been on a journey over the past 18 months towards a culture that embraces and practices the Participatory Leadership methodology.
Participatory Leadership for annecto is a powerful framework that enables our people to strategically take and evoke leadership. Using methods that foster conversations that matter, we have demonstrated that practical and "hands-on" approaches help our people become engaged, become clear on their commitment, and can take action - supporting each other to "step in and step up"
Our framework is based in the Art of Hosting theories and technologies that include:
• Circle Practice
• Appreciative Enquiry
• Open Space
• Art of Harvesting
• World & Pro-Action Café
• Organisational Living Systems Theory
Core to these practices are principles that strongly align to annecto's Vision, Mission and Values of social inclusion and participation. The benefits of applying these principles in real and meaningful ways has seen our leadership develop greater trust and confidence in one another, respecting and listening to each other and groups working as one towards a clear purpose. Developing the skills and theoretical knowledge-base of our leadership was the first step in our journey which has now emerged as one of learning and is a balance of practice & reflection and passion & responsibility.
Values into practice, Practice, Paper
Wednesday 7 November, 3:50pm - 4:20pm, Civic 3

Herbert, Colene (IHC NZ Inc, colene.herbert@idea.org.nz), **Williams, Gwen**

What does the future hold? Supporting older families to plan for the future

Older families of people with intellectual disability often speak of their fears for the future, and their worry about what will happen to their family member when they are no longer there. This is of special concern to families when the person with intellectual disability lives at home. This presentation will outline a sub-project that was part of IHCs four-year Successful Ageing Project. It will describe 1) the outcomes of consultation with older families and people with intellectual disability about their wishes and needs, 2) the development of tools and support systems for, particularly around provision of information and Future Planning tools, and 3) the next step in the roll-out of these tools and systems across IHC and IDEA Services nationally.

Easy English Abstract:

Some older people with intellectual disability live at home with family. Some families and people worry about the future. We worked with people to help them plan for the future. This helped people feel confident about the future. We will talk about how we did this.

Cultural and social contexts, Practice, Paper

Wednesday 7 November, 3:50pm - 4:20pm, Square Affair

Laborde, Randell (Tautoko Services, randell.laborde@tautoko.org.nz), **Prebble, Philippa** (Tautoko Services, philippaprebble@tautoko.org.nz)

Services and supports through the lifespan

This presentation will explore how the needs of individuals with autism and their families change at key points in their lives. Emphasis will be placed upon discussing important aspects of the beginning and ending of the lifespan and its impact upon the family's well being. These aspects include screening diagnosis and intensive early intervention at the beginning of the lifespan and retirement, specialized medical needs and environmental supports later in life. While there is significant research regarding the benefits and effectiveness of services and supports for young children and their families, information regarding the needs of individuals as they age is only emerging. Emphasis will be placed on services and supports required by all family members, including the wider family and whanau.

Supports needed vary by such factors as the type and severity of the individual's disabling condition(s), family make up, age of all involved, and the type and effectiveness of supports received. How family members are perceived by their friends, family and communities play an important role as well. The impact of each of these factors will be examined in the context of current understanding of how support can best be provided. Common beliefs held by families prior to having a family member with autism will be reviewed. The impact of having a child with autism upon family identity and beliefs will also be discussed. Finally, beliefs held by general and specific service providers, school personnel, extended family members as well as the general community will also be touched upon.

Easy English Abstract:

This presentation explores how the needs of people with autism and their families change at key points in their lives. You will learn about important things about the beginning and end of a person's life. At the beginning of life, there are things like screening, diagnosis and intensive early intervention. Later in life retirement, specialised medical needs and environmental supports become very important for caregivers and people with autism alike. While there is significant research regarding the benefits and effectiveness of services and supports for young children and their families, information regarding the needs of individuals as they age is only emerging. We will discuss

services and supports required by all family members, including the wider family and whanau. Supports needed by each individual and family vary by many factors. How family members are seen by their friends, family and communities play an important role as well. You will learn about the impact of these factors and how support can best be provided. Common beliefs held by families prior to having a family member with autism will be reviewed. The impact of having a child with autism upon family identity and beliefs will be discussed. Finally, beliefs held by general and specific service providers, school personnel, extended family members as well as the general community will also be discussed.

Health and well-being across the lifespan, Practice, Paper
Wednesday 7 November, 3:50pm - 4:20pm, Lion Harbourview